The Development and Validation of the Dementia Quality of Life Scale for Older Family Carers

(DQOL-OC)

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ABSTRACT

Background: Family carers are considered to be the most important resource available to support people with dementia. The number of older people who are carers is increasing in the United Kingdom, and little is known about how caregiving affects their quality of life (QoL). The World Health Organization has established the importance of measuring individuals' QoL and of developing and using age-specific QoL tools. However, to date no dementia- and age-specific QoL scale has been developed for use with older family carers.

Aim: This PhD study aimed to develop and evaluate the psychometric properties of the 'Dementia Quality of Life Scale for Older Family Carers' (DQoL-OC), a dementia- and age-specific scale for the evaluation of QoL of older family carers. This tool might provide more robust QoL outcomes than scales currently being used with this particular population, helping to improve the quality of the evidence that results from studies and interventions aimed at evaluating and enhancing the QoL of these individuals.

Methods: This is a sequential exploratory mixed-methods research. The DQoL-OC items were identified in four focus groups with 19 older family carers in Nottinghamshire. Data were transcribed verbatim and analysed by two researchers independently, using Interpretative Phenomenological Analysis. Inter-coder reliability was established using the Cohen's kappa coefficient. A set of 89 items assessed using a five-point rating scale was generated and evaluated for content and face validity by a panel of six experts. The modified version of the DQoL-OC containing 100 items was then tested with a non-probabilistic sample of 182 older family carers in the UK who were providing care at home for family members with dementia. A battery of additional scales was administered to establish convergent construct validity: the Satisfaction with Life Scale; the WHOQOL-AGE QoL Scale; Perceived Health Status Visual Analogue Scale; and Overall Perceived Health-Related Quality of Life Visual Analogue Scale. The QoL model was identified using Exploratory Factor Analysis. Eighteen participants took part in the test-retest reliability, and the two measurement sets were correlated using Intraclass Correlation. Cronbach's alpha was used to measure internal consistency reliability. The Pearson coefficient was used to provide evidence of convergent construct validity and the Spearman’s rho coefficient was used to correlate the DQoL-OC with other sociodemographic and caregiving variables.

Results: Thirty-three themes emerged from focus groups and were collated into three superordinate themes: aspects of care and caregiving; feelings and concerns; and satisfaction with life and with caregiving. Very good inter-coder reliability was established (r=0.839). The psychometric study demonstrated that a one-factor solution containing 22 items best represented the new QoL model. Excellent test retest reliability (lower bound r=0.835; <0.0001) and internal consistency (α=0.936) scores were obtained. Convergent construct validity was established for all tested scales (<0.0001). Significantly lower levels of QoL were found in female older carers, those who perceived their relatives with dementia as being at the earlier stages of the disease and with unstable dementia symptoms, those providing care more hours per day and more days per week, and those in younger-old age.

Conclusion: This study allowed the exploration of a broad range of aspects that are of particular importance for the QoL of older family carers of people with dementia. The DQoL-OC was considered by participants to be a relevant and useful measure of QoL. DQoL-OC is a valid and reliable 22-item tool assessed using 1 to 5 rating scales, which may be useful in clinical practice and in research in order to improve the QoL of older family carers of people with dementia. These findings will inform future health and social care practice with regards to improving life quality for this overlooked sector of the population.

RESEARCH DISSEMINATION

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- Oliveira DC, Vass C, Aubeeluck A. Ageing and quality of life in family carers of people with dementia being cared for at home: a literature review. Quality in primary care (Open Access) 2015; 23(1):18-30.

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- Research Away day, The University of Nottingham. Panel of questions: Prof. Avril Drummond, SHS Director of Research (Chair); Prof. John Atherton, PVC and Dean, Faculty of Medicine and Health Sciences; Dr Kristian Pollock, SHS Ethics Officer and Dr Maria Michail, Director of Postgraduate Research (Interim); and Déborah Oliveira, 3rd year PhD student representative.

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I dedicate this PhD thesis to Zico, my beloved grandfather, who passed away when he was 92 years old while he was an older carer.

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ABBREVIATIONS

AC-QoL	Adult Carers Quality of Life
AD	Alzheimer's disease
ADI	Alzheimer's Disease International
ADLs	Activities of daily living
AD-QoL	Alzheimer's Disease Quality of Life
CASP-19	Needs satisfaction model in early old age: control, autonomy, self-realization, pleasure
CCG	Clinical Commissioning Group
CF	Consent form
CFA	Confirmatory factor analysis
CGQOL	Caregiver Quality of Life questionnaire
CI	Confidence interval
CQoLC	Caregiver Quality of Life Index-Cancer
DQoL-OC	Dementia Quality of Life Scale for Older Family Carers
ESRC	Economic and Social Research Council
EFA	Exploratory factor analysis
FG	Focus group
FTD	Frontotemporal dementia
GCP	Good Clinical Practice
HD	Huntington's disease
HRQoL	Health-Related Quality of Life
HDQoL-C	Huntington's Disease Quality of Life Battery for Carers
ICC	Intraclass correlation
IPA	Interpretative phenomenological analysis
KMO	Kaiser-Meyer-Olkin
MI	Multiple imputation
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NPIs	Non-pharmacological interventions
OPQOL-35	People's Quality of Life Questionnaire
PA	Parallel analysis
PAF	Principal axis factoring
PCA	Principal component analysis
PGR	Postgraduate
PHS-VAS	Perceived Health Status Visual Analogue Scale
PIS	Participant information sheet

PPI	Patient and public involvement
PR	Promax rotation
OPHRQOL-VAS	Overall Perceived Health-Related Quality of Life Visual Analogue Scale
QLQ	Quality of Life Questionnaire
QoL	Quality of life
RCT	Randomized controlled trial
REC	Research and Ethics Committee
SD	Standard deviation
SEIQoL	Schedule for Evaluation of Individual Quality of Life
SF	Short form
SF-36	36-Item Short Form Survey
SWLS	Satisfaction with Life Scale
UK	United Kingdom
USA	United States of America
VAS	Visual Analogue Scale
VD	Vascular dementia
WHO	World Health Organization
WHOQOL	The World Health Organization Quality of Life Instrument
WHOQOL-AGE	The World Health Organization Quality of Life Scale
WHOQOL-BREF	The World Health Organization Quality of Life Instrument Brief Version
WHOQOL-OLD	The World Health Organization Quality of Life Instrument Older Adults Module

Chapter 1

CHAPTER 1. INTRODUCTION

1.1. OVERVIEW

The main purpose of this PhD research is to pioneer the knowledge base relating to the quality of life (QoL) of older people providing care for their family members with dementia in the United Kingdom (UK). Although the population of older family carers is rapidly increasing, little is known about how caregiving affects their QoL. There is currently no age- and dementia-specific QoL scale available for the measurement of the particular views of these individuals. This study therefore aims to develop and to evaluate the psychometric properties of the 'Dementia Quality of Life Scale for Older Family Carers' (DQoL-OC), a unique dementia- and age-specific tool for the evaluation of the QoL of older family carers.

This first introductory chapter is divided into two sections. The first section outlines the relevance of this study by situating it within current policies and will define the main population under study. The second section provides an overview of the thesis, outlining the content of each subsequent chapter.

1.2. RELEVANCE OF THIS STUDY

The number of people affected by dementia is increasing worldwide (Alzheimer's Disease International, 2015). This is a chronic and progressive syndrome with no available cure, and which leads those it affects into a state of complete dependence and consequent need of care. Family members are considered to be the most important resource available to these individuals, saving the National Health Service (NHS) and care systems billions of pounds every year. They are also often considered the preferred source of care by individuals living with dementia (Age UK, 2010, White, 2013).

Because caregiving can have a huge impact on carers' lives, family carers currently represent a major concern for the UK government (HM Government, 2008, Parker et al., 2010, Hoff, 2015, NICE, 2016). Recent statistics showed that 6.5 million people in the UK are carers and this number is expected to increase to 9 million by 2037 (Carers UK, 2015).

Older people who are carers currently constitute a group of around 1.5 million people in the UK (White, 2013, Carers UK, 2016). This number is expected to increase, particularly among those aged 85 and over, whose numbers have more than doubled in the last ten years (Carers UK, 2015). These numbers are alarming, as caregiving can be particularly harmful to older adults. These people often have reduced incomes, may be living with long-term conditions themselves, and have reduced social networks. Older carers often provide intensive care, with more than half of those aged over 85 providing 50 or more hours a week of care (Jopling, 2015). This has a huge impact both on these individuals' QoL (Carers UK, 2015) and on the quality of the care they are able to provide (Lima et al., 2008).

A recent report from Independent Age and Carers UK pointed out the importance of focusing research on these older people who provide care in the UK, as little is known about their needs (Jopling, 2015). The UK Care Act (HM Government, 2014) and the UK National Dementia Strategy also state that family carers have a right to assessment of their needs (HM Government, 2008, HM Government, 2009), particularly their QoL (HM Government, 2010). It has, however, been demonstrated that the QoL of older family carers of people with dementia is widely overlooked (Carers UK, 2015).

As a fully accepted multidimensional outcome (WHO, 1994, WHO, 1995), the QoL construct provides useful information for clinicians and researchers seeking a better understanding of the impact of caregiving on a wide range of life aspects. QoL measures are increasingly used in health economics and clinical trials: for example, to inform decisions by clinicians and application of resources. Disease-specific QoL scales evaluate the impact of particular diseases on individuals, providing means for appropriate interventions aimed at improving QoL levels of people affected by particular illnesses (Fayers and Machin, 2016).

The need for age-specific QoL measurement tools has been established by WHO (The WHOQOL-OLD Group, 2011, Caballero et al., 2013), with the rationale that because psychological views and appraisals change as people grow older, QoL measures should therefore address specific aspects relevant to each age group. When studying older populations, for example, a focus on aspects of life relevant to younger generations, and which are likely to affect most older people, such as physical health, may compromise the validity of the QoL research (Hyde et al., 2003). Use of instruments that lack appropriate content can thus lead to invalid conclusions, thereby impacting on decisions about treatments, allocation of resources, and development of policies (Haynes et al., 1995). Moreover, it has been pointed out that age-specific scales are more responsive to changes in QoL levels, which makes them more robust measures for use in clinical trials to identify the degree of improvement in QoL resulting from social and health interventions (Hyland, 2003).

National policies state that people with dementia should continue to live in the community for as long as possible (HM Government, 2009). Care and support for these people is mostly provided by family carers, who are often older people themselves. Considering that more research and age-specific interventions are necessary in order to understand and to meet the needs of older carers (Age UK, 2010, Carers Trust, 2011, NICE, 2015), and that the use of measurement tools valid for use with the target population can lead to advances in theory and practice of the area being studied (Vogt et al., 2004), it follows that the use of an age- and dementia-specific QoL tool will provide valid information that will enable researchers, clinicians, and policy makers to improve the QoL of older carers. In addition, such a tool can be more responsive to changes in QoL when implementing new interventions aimed at improving the life quality of these individuals. Besides improving the lives of these people, such an instrument may therefore benefit the broader society and its resources.

A European consensus on outcome measures for dementia research has highlighted the lack of research and measurement tools related to QoL for use with family carers (Moniz-Cook et al., 2008). In addition, a literature review carried out as part of this PhD study showed that a wide range of instruments developed for use with the general population or applicable to carers in all age groups has been used with older family carers. These general instruments may not reflect the specific aspects of QoL relevant to this group or represent caregiving issues that are particularly related to their own QoL. The current study therefore aims to fill this gap by exploring the particular aspects of QoL relevant to older carers of people with dementia, and by developing and validating a unique and age-specific QoL scale for use with these people. It is a response to policies and public reports which highlight the need for research with older family carers of people with dementia and for the development of valid and reliable QoL scales for use with these individuals. This mixed-methods research will help to improve the quality of future investigations with this particular population and will inform current and future care and research in this field. It will provide a robust measurement tool for use with older carers of people with dementia, which will help to improve the quality of health and social interventions focused on these individuals, as well as in research aimed at measuring their QoL.

1.2.1. Who are the 'older family carers' in this research?

There is no consensus in the literature about the nomination and definition of carers. These individuals are often called 'family carers' if the requirement is to emphasize their relationship with the care recipient (Chenoweth and Spencer, 1986, Cooper et al., 2010); 'primary carer' or 'principal carer' when the carer is the major provider of care (Zanetti et al., 1999, Allen et al., 2012); concepts such as 'dementia carers', 'cancer carers', or 'elderly carers' when researchers want to relate them to the disease affecting the cared for (Roberto, 1993, O'Connell et al., 2013, Applebauma and Breitbarta, 2013); and 'formal or informal carers' when the wish is to address the person's expertise in health or social care relating to this task (e.g. nurses as formal carers, family members as informal carers) (Richtera et al., 1995, McGarry and Arthur, 2001, Andrieu et al., 2007), which is also related to the fact that some carers are 'paid' or 'unpaid' for their carer role (Hileman et al., 1992, Thies et al., 2013). Nolan et al. (1996) argued that carers do not appreciate the word 'informal' and that care recipients do not wish to be called 'dependants'. For these authors, not all carers are family members and being cared for does not represent "the reciprocal nature of caring relationship" (Nolan et al., 1996 p.4). However, the authors chose to adopt the terms 'family carer' and 'cared for', arguing that these may represent the least judgmental or pejorative terms for the study of carers.

According to WHO and the United Nations, 'older people' are individuals aged 60 or above (WHO, 2005, WHO, 2011, United Nations, 2013, WHO, 2014). The British charities Age UK and Carers UK (Carers UK, 2015) consider 'older carers' to be individuals aged 65 or older who provide unpaid care to a relative or friend. There is no agreement in the general literature about the age cut-off point for defining older family carers, however, with various studies defining them as anywhere from 45 to 65 years old.

Taking this into consideration, participants in the current study are called older family carers and defined as being individuals 60 years old or above currently providing unpaid care for a family member with dementia at home, supervising or helping them with the activities of daily life that they can no longer perform independently. Establishing this specific age boundary will allow comparisons between the results of this research with other studies. Moreover, some studies refer to carers between 60 and 79 years old as 'younger-old carers', and those aged 80 or above as 'old-old carers' or 'oldest-old carers'. These terms will be used in this current study to classify these subsets of carers within this particular age group. All carers below 60 years old will be hereafter called 'young carers' or 'young adult carers'.

1.3. OVERVIEW OF THE CHAPTERS

This PhD thesis is divided into seven chapters.

Chapter 1 introduces and situates the study within current policies.

Chapter 2 presents a literature review on dementia and family caregiving. The first part provides some factual information about dementia and how this syndrome impacts on patients, family members, and society. The societal and economic burden of the disease is demonstrated, indicating the importance of carrying out research within this specific disease context. The second part introduces some of the most commonly used family caregiving models and presents the available literature on older family carers particularly related to dementia in order to provide a rationale for focusing on QoL research outcomes.

Chapter 3 presents a literature review on QoL, its main theoretical foundations, domains, and measurement aspects. It presents the current debate around conceptualization and operationalization of the construct, followed by a critical discussion of why QoL scales should be age specific. Particular aspects of QoL for older individuals are presented, and the psychological aspects involved in QoL evaluation are detailed. A brief discussion follows on how ageing and life experiences can change the way older carers perceive and appraise their own QoL, justifying the need for the development of an age-specific QoL scale for use with these individuals. A rationale for the development of this research is then presented, based upon the intersection between QoL in later life, older family carers, and dementia, leading to the development of the aim and objectives of this research.

Chapter 4 presents the research methodology and methods employed to reach the research aims and objectives. It explores the relationship between the chosen methodology, philosophical assumptions, and theoretical frameworks adopted in this study, providing a rationale for the chosen research design and the methods of data collection and analysis. An overview of the study design is outlined and relevant aspects of scale development are presented. The research process is described, including detailed information about the epistemological assumptions underpinning this research, theoretical frameworks, methodological approach, and methods.

Chapter 5 presents the findings from focus groups carried out with older family carers of people with dementia. It details the recruitment process, characteristics of participants, data analysis, and strategies employed to maintain the study’s rigour. Themes emerging from this qualitative study are collated into superordinate themes and described individually, aiming to provide the basis for developing items in the Dementia Quality of Life Scale for Older Family Carers (DQoL-OC). These findings are then discussed in the context of the current literature in order to justify the selection of a specific set of items to be tested as part of the DQoL-OC.

Chapter 6 presents the process of item development and the psychometric evaluation of the DQoL-OC. In the first part, decisions regarding scale design and item generation are detailed, resulting in an item pool for subsequent scale development and psychometric testing. The process of recruiting and consulting an expert panel to ensure face and content validity of the DQoL-OC is then described. Following this the psychometric study is detailed, establishing the validity and reliability of the DQoL-OC and providing the final version of the scale.

Chapter 7 discusses the quantitative findings used to provide evidence of validity and reliability of the DQoL-OC for use in research and clinical practice. First, methodological considerations are made regarding sample characteristics and the statistical tests employed. The psychometric properties of the DQoL-OC are then compared and discussed in relation to other available QoL tools and outcomes with this specific population. Finally, the study limitations and implications for research, older family carers, clinical practice, and future research are presented.

Chapter 2

CHAPTER 2. DEMENTIA AND FAMILY CAREGIVING IN LATER LIFE

2.1. OVERVIEW

This chapter will provide a context for dementia and family caregiving prior to an in-depth exploration of QoL theories and measurement. First, current dementia statistics and symptomatology will be presented in order to demonstrate the importance of carrying out research within this disease context. This section will also show the impact of dementia on patients and society, particularly on family members who provide care to people affected by this syndrome. Finally, the results of an exploratory literature review about older family carers will be detailed in order to demonstrate the importance of research on this particular carer population. The shortage of research into the QoL of these people will be evidenced, providing a rationale for focusing on this particular research outcome.

2.2. DEMENTIA

2.2.1. Current statistics

As the older population increases worldwide, the prevalence of diseases that commonly affect this group of people is increasing proportionally. The incidence of dementia rises exponentially in later life and doubles with every 6.3 year increase in age (Prince et al., 2015). Alzheimer's Disease International (ADI) has recently estimated that over 46 million people worldwide are currently living with dementia and that this is expected to increase to 131.5 million by 2050 (Prince et al., 2015). The regional distribution of new cases is around 4.9 million (49%) in Asia, 2.5 million (25%) in Europe, 1.7 million (18%) in the Americas, and 0.8 million (8%) in Africa (Prince et al., 2015). There are around 850,000 people currently living with dementia in the UK, and this number is expected to increase to one million by 2025 (Prince et al., 2014). On the other hand, recent UK evidence has identified a lower incidence of dementia in older adults, particularly in the male population, probably due to improved lifestyle (Matthews et al., 2016).

2.2.2. Causes and symptoms

Dementia is a syndrome characterized by intellectual and behavioural deterioration, changes in concentration and memory, and decline in physical and cognitive abilities and is caused by a range of diseases (Prince et al., 2013c), some of which have been recognized as brain conditions, particularly those affecting older people (Prince et al., 2013a). According to a report published by Alzheimer's Society UK (Prince et al., 2014), about 62% of all cases of dementia are caused by Alzheimer's disease (AD) and 17% by vascular dementia (VD); 10% are mixed dementia, 5% are rarer causes of dementia, 4% are dementia with Lewy bodies, and 2% of cases are frontotemporal dementia (FTD). About 5 to 10% of the population aged 65 and over and 40% of the population aged 85 or over are likely to be affected by AD (WHO, 2012).

In AD, problems with day-to-day memory are often the first noticeable signs, but symptoms may also include difficulties in finding the right words, solving problems, making decisions, or perceiving dimensions of objects (Chiu et al., 2006, Prince et al., 2014). Individuals affected by VD often show difficulties with problem-solving, planning, thinking quickly, and concentrating, as well as fluctuating periods of confusion. People diagnosed with mixed dementia are affected by more than one type of brain disease and present with a mixture of symptoms. In these cases, it is very common for individuals to be diagnosed with both AD and VD, in which cases symptoms may overlap (Chiu et al., 2006, Prince et al., 2014).

Early symptoms of dementia with Lewy bodies can include fluctuating alertness, difficulties with judging distances, and hallucinations. Day-to-day memory is usually affected less than in early AD. It is closely related to Parkinson's disease, often with the same symptoms, including difficulty with movement (Chiu et al., 2006, Prince et al., 2014). In frontotemporal dementia, however, changes in personality and behaviour are the most common symptoms in the early stages of the disease. The person affected may have difficulties with fluent speech or forget the meaning of words (Chiu et al., 2006, Prince et al., 2014).

Despite the particular characteristics of each cause of dementia, individuals experience the syndrome in their own way, especially in the early onset period. The symptomatology tends to become similar as the brain becomes more affected by the different brain diseases (Prince et al., 2013b, Prince et al., 2014). Stages of dementia are also likely to overlap (e.g. the person may need help with one task but be able to manage another activity on his/her own); some symptoms may appear at one stage and then disappear, while others will worsen over time, or not appear at all (Dowrick and Southern, 2014). The individual's behaviour and mood are likely to change, and daily living skills (e.g. dressing, managing medication) and overall functioning are likely to be affected as the disease progresses (Prince et al., 2015).

During the middle and late stages of dementia, symptoms of the different types of dementia tend to become similar. Individuals lose their autonomy, becoming dependent and requiring complete support for the activities of daily living (ADLs) (WHO, 2012, Prince et al., 2013b). Many factors are involved in how this process unfolds, such as the type of disorder affecting the brain, the individual's physical state, the presence of other associated illnesses, emotional resilience, the treatment in use, and the support available (Dowrick and Southern, 2014).

2.2.3. Diagnosis and treatment

Diseases causing dementia syndrome have no available cure, even though new treatments and vaccines are continuously being developed. Pharmacological treatments depend on the type of dementia; these can help to control symptoms or may delay the disease progression for a certain period of time. Non-pharmacological interventions (NPIs), such as cognitive therapies, social interventions, good quality care and support, have been demonstrated to help the person with dementia to live independently for longer (Prince et al., 2014).

The diagnosis and differentiation of each type of dementia often remain inconclusive due to the boundaries between these subtypes being indistinct and the person affected presenting with mixed causes and symptoms (McKhann et al., 1984, Geldmacher and Whitehouse, 1996, Jack Jr et al., 2011, McKhann et al., 2011). For this reason, social and health research has grouped people with different dementias and their carers, using dementia as an 'umbrella term' and investigated them as an homogenous group (see, for example: Ory et al., 1999, Connell et al., 2001, Prince et al., 2013c, Joling et al., 2013, Camic et al., 2013, Moon and Dilworth-Anderson, 2014, Lambert et al., 2014, Stewart et al., 2014). In order to allow comparisons of these studies with the findings of the present research, as well as to allow the inclusion and benefit of a wider population of older carers, the current study has also investigated carers of individuals living with different dementias.

2.2.4. The societal cost of dementia

It has been estimated that the total global societal cost of dementia was $422 billion in 2009, including $142 billion spent on informal care (34%) (Wimo et al., 2010). This amount increased to US $818 billion in 2015 and is expected to achieve one trillion dollars by 2018 (Prince et al., 2015).

Dementia in the UK incurred an annual cost of £26.3 billion in the last few years, which is equivalent to 25% of the total NHS annual budget (2014-2015) (Prince et al., 2014, NHS, 2015). Of this, only £8.8 billion has been contributed by the UK Government, with the remaining £17.4 billion coming from people with dementia and their family members (Kane and Terry, 2015). It has been demonstrated that dementia costs match the combined costs of cancer, heart disease, and stroke. However, a study carried out in 2012 demonstrated that 71% of the total public budget is being allocated to cancer, 20% to cardiovascular diseases, and only 6% to dementia (Luengo-Fernandez et al., 2012). In addition, relatively little research has been carried out within dementia, and therefore more studies need to be undertaken focusing on the individuals affected and their families (Sousa et al., 2009).

2.2.5. The impact of dementia on families

As dementia leads the person to high levels of dependence, individuals affected will increasingly need help to perform their daily activities (such as cleaning the house, answering the phone, bathing, feeding, and toileting). Most of the time, family members assume these tasks, assisting relatives with activities that they are no longer able perform independently (National Institute on Aging, 2005, WHO, 2012, Prince et al., 2013b). Additionally, it has been shown that 7 in 10 people with dementia in the UK are living with another medical condition or disability, which generates even more care demands (Dowrick and Southern, 2014).

Besides providing physical care and assuming the responsibilities involved with caregiving, family members also offer emotional support and manage the person’s behavioural and cognitive symptoms. In addition, being a carer involves facing one's own feelings of insecurity in having responsibility for the life of a family member and the frustration of seeing their loved one deteriorating. Despite these challenges, family carers do not receive adequate support and are expected to put their own lives and interests to one side in order to provide care, which can have significant impact on their own QoL and well-being (Kane and Terry, 2015). This research will focus on the needs of these family carers.

2.3. FAMILY CAREGIVING

This section will first provide a brief outline of the theoretical models commonly applied to family caregiving research and will introduce some of the concepts mostly used within this field of study. A literature review on older family carers will then be presented, demonstrating the rationale for focusing on QoL research when examining the needs of family carers.

2.3.1. Family caregiving models

Caring for a family member is intrinsic in relationships between human beings. However, in some circumstances, caregiving is transformed from a normal exchange of assistance to an extraordinary and unequally distributed burden (Pearlin et al., 1990). Under conditions of chronic and progressive impairment, such as dementia, caregiving may expand to the point where it occupies the totality of the relationship. Help, assistance, and affection progressively become unidirectional, so that they are predominantly from the carer towards the cared for (Pearlin et al., 1990).

Considering that family caregiving can become such a negative aspect of life, researchers have questioned why family members continue to provide such care, often until the death of the person affected by the chronic condition. Attitudes to this type of caregiving are associated with individual and social factors, which are strongly influenced by ethnicity and culture. Some of the reasons for caregiving discussed in the literature are, for example, acceptance of cultural norms, which includes familism, obligation, and reciprocity; affection; giving meaning to life, which includes dignifying, feeling competent, and desire to live in relationships; financial compensation; and lack of choice (Schulz, 1990, Feeney and Collins, 2003, Dilworth-Anderson et al., 2004). Other aspects discussed are egoistic and self-serving motives, together with compassion, altruism, attachment or empathy, reciprocity, equity, social responsibility (or duty) or pro-social behaviour (Schulz, 1990, Feeney and Collins, 2003).

Because providing care can be a challenging experience, most of the available literature has focused on negative caregiving outcomes, such as stress (Lazarus, 1966, Lazarus and Folkman, 1984, e.g. Pearlin et al., 1990). Lazarus and Folkman's transactional stress and coping model (Lazarus, 1966, Lazarus and Folkman, 1984), for example, is one of the most common psychological concepts applied to family caregiving. It posits that a stressful experience is not inherently so but may be experienced as such after having passed through an individual two-step appraisal process. Stress is located in the relationship between the person and the environment, and the meaning given to it varies according to personal goals, beliefs, and environmental aspects. This is a complex process, located within the individual, which incorporates mental activity as a driving force. Figure 1 gives a brief interpretation of this model in the caregiving experience.

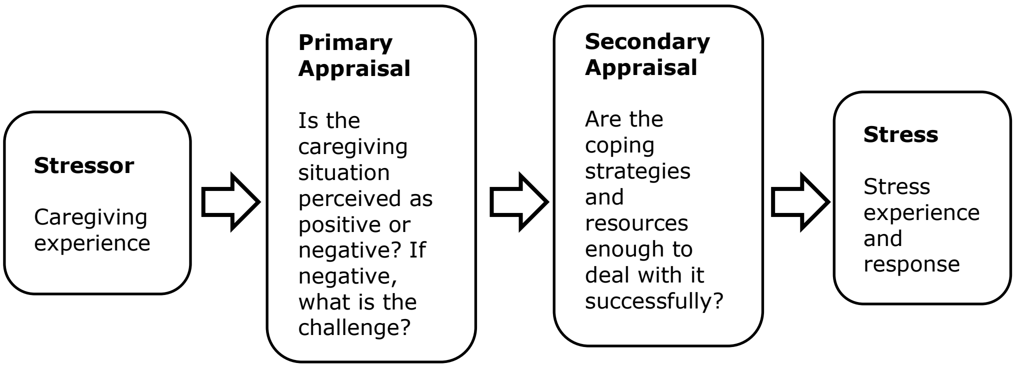

Figure 1. Interpretation of Lazarus and Folkman's transactional stress and coping model to caregiving situation (Lazarus, 1966, Lazarus and Folkman, 1984)

Burden is also a concept commonly investigated in family caregiving research, both as a predictor and as an outcome (Chou, 2000). Zarit et al. (1980) defined burden as being a multidimensional response to negative appraisal and perceived stress resulting from taking care of an ill individual, which may affect the physical, psychological, emotional, and functional health of carers. According to these authors, burden is the product of a specific, subjective, interpretive process. Later, it was suggested that burden could be divided into two concepts: objective and subjective burden. Objective burden is defined as observable costs to the family which result from the disease (e.g. disruption to everyday life, financial pressure, limited social life), whereas subjective burden is the carer's perception of the situation as being burdensome (Montgomery et al., 1985).

Even though such concepts have been commonly applied to caregiving, there has been a shift in this pattern in the recent years. Researchers have started to demonstrate the existence of positive aspects of caregiving and their usefulness for health professionals and researchers in order to help carers cope with this experience. Satisfaction and reward, for instance, may explain why some carers cope better than others (Noonan and Tennstedt, 1997, Carbonneau et al., 2010, Lloyd et al., 2014). Research focusing solely on negative aspects of caregiving has therefore been criticized (Noonan and Tennstedt, 1997, Carbonneau et al., 2010) and has been seen as preventing development of a better understanding of coping and the factors that influence it (Folkman and Moskowitz, 2000).

In an attempt to change this, a recent literature review carried out by Lloyd et al. (2014) has identified several positive aspects of caregiving in dementia which should be considered in future research (Table 1). In addition, other authors have attempted to create new caregiving models relating to positive aspects of being a carer. Nolan et al. (1996), for example, developed a multidimensional model of caring and coping integrating several theories and perspectives aiming to provide a more holistic view of carers' needs. The authors emphasized the balance between burden and satisfaction of caring, as well as the coping mechanisms involved. One criticism of this model, however, is the fact that positive and negative aspects of caregiving are not opposite ends of the same continuum and that correlations between the two tend to be low; therefore they should not be included as part of a single stress-coping model (Lloyd et al., 2014).

Table 1. Positive aspects of dementia caregiving (adapted from: Lloyd et al., 2014)

Positive aspect	**Associated factors**
Role satisfaction	Sense of doing a good job; keeping the care recipient safe or making them as comfortable as possible; feeling that they are 'doing their best'; sense of pride; sense of purpose; previous quality of relationship between carer and care recipient.
Emotional rewards	Feeling appreciated or successful, particularly from the care recipient themselves; enjoying each other's company; perceived social honour.
Personal growth	Increased patience, self-respect, and being more self-aware; sense of peace; becoming humbler; personal growth; spiritual growth; relationship gains.
Competence and mastery	Opportunity to learn new skills in terms of caring and transferable skills, such as problem-solving; feeling of achievement of something they did not think they were capable of; wish to share their skills and knowledge with others; considering changing career to a caring profession; increased confidence and self-worth as a result of learning new skills such as cooking or housework.
Faith and spiritual growth	Enable carers to take on the caring role and provide them with the strength to continue; valuable source of support; broader positive change in philosophy, by placing less value on material goods and focusing more on relationships; gaining a broader perspective on life; new meaning in life.
Relationship gains	Gains relating to companionship; strengthening their relationship; bringing greater emotional closeness; increasing the intimacy in the relationship; strengthening a relationship with a parent that had become distant as a result of everyday life; gains in the relationships with immediate family; appreciate those around them more.
Sense of duty	Intrinsic reward in upholding their marital vows and expressing pride in being able to care for their lifelong spouse; pleasure in being able to uphold cultural values; pride in following tradition.
Reciprocity	Opportunity to give back to their loved one; wanting to repay the love and care they have received from their spouse or parent; demonstrate positive attitude to their children.
Variables leading to positive appraisal	**Associated factors**
Acceptance	Giving up previous plans, focusing on living day by day and accepting the limitations of the person being cared for; gaining an understanding and being compassionate and empathic towards the person being cared for.
Choosing a positive caregiving attitude	Active choice; practising a positive attitude by dwelling on positive thoughts and avoiding negative ones; counting blessings; cherishing what remains; choosing to use humour.
Commitment to relationship	Feeling and receiving love; helping carers to put their partner first and be compassionate; maintaining commitment enables them to maintain their stamina for caring; cherished memories; being able to find joy in memories informs how carers view them in the present.
Creating opportunities	Actively choosing to create opportunities for the person to engage in meaningful activities; being happy and comfortable if they feel that their care recipients are too; providing hope.
Drawing strength from faith/past experiences	From faith, from past challenges, from supportive friends, family, or services.

As briefly demonstrated, caregiving models have been developed and modified over the years in order to provide a better understanding of the caregiving experience and to provide means for interventions. Even though these offer researchers and clinicians useful guidance for a better understanding of caregiving mechanisms, they are still limited to particular aspects of the experience of providing care. Available theories have limitations related to the restricted number of dimensions or variables included, with a focus on the negative or positive aspects of caregiving only, rather than providing a more holistic view of the caregiving experience and its actual impact on carers' lives. The literature has therefore emphasized the need for research focused on the particular views and needs of older family carers from the perspectives of the carers themselves. This could be done by using multidimensional measurement outcomes in order to shed light on the link between caregiving negative and positive aspects with the carers' different life aspects (Bowling, 2005a, Steptoe et al., 2015b).

2.3.2. Family caregiving in later life

As the number of older adults is expected to increase worldwide, it is estimated that the number of carers will increase by around 60% during the next 30 years (White, 2013). Current statistics in the UK suggest that there has been an increase of 600,000 family carers in various disease contexts during the period from 2001 to 2011. There are currently 6.5 million people who are family carers in the UK, and this number is expected increase to 9 million by 2037 (Carers UK, 2015). These people have saved the public purse approximately £119 billion every year (White, 2013).

Although health care providers usually view older people as the recipients of informal care, these individuals provide an increasing and substantial amount of care to family members with health problems and disabilities. In the UK, the proportion of older family carers has increased by 35% since 2001 and is rising as the older population increases (White, 2013, Jowsey et al., 2013, Lautenschlager, 2013, Lautenschlager et al., 2014, Carers UK, 2015, Luchesi et al., 2015). In particular, there has been an increase of 33.6% in the group of carers aged 60 to 74 and 39.5% in the group aged 75. In total, half of all family carers are aged over 50 and 1.5 million are over 60 (White, 2013). Nearly a quarter of all family carers are older spouses who co-reside with their care recipients (Schneider et al., 1999, White, 2013).

Similar figures are identified in other high-income countries, such as in the United States of America (USA) (AARP Public Policy Institute and National Alliance for Caregiving, 2015), Canada (Smith and Binder, 2011), Australia (McCann et al., 2000, Loi et al., 2014), and Iceland (Sigurðardóttir and Bravell, 2013), and in some low- to middle-income countries (Hosseinpoor et al., 2013). Furthermore, the incidences of family caregiving appears to increase as people grow older, with both the probability of being a care provider and the amount of time spent providing care each week increasing significantly with age, particularly for married people (McCann et al., 2000, Burton et al., 2003).

It is also important to highlight that family caregiving in later life is a long-term commitment. A study examining longitudinal data from 5,220 people in their 50s and 60s in the USA found that more than 90% of these individuals had been involved with some kind of informal support provision to a family member or a friend over the 10-year period of the study (Kahn et al., 2011). Besides caring for other older people, older carers are often also involved in the care of their children and grandchildren (Vlachantoni, 2010) and therefore are more likely to be caring for more than one person at the same time (Carers Trust, 2011, Ghosh et al., 2012). Carers for children with disabilities are likely to be providing care for their spouses with a disability at about the same time, which makes these individuals more vulnerable to the negative effects of caregiving (Ghosh et al., 2012). Older people providing care for more than one person have also been identified as dedicating more time to care provision, as well as having increased desire to place their cared for into residential care (Perkins and Haley, 2010).

The increasing number of older people involved with caregiving is therefore a matter of public concern, and it is necessary to investigate how this activity impacts on these individuals' lives. Dementia is considered one of the most prevalent chronic disorders in older adults and is responsible for the greatest incidences of disability in this population (Hoffman et al., 1995, Sousa et al., 2009, Prince et al., 2013a, Lambert et al., 2014). Because this syndrome is considered one of the most disabling and burdensome health conditions worldwide (Ferri et al., 2005, Kukull, 2006, National Institute on Aging, 2011, WHO, 2012, Prince et al., 2013a, Lambert et al., 2014), research in this area is considered paramount (Sousa et al., 2009). For this reason, it was decided to focus this PhD study on the impact of dementia caregiving on older people who are carers in the UK.

2.3.3. Literature review of older family carers

Prior to conducting empirical work, a narrative review using a systematic approach to the literature was carried out in the main social and health care databases. This aimed 1) to identify current research outcomes in older family carers; 2) to identify the research gap that needed to be addressed within the study; and 3) to provide a rationale for focusing on the QoL construct (Green et al., 2006, Rother, 2007). Even though a systematic review is often used prior to scale development to identify current measurement tools being used with the target population, conducting a broader review using a transparent and reproducible search strategy facilitated a clear and robust exploration of a wide range of aspects associated with the QoL of older carers, as well as the identification of the types of measurement tools used with these people.

The following databases were used: Embase, MEDLINE, PsycINFO, CINAHL, ASSIA, and Google Scholar. The search was limited by the population age (≥45 years old) and language (English). The literature search aimed to identify articles that contained at least one of the combinations given in Table 2. These keywords should be present in the title, abstract, or indexing key-words of the publications. Because the amount of research exploring the older family carers of people with dementia was expected to be limited, the review search was not limited to dementia context or study design. A general search strategy also provided a broader overview around family caregiving in later life and allowed for the identification of the particular aspects of dementia care, as well as facilitated comparisons with older people providing care within different disease contexts.

Table 2. Search strategy

Key-word combinations[1]			
OR	aged	(informal)	caregiver*
	ageing	(non-professional)	carer*
	aging	(non-formal)	spouse*
	elder	(family)	couple*
	elderly	(unpaid)	husband*
	older	(spousal)	wife
	senior		wives

[1] Terms were adapted according to each database

A total of 3,244 documents were initially identified. After screening by title and abstract, 1,081 possibly relevant documents were selected. A more detailed review of the full content of each publication was then carried out, and the final search resulted in 623 documents. Publications not associated with caregiving, for example grand parenting and older couples' relationships without caring, were excluded. In addition, studies addressing older carers of children (e.g. with learning disabilities) were mostly excluded, as the caregiving experience and impact can be considerably different to that of the care provided to parents or spouses with chronic illness. Only peer-reviewed articles were included.

The selected studies were screened and categorized in themes, according to their specific focus (e.g. mental health or social relationships). The search history was saved and retrieved monthly throughout this PhD research to ensure the literature review remained current on completion of the study. After the initial literature search, very few further studies about older carers were published in subsequent years, with none investigating the QoL of these people, particularly within a dementia context. This underlined the need for further research on this topic.

Even though this thesis is mainly focused on QoL, the researcher drew from a wider pool of variables to inform initial phases of tool development in line with existing literature. Because the QoL construct comprises a wide range of life domains (see Chapter 3) and is affected by several other outcomes (such as levels of burden, strain, stress), these were also explored in order to identify factors that could potentially affect older carers' QoL. Because of the large number of documents identified (n=623), these were read and allocated into major groups, such as focus on mental health, physical health, etc. in order to facilitate the presentation of the results within this chapter. The studies hereafter detailed represent an overview of the main findings, and so not all the selected studies are cited.

2.3.3.1 Sociodemographic characteristics of older carers

Gender

It has been demonstrated that women of all ages are more often involved than men with providing care for family members, most especially in middle age (Gierveld et al., 2009). In the UK, for example, around 58% of all family carers are female and 42% male (White, 2013). However, this tendency is likely to disappear with older carers, as research has shown that older carers of both genders are equally involved with care provision for dependent family members, differing only in the type of care provided (e.g. emotional support, housework, etc.) (Ducharme et al., 2006, Kahn et al., 2011).

Even though the male population of older carers tends to be higher when compared with young adult carers (Del Bono et al., 2009, Neri et al., 2012), in the group of those providing 50+ hours of care a week the percentage of female is significantly higher (White, 2013). In addition, older women are more likely than older men to be poor, widowed, and in poor health (Kadena and McDaniel, 1990, Gibson et al., 2015), which is likely to affect their ability to provide care. These challenges may also affect how carers engage with their carer role and how they perceive the impact of caregiving on their lives. Male and female carers may therefore experience or conceptualize care differently, and this should be taken into consideration by practitioners and researchers in any work involving family carers (Ducharme et al., 2006, Baker et al., 2010).

Ethnicity

Different levels of care provided by older people may also reflect particular cultural backgrounds (for example, religious values, family obligations, and expectations for reciprocal care), as well as legal and health environment issues. Evidence suggests that even when living in another country, the cultural ties of migrant older populations remain and still influence the experience of caregiving (Kim and Theis, 2000, Oudijk et al., 2011, Hosseinpoor et al., 2013). For Koreans living in the USA, for example, familyism plays a significant role in caregiving activities. Carers with this cultural background are often older females who consider their caring activity as an obligation and duty expected of them as a spouse (Kim and Theis, 2000). Differences in caregiving patterns and carers’ outcomes among different ethnic backgrounds have been identified by several other studies (McCann et al., 2000, Phillips et al., 2000, Holroyd, 2005, Parveen and Morrison, 2009, Chan and Chui, 2011), suggesting the importance of considering this when investigating family carers.

Relationship with the cared for

The relationship of the carer with the person being cared for is also associated with differences in carers' outcomes. For this reason, researchers have advised consideration of this variable when planning interventions to improve support, for example, as it is likely to affect the effectiveness of health and social interventions (Pinquart and Sorensen, 2011, Wilcox et al., 2001).

While young adult carers are mainly daughters, older carers are usually cohabiting spouses or partners who provide intensive levels of personal care for longer periods (Burton et al., 2003, de Vugt et al., 2006, Ross et al., 2008, Lavela and Ather, 2010). Particularly in dementia, older spousal carers are often engaged in demanding and time-consuming care, ranging from supervision to heavy physical responsibility, with the care provided not just restricted to the practical aspects of caregiving, but also involving considerable levels of worry and concerns about their partners (Jansson et al., 2001). This is likely to affect the closeness of the relationship (Robinson-Smith and Mahoney, 1995, Barusch and Spaid, 1996, Rudd, 2003) due to a profound sense of loss, added to the need to adjust to a new kind of relationship with the spouse (Coombs, 2007).

In addition, pre-existing gender relations continue to be powerful determinants of the experience of caring in older couples. With marital power often retained by men, the care contribution of older husbands is often associated with positive meaning, is highly valued, and offers a distinctive role and identity. This is very different from the experiences of older wives, for whom providing care is an expectation (Milne and Hatzidimitriadou, 2003). In being a spousal carer, the demands of additional caregiving roles, such as caring for children or parents, do not seem to affect the amount of spousal care provided (Lima et al., 2008). This type of caring is particularly important not only because of its high prevalence and impact on carers but also because it is often invisible and performed silently within the family. Some argue that this is due to a societal and familial belief that considers it as a marital duty (Jansson et al., 2001).

2.3.3.2 Impact of caregiving on older family carers

Older carers, especially those aged 70+, are responsible for providing care for the longest periods of time (often ≥ 60 hours per week over a seven-day period) (Schneider et al., 1999, Carers Trust, 2011). These individuals usually co-reside with their cared for and care is provided with no respite breaks (Carers Trust, 2011, Steptoe et al., 2015b). The costs of caregiving at home are high and normally paid for by the care recipients or the pensioner family member (Weinbeiger et al., 1993). Older carers usually provide care for chronically impaired family members for many years, during which time they will be burdened by both caregiving and the physiological and physical changes resulting from their own ageing process. As older carers are more likely to provide personal care to another person of a similar age, caregiving can thus be physically demanding for an older person (Carers Trust, 2011).

As a consequence, older carers generally demonstrate poorer mental and physical health outcomes when compared with young adult or age-matched controls (Butterworth et al., 2010, Huang, 2012) and have a higher risk of general psychiatric morbidity (Al-Zahrani et al., 2015). Caregiving can lead older carers to a decline in self-care (Gallant and Connel, 1997), lower levels of QoL (Serrano-Aguilar et al., 2006, Bruvik et al., 2012), poor family relationship quality (Quinn et al., 2009), higher levels of depression (Covinsky et al., 2003), and also to a higher risk of deterioration in their own cognitive level (Vitaliano et al., 2011). Older carers may also be in greater financial distress, and household tasks may be more burdensome. They often suffer more often from family conflicts and have less social support from their family and spouse (Butterworth et al., 2010).

Physical health

Because of their advanced age, older carers have more reported chronic diseases than young adult carers and a higher risk of developing comorbidities or worsening of current conditions (Jowsey et al., 2013, Wang et al., 2014). A study from WHO with 13,892 older carers identified that 26.9% to 42.5% of the individuals from high- to low-income countries presented with serious relative health conditions (Shahly et al., 2013). Older carers are more likely to report backache, high blood pressure, arthritis, insomnia, arthritis, and hearing problems, or to have two or more current health conditions of any kind when compared with older individuals who are non-carers (Scharlach et al., 1994, Dilworth-Anderson, 2015). Female older carers are often more affected by chronic diseases than the general population, especially white individuals (Fredman et al., 2008, Yamaki et al., 2009, Neri et al., 2012, Wang et al., 2014) and have a higher risk of becoming frail (von Kanel et al., 2006a, Neri et al., 2012).

Furthermore, caregiving can decrease the capacity of the immune system in older carers, as higher levels of stress may dysregulate multiple components of innate and adaptive immunity (Mausbach et al., 2007). This can lead to impaired control of latent viruses, exaggerated production of inflammatory mediators, accelerated cellular ageing, lower cell-mediated immune response to vaccination (Gouin et al., 2008, Wong et al., 2013, Phillips et al., 2015), greater total cortisol levels across the day (Scheyer et al., 2014, Phillips et al., 2015), impaired endothelial functioning (Mausbach et al., 2010), and higher levels of pro-thrombotic markers over time (Mausbach et al., 2007). This may greatly increase older carers' risk of cardiovascular disease and mortality (Mausbach et al., 2007).

Sleep quality

Poor sleep quality in older carers was also identified in this review (Fredman et al., 2014, Dilworth-Anderson, 2015). These outcomes were associated with increased levels of norepinephrine as well as inflammatory and pro-coagulant markers as a result of high levels of stress, especially in dementia carers (von Kanel et al., 2006b). Older carers, especially women, were more likely to report poor sleep outcomes and feel tiredness during the day when compared with non-carer older adults, younger-old adults, and those with low socioeconomic status (Gibson et al., 2015).

Mental health

Depression and stress are the most common conditions investigated in older carers (Schulz and Sherwood, 2008) and are considered major consequences for those providing care for a relative with cognitive impairment (Pearlin et al., 1990, Ballard et al., 1995, Aberdeen, 2007, Arias-Merino et al., 2009, Valimaki et al., 2009, Mould-Quevedo et al., 2013, Seeher et al., 2013), particularly dementia (Lautenschlager et al., 2014).

Overall poorer mental health was identified in those who have physical impairment, lack of social support, greater conflict with the cared for, role captivity, and higher care intensity (Bertrand et al., 2006, Butterworth et al., 2010, Givens et al., 2014). High levels of stress were associated with higher risk for depressive symptoms (Bookwala and Schulz, 2000, Valimaki et al., 2009, Mausbach et al., 2012, Neri et al., 2012, Litwin et al., 2014, Chow and Ho, 2015, Luchesi et al., 2015) and increased older carers' short-term risk of mortality (Fredman et al., 2010).

Older family carers also experience more distress when compared with age-matched non-carers or younger adult carers (Ducharme et al., 2007, Kochar et al., 2007, Anderson et al., 2013, Chow and Ho, 2015), even though old-old spousal carers have been identified with lower distress than younger-old carers (Chow and Ho, 2015). The quality of prior husband–wife relationships, the frequency of disruptive behaviours, existence of family conflicts, and self-efficacy levels are associated with psychological distress in older husband carers (Ducharme et al., 2007). Self-efficacy has been identified as a mediating effect between subjective stressors and psychological distress, whereas the number of services received has a moderating effect on the intention to end home caregiving among husbands with high role captivity (Ducharme et al., 2007).

Older carers co-residing with their loved ones with dementia have higher levels of strain (Moritz, 1996). High perceived strain has also been associated with lower levels of QoL, more emotional distress, poorer physical functioning, fewer social contacts (Roth et al., 2009), functional limitations (Mui, 1995), and 63% higher risk of mortality in this population (Schulz and Beach, 1999). Lower levels of strain were, however, found in older carers (aged 55+) reporting lower distress and depression levels, better mental health, higher subjective well-being, life satisfaction, and purpose in life (Chow and Ho, 2015).

Older family carers have been identified as having a higher prevalence of cognitive impairment when compared with an age-matched non-carer population and a higher incidence of cognitive problems when becoming carers compared with non-carers (Kochar et al., 2007, Norton et al., 2010, Amer et al., 2015). Another study has demonstrated that receiving help with their caring role, as well as having a better financial situation, was associated with better cognitive function in participants (Amer et al., 2015).

Burden

Recent literature has demonstrated high levels of burden in family carers of all age groups (Mould et al., 2012, Mould-Quevedo et al., 2013, Stewart et al., 2014, García-Alberca et al., 2014, Adelman et al., 2014, Costa-Requena et al., 2015). The majority of studies identified in this review suggest high levels of burden in older carers (Kim et al., 2007, Limpawattana et al., 2013, Iavarone et al., 2014, Tuluce et al., 2015) and in older carers when compared with the general non-carer older population (Gill and Feinstein, 1994, Jowsey et al., 2013). However, some studies suggest higher levels of burden in young adult carers when compared to older groups (Cain and Wicks, 2000), whereas others suggest no difference between the two groups (Harris et al., 2000). This inconsistency regarding different age groups may be due to the wide diversity of disease contexts, their different impact on carers, and carers' different socioeconomic and cultural contexts or even to the different age cut-off limit in each study.

Increased levels of burden are associated with female gender (Shahly et al., 2013, Iavarone et al., 2014, Stewart et al., 2014), neuropsychiatric symptoms of the care recipient (García-Alberca et al., 2014, Stewart et al., 2014) and with carers from rural areas caring at home (Stewart et al., 2014). Higher levels of burden may lead to lower levels of self-rated health (Abdollahpour et al., 2014), as well as poor quality of care and poor QoL of care recipients (Opara, 2012) and of QoL carers (Coen et al., 2002, Sands et al., 2004, Vellone et al., 2008, Perrin et al., 2014, Tay et al., 2014). Other risk factors for higher burden in older carers are poor physical and mental health, low learned resourcefulness (Chen et al., 2015), severe dementia, and higher levels of anxiety (Iavarone et al., 2014). Being the spouse of the cared for (Shin et al., 2012, Shahly et al., 2013), having depressive symptoms (Shin et al., 2012), poor self-reported health status, longer duration of care, and low income (Limpawattana et al., 2013, Shahly et al., 2013) are also related factors. Social and behavioural problems of the cared for, perceiving the carer role as a threat and having low perceived instrumental support, poor functional health and self-efficacy (Van Den Wijngaart et al., 2007), and negative affect (Wilson-Genderson et al., 2009) also increase older carers' burden. Socioeconomic conditions appear strongly associated with levels of burden in older carers particularly in middle- to low-income countries and especially in women and spouses (Shahly et al., 2013).

Overall satisfaction and well-being

Even though older carers have been identified as having poorer adaptation to caregiving when compared with young adult carers (Rohr et al., 2013), the literature often suggests that older carers, particularly male older carers (Ekwall and Hallberg, 2007), experience higher positive feelings toward caregiving (Tang, 2011), as well as more satisfaction with life and lower mental distress, than young adult carers (Anderson et al., 2013). This has even led some authors to affirm that appraised satisfaction can be predicted by older carer age (Harwood et al., 2000).

Tang (2011) suggests that higher levels of satisfaction in older carers may be related to the provision of care for an older spouse (which is often the case with older carers), as this might generate greater satisfaction than providing care for older parents. Being involved in the caregiving of their spouses can help carers to affirm their marital bond and to participate in personally meaningful acts (Ka'opua et al., 2005), which seem to give meaning to their lives, especially for male carers (Ekwall and Hallberg, 2007, Shim et al., 2013). In spousal caregiving, individuals also develop effective coping mechanisms to deal with their caregiving role and with the cared for’s health issues, particularly in dementia (Rodda et al., 2011).

As with overall satisfaction, studies have shown that subjective well-being increases as carers get older (Dracup et al., 2004, Chow and Ho, 2015). Good levels of well-being are associated with satisfaction with services, good subjective health, and higher control (Raivio et al., 2015). However, a more recent investigation carried out in the UK showed that long-term caregiving was associated with poor general well-being in older carers (Steptoe et al., 2015b). Overall lower levels of well-being in this population have been associated with poor subjective health, the poor function of the cared for (Yamaki et al., 2009), isolation (Raivio et al., 2015), the carer’s avoidance and anxiety (Perren et al., 2007), and the overall well-being of the cared for (Stephens et al., 2006).

Social network and support

Lavela and Ather (2010) have pointed out that older spousal carers often experience more loneliness, which can decrease QoL levels (Ekwall et al., 2005), and exhibit more depressive symptoms over time than those who do not feel lonely (Jaremka et al., 2014). Higher levels of loneliness in this population may be caused by the high levels of social activity conflict resulting from the demanding caregiving role, especially in dementia (Dilworth-Anderson, 2015). However, a large study from Sweden (n=783, 3,495 controls, all participants aged 75+) showed that older carers have larger social networks and report fewer feelings of loneliness than non-carers (Ekwall et al., 2005). Significant associations between loneliness, weak social network, and low mental QoL were identified in the same study, with loneliness and small or non-existent networks being the strongest factors predicting low QoL levels in this population of carers and non-carers.

The literature also suggests that levels of loneliness in older carers may vary according to gender. In Sweden, higher intense feelings of loneliness were found among older women (Ekwall et al., 2005). A population study carried out in the Netherlands with a group of community-dwelling older people showed that the disability of older women was related to higher levels of social loneliness in their older husbands, and emotional loneliness was reported by both genders when disability was present, even after controlling for social networks and marital relationship (Gierveld et al., 2009). Neri et al. (2012) have suggested that social isolation in male carers may be due to discontinuity of activities and social roles when becoming a carer.

Quality of life

Lower levels of QoL of older family carers of people in different disease contexts are often associated with high levels of strain (Roth et al., 2009), long-term caregiving, and female gender (Kim and Spillers, 2010, Steptoe et al., 2015b). It is also associated with increased age (Clay et al., 2013, Godwin et al., 2013, Kim and Spillers, 2010), number of illnesses (Godwin et al., 2013), poor economic situation, and the demand for social and practical support (Ekwall et al., 2004, Ekwall et al., 2007, Ratcliffe et al., 2013). Those with poor health, low social support, perceived stigma (Chou et al., 2009), living alone (Ratcliffe et al., 2013), feeling lonely, and with a small or non-existent network (Ekwall et al., 2004) are also more likely to be affected. Older carers who have to adapt their own activities and those with need for help with instrumental ADLs themselves (Ekwall et al., 2004) also report lower QoL. Higher levels of QoL are associated with better coping abilities and high sense of coherence (Ekwall et al., 2007).

Particularly in a dementia context, the literature investigating the QoL of family carers from any age group is still lacking (Moniz-Cook et al., 2008). With regard to older carers, the current literature review identified only four studies with small sample sizes investigating the QoL of this population (Draper et al., 1992, Clark and Bond, 2000, Bond et al., 2003, Scholzel-Dorenbos et al., 2009), and the main focus of some of these studies was not the family carers' QoL but that of their cared for. Results of the association between QoL levels in older family carers of people with dementia and several other variables are given in Table 3.

Table 3. Variables associated with the quality of life of older family carers of people with dementia

	Gender	Age	Marital status	Patient issues	Burden	Depression	Physical health	Mental health	Domestic chores	Household maintenance	Service to others	Changes in caregiving status
Clark and Bond, 2000 (n=150)	-	-	-	Y	-	Y	-	-	Y	Y	Y	-
Bond, Clark and Davies, 2003 (n=51)	Y	-	-	-	-	-	-	-	-	-	-	Y
Draper et al., 1992 (n=80)	-	-	-	N	-	-	Y	Y	-	-	-	-
Scholzel-Dorenbos et al., 2009 (n=97)	Y	Y	Y	Y	Y	-	-	-	-	-	-	-

-: not evaluated; Y: associated; N: not associated

These studies showed that older carers' QoL levels are lower in those of greater age, those with more dependent care recipients, those with high levels of burden, those with more time committed to care, those more depressed, and in females. These are also risk factors for low QoL in dementia family carers from any age group (Broe et al., 1999, Pinquart et al., 2003, Vitaliano et al., 2003, Pinquart and Sörensen, 2007, Leggett et al., 2010, Moon and Dilworth-Anderson, 2014, Wang et al., 2014) and are also likely to be associated with higher levels of burden in this population (Schneider et al., 1999, Harwood et al., 2000, Leggett et al., 2010, Abdollahpour et al., 2014, Adelman et al., 2014).

Studies suggest an increase of carers' burden as the severity of the care recipient's symptoms increases and dementia progresses (Mioshi et al., 2013, García-Alberca et al., 2014). Despite the lack of longitudinal studies investigating older family carers' QoL or correlating carers' ageing with their perception of QoL over time, it is known that QoL is likely to be affected by high levels of burden in dementia family carers (Coen et al., 2002, Riedijk et al., 2006). Likewise, the single prospective longitudinal study identified in the current review showed an improvement in physical capacity, mental health, and depressive symptoms and, ultimately, an improvement in their QoL levels, when older family carers stopped their caring role (Bond et al., 2003).

Three different tools were used to measure the QoL of older family carers of people with dementia in these studies, none of which was designed specifically for use with older people (Table 4).

Table 4. Quality of life tools used with older family carers of people with dementia

QoL tool	**Characteristics of the tool**	**Dimensions**	**Studies using this tool**
SF-36 (Ware and Sherbourne, 1992, Ware et al., 1993)	Generic, multidimensional. 36 items (0-100).	8 dimensions divided into: Mental component – vitality, social functioning, role limitations resulting from emotional problems, and psychological distress; Mental component – physical functioning, role limitations due to physical health problems, bodily pain, and general health.	(Riedijk et al., 2006) (Clark and Bond, 2000, Bond et al., 2003)
Schedule for Evaluation of Individual Quality of Life (SEIQoL) (Hickey et al., 1996, Joyce et al., 2003)	Individual QoL. Level of functioning in 5 self-nominated aspects of life and the relative weight or importance attached to these areas.	The relative importance of each aspect of QoL is measured by deriving the weight the individual assigns to each in judging overall QoL.	(Scholzel-Dorenbos et al., 2009)
Quality of Life Questionnaire (QLQ) (Wells and Jorm, 1987)	Dementia caregiving specific. Adapted from the results of a randomized controlled trial (RCT). Dichotomous, 10 items.	Items assess the carer's participation in social and recreational pursuits in the last few weeks.	(Draper et al., 1992)

The SF-36 (Ware and Sherbourne, 1992, Ware et al., 1993) is a generic health-related QoL tool (HRQoL), with a major focus on physical health, developed for use with the general adult population. The Quality of Life Questionnaire (QLQ) is a dementia-caregiving-specific scale focused on the ability of carers to engage in social and recreational pursuits only. This tool was developed by researchers to measure the efficacy of a randomized controlled trial (RCT) and lack of appropriate psychometric evaluation (Wells and Jorm, 1987). The Schedule for Evaluation of Individual Quality of Life (SEIQoL) is an individual QoL measure (Hickey et al., 1996, Joyce et al., 2003), in which participants nominate aspects of life and attach relative weight or importance to these areas. Because this tool values individual preferences, comparisons with other studies can be limited.

2.4. SUMMARY AND RATIONALE FOR FOCUS ON QUALITY OF LIFE

This literature review demonstrates the dearth of research on older family carers of people with dementia. The available studies are based on narrowed outcomes, mainly focused on the negative impact of caregiving on various aspects of life, which ignore a range of other factors, including level of independence, ability to pursue goals in life, identity, and relationships. Even though older carers show overall poorer mental and physical health when compared with young adult carers or with the general older population who are non-carers, positive outcomes, such as well-being, satisfaction and coping, are at times higher in this population, demonstrating that these individuals may have a more positive perception about their caregiving role than young adult carers do.

There is therefore a need for broader research that balances negative and positive outcomes and provides a more holistic view of caregiving. Considering the chronic and progressive nature of dementia, with an increasing number of family members involved in the care provision for these people, having relevant and multidimensional outcome measures, as well as setting up appropriate interventions, thus becomes a primary goal for health care. There is a need for more and better quality research with this particular group of people, with larger sample sizes and better methodological design. It is also necessary to use appropriate instruments including items that are relevant to this population.

QoL is an accepted outcome measure used in health care and has become a standard method for assessing the results of interventions, for determining choice of treatment and care, and for prioritizing funding in health and social fields. It represents a broad and multidimensional concept that incorporates information about various relevant aspects of people's lives, such as physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship with the environment in which they live. In comprising all these factors, QoL outcomes therefore indicate how conditions in which the individuals live may be affecting their lives.

In a family caregiving context, QoL outcomes and associated dimensions reflect how much of the stress and burden often generated by caregiving does in fact affect how carers perceive their mental health, physical health, and social lives, giving a better understanding of the impact of the caregiving role on the lives of carers from different cultures and with different social and education backgrounds and health conditions, providing a basis for appropriate interventions. Even though QoL is considered a broad, multidimensional, valid, and reliable measure in health care, the QoL of older family carers in a dementia context is still under-researched.

Chapter 3

CHAPTER 3. QUALITY OF LIFE

3.1. OVERVIEW

This chapter provides the rationale for development of an age-specific scale for measuring the QoL of older family carers of people with dementia. First, some general aspects of QoL, its main concepts and approaches, will be outlined. The importance of developing and using appropriate disease-specific scales will be discussed. Theories related to the psychology of ageing and their association with the subjective QoL of older adults will then be explored, providing a rationale for the development of age-specific QoL scales. These discussions will introduce the aim and objectives of the current research, as well as the appropriate methodological approach used.

3.2. GENERAL QUALITY OF LIFE CONCEPTS AND APPROACHES

QoL is a multi-level and amorphous term, often used in everyday conversations. QoL, good life, happy life, well-being, and comfortable life, for example, are terms often used interchangeably by the general public. Attempts to define QoL and its components date from the 1960s, but no consensus on its conceptualization and measurement is available yet.

Historically, the term ‘public happiness’ had been used as a synonym for QoL by philosophers, who considered happiness as the highest goal and ultimate motivation for human action (Kerce, 1992, Sirgy, 2012). Contemporary ideas of QoL are being explored in three major fields: economics, medicine, and the social sciences. Each discipline has developed its own quite different view on how QoL should be conceptualized and measured, underpinned by various theories and models (Cummins, 1997, Cummins et al., 2004, Galloway et al., 2005, Michalos, 2008, Fayers and Machin, 2016).

This has led to the development of numerous studies and measurement tools that lack a clear justification or conceptualization of the term QoL and its components (Gill and Feinstein, 1994, Hunt, 1997). In a literature review carried out by Hughes and Hwang (1996), more than one thousand measures of various aspects of QoL were identified. In 1997, another literature review demonstrated that over a hundred definitions and models of QoL had been developed up to that time (Cummins, 1997). Problems in conceptualizing QoL exist because it not only means different things to different people, but it may also mean different things to the same person over time (Browne et al., 1997, Sprangers and Schwartz, 1999). As a result, it is questionable whether the conceptualization of QoL among older adults is the same as for young adults, considering that older people often have their QoL conceptualized and evaluated as being homogenous with young adults (Bowling et al., 2002).

In addition, there is a tendency to overlap the term 'quality of life' and a number of other terms, such as 'well-being', 'social indicators', and even 'health', despite the fact that these are not synonymous (Andrews and McKennell, 1980, Hyde et al., 2003, Galloway et al., 2005, Cummins, 2010). This may be a due to a common but erroneous practice, particularly in health care research, of using indicator variables (a measure of end-state, such as the perception of health quality) and causal variables of QoL (which cause the end-state to change, such as patient-perceived symptoms, fluency impairment, anxiety, etc.) interchangeably (Fayers et al., 1998). This confusion may cause the erroneous idea that perceived health and subjective well-being are synonymous (Cummins, 2010).

If QoL is equated to health state in a particular study, this means that models equating QoL to well-being in other studies are no longer comparable, which can be problematic for research and health outcomes. Moreover, because older people are more likely to have an impaired health state than young adults, equating QoL to health status could actually result in negatively skewed outcomes in older populations, when indeed other factors not considered (such as satisfaction with life and well-being) are likely to improve the QoL of these people.

3.2.1. Approaches to and definitions of quality of life

According to Brook (1993), QoL research is often divided into three distinct approaches: 1) the normative approach, in which the norms are dictated by individual and social beliefs, principles, and philosophies about a good life; 2) preference satisfaction, which depends on the availability of resources to choose from and the individual's ability to get them; and 3) subjective evaluation, which argues that a good life is one which is perceived as such. Examples of available models of QoL range from needs-based approaches derived from Maslow's hierarchy of human needs (Maslow, 1954, Maslow, 1968) to classic models based on psychological aspects (Andrews, 1986), social expectations (Calman, 1984), or individuals' perceptions (O'Boyle, 1994).

Needs-based approaches to QoL driven by Maslow's theory of the hierarchy of human needs are grounded on an existentialistic psychology of self-actualization and personal growth (Maslow, 1954, Sirgy, 1986, Hagerty, 1999, Ventegodt et al., 2003). According to this model, a good QoL is one in which all hierarchical needs are met, in which individuals gain happiness, health, and the ability to function as they take responsibility for fulfilling their own needs. In the pyramid proposed by Maslow, the next need in the hierarchy is revealed as the individual achieves the previous ones (Figure 2).

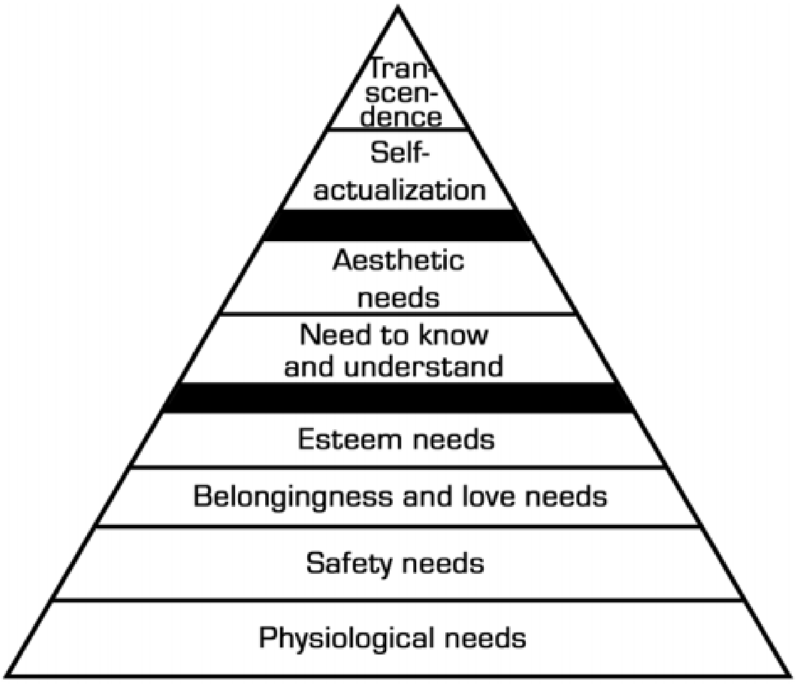

Figure 2. Maslow's hierarchy of needs (Maslow, 1954)

Even though this theory has been widely accepted, it has been extensively criticized for positing that there is a consensus among individuals about what constitutes a good or bad QoL. Also, this theory maintains that individuals' needs are more important than their wish to determine QoL and that all individuals universally share the same needs and in the same order. Browne et al. (1997) stress that this model fails to represent the true nature of QoL for groups of people living in different contexts and experiencing life differently.

Others believe that the conditions of happiness and satisfaction depend on the ability to survive, state of health, and things that permit or cause achievement of aspirations (Henshaw, 1973). Variation in aspiration levels, for example, can explain why two individuals sharing the same circumstances can report differing levels of satisfaction, as those who feel that their potential is not being achieved may be more dissatisfied. In addition, previous experiences can play a role in these cognitive assessments, and adaptation may influence individual appraisal (Kerce, 1992, Haas, 1999). In this case, QoL is the result of the difference between an individual's expectations and actual experience, focusing on how that person evaluates it. This idea is based on a developmental perspective, with QoL outcomes reflecting the person's past experience, present circumstances, and future aspirations. Experience constantly changes expectations, and the smaller the gap between expectations and experience, the higher one's QoL is likely to be (Carr et al., 2001).

3.2.1.1 Subjective and objective quality of life

Despite the lack of agreement of a definition of QoL or of an all-encompassing and acceptable QoL theory, there has been relative consensus that QoL should constitute objective and subjective interrelated and measurable indicators (Lawton et al., 1999, Sirgy, 2012), creating a single but multidimensional concept (Felce, 1997, Galloway et al., 2005). Objective indicators are those related to economic, social, health, and environmental well-being (e.g. income, employment, mortality, and morbidity rates) and are independent from the individual whose QoL is being evaluated (Michalos, 2008). For decades these have been used as indicators of social quality (Sirgy, 2012), failing to take into account non-economic aspects leading to a good life (Greenfield, 1973).

Subjective QoL, however, requires a personal judgment according to one's state of mind (e.g. values, attitudes, experiences, emotional state) (Michalos, 2008) and appears to be more responsive than objective variables to individuals' QoL (Felce, 1997). A subjective representation of the psychological views of individuals concerning their 'life quality' (e.g. satisfaction with life, positive and negative affect) became relevant later, meaning that an event can be considered as either positive or negative depending on the individual or the specific population (Lawton et al., 1999).

Following this tendency, contemporary definitions of QoL have been partially centred on the so-called ‘objective’ and ‘subjective’ QoL indicators as an attempt to distinguish between objective and perceived QoL. One example is from Rice et al. (1985), who define objective QoL as being “the degree to which specified standards of living are met by the objectively verifiable conditions or activities, and consequences of an individual’s life” (Rice et al., 1985 p.296-297). Perceived or subjective QoL, on the other hand, is defined as “a set of affective beliefs directed toward one’s life”. These two definitions suggest that objective QoL depends on the judgment of pre-determined factors independent of the individual whose QoL is being measured, whereas subjective QoL depends on how individuals define or experience the quality of their own lives.

Accordingly, QoL can be seen as a construct that reflects macro-societal and micro-individual influences, with subjective and objective dimensions interacting (Lawton, 1991). What a person or community makes of the objective conditions is actually a function of how these conditions are perceived, what is thought and felt about them, and the subsequent consequences. People’s perceptions, thoughts, feelings, and actions have an impact on their own lives and those of others (Sirgy, 2012).

3.2.1.2 Quality of life as a multidimensional construct

There is also a consensus that QoL should be treated as a multidimensional construct, covering a wide range of aspects of life, such as psychological, social, environmental, and physical issues. Accordingly, the World Health Organization (WHO) has defined QoL as being “the individuals’ perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 1995 p.1405). This is considered a complex and multidimensional concept incorporating information about various aspects of people’s lives, such as physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship with the environment in which they live (WHO, 1994, Bosboom et al., 2012, Bruvik et al., 2012). This definition is derived from the previously stated WHO definition of health, considered as being a “state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1946 p.100). Accordingly, measurement of health and the effects of health care must include an estimation of the individual's well-being during all stages of the disease (WHO, 1995).

Similarly to the construct proposed by WHO, Haas (1999 p.219) carried out a concept analysis of the term and proposed that QoL should be considered as

> "a multidimensional evaluation of an individual's current life circumstances in the context of the culture and value systems in which they live and the values they hold. QoL is primarily a subjective sense of well-being encompassing physical, psychological, social, and spiritual dimensions" (Figure 3).

Terms such as satisfaction with life, functional status, and well-being represent different levels and aspects of the broad concept of QoL, and therefore researchers should clearly state their choices when researching this construct (Haas, 1999).

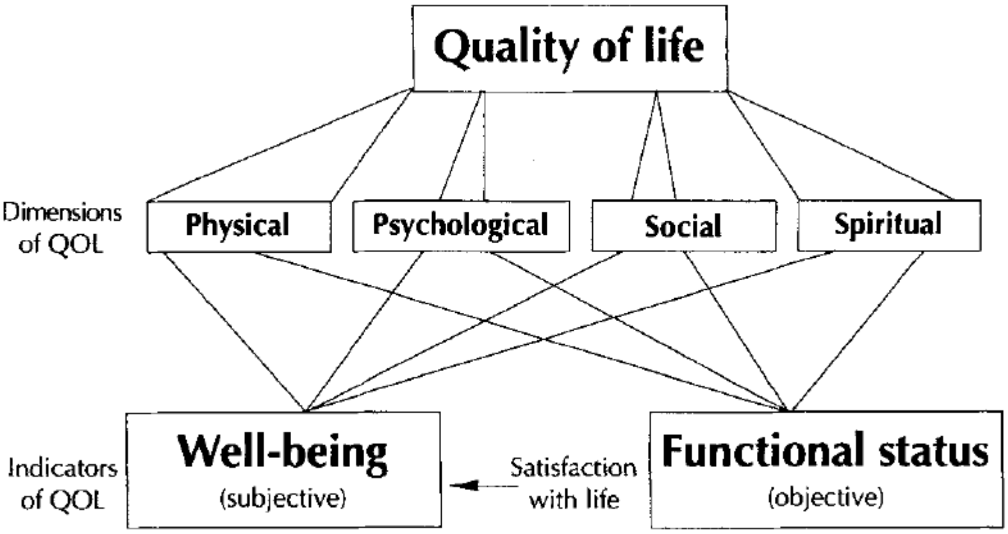

Figure 3. Well-being and functional status as subjective and objective components of quality of life (Haas, 1999)

In summary, the general literature on QoL research emphasizes the importance of using a subjective and multidimensional approach. It is the individuals' experiences in using the available resources and their subjective appraisal of a wide range of life domains, rather than the availability of resources itself, that will truly reflect the quality of their lives. The way QoL is understood and operationalised will influence how much health and social services are actually able to improve people's experiences within the context of illness and health. Researchers and health and social care professionals should thus focus on the most appropriate methods of capturing these views in order to identify the best ways to improve individuals' life quality and should make it clear how QoL is conceptualized within their research.

3.2.1.3 Health-related quality of life

Health-Related Quality of Life (HRQoL) is one vignette within QoL research used to identify how QoL may be affected over time by general health states, as well as specific diseases, disabilities, or disorders. This is particularly important for this current research.

There are two different approaches to HRQoL evaluation. Generic HRQoL instruments are generally designed for use in clinical practice and research, health policy evaluations, and general population surveys to assess overall QoL related to health (Ware and Sherbourne, 1992). Examples of generic instruments are the 116-item MOS core survey, which includes measures of physical, mental, and general health (Hays et al., 1995) and its short form (SF), the 36-Item Short Form Survey (SF-36) (Ware and Sherbourne, 1992, Ware et al., 1993). While these generic QoL scales have the benefit of allowing comparisons among different populations, they are less responsive to changes in QoL when compared with specific QoL scales. As specific instruments are focused on problems associated with single disease states, care recipient groups, or areas of function (Guyatt et al., 1993), and therefore items are relevant to individuals who are suffering from particular diseases affecting their QoL, these are likely to have higher reliability scores and to be more responsive to changes in QoL (Hyland, 2003). Examples of validated instruments measuring specific HRQoL are the Alzheimer's Disease Quality of Life (AD-QoL) for people with AD (Logsdon et al., 1999) and the Caregiver Quality of Life Index-Cancer (CQoLC) for carers of people with cancer (Weitzner et al., 1999).

Even though HRQoL approaches can be valuable for health evaluations with several different purposes, the development and use of HRQoL instruments have been criticized for often embracing a variety of issues on which these QoL models were based, rather than QoL itself (Taillefer et al., 2003). For example, because HRQoL concerns the impact of diseases on QoL, researchers have used the evaluation of symptoms as the sole indicators of QoL, overlooking its multidimensional nature. Instruments with such characteristics fail to consider that not only does the magnitude of symptoms vary from person to person but also the person's perception of the relative severity of these symptoms is likely to be influenced by other factors happening at the same time in their lives (e.g. financial situation, level of support), which may reduce the reliability of QoL measures based solely on these factors. For this reason, it is been argued that specific HRQoL scales with such characteristics should be used together with generic ones in order to provide a better understanding of the individual's QoL (Guyatt et al., 1993).

3.3. MECHANISMS INVOLVED WITH SUBJECTIVE APPRAISAL OF QUALITY OF LIFE IN OLDER ADULTS

Significant changes occur in individuals' biological, social, emotional and psychological circumstances as they age, affecting behaviour, cognition and emotional goals (Davis et al., 2007). This results in a complex range of interactions reflecting an individual's past, present and future, and the opportunities provided in the environment in which these individuals live (Baltes, 1987, Carstensen, 1995). As a consequence, QoL definitions and appraisal are different in later life.

Even though the importance of developing and using age-specific QoL scales with older people has already been established by the WHO (World Health Organization) (The WHOQOL-OLD Group, 2011), further justification for the need for an age specific scale for use with older family carers of people with dementia will be provided below. Awareness of the modifications that occur in QoL perception and appraisal as people grow old will also enable a better understanding of how caregiving affects the QoL of older people who are carers.

3.3.1. Mechanisms of subjective appraisal of quality of life

Subjective QoL is concerned with how people feel about, and how satisfied they are with, their lives, thus including affective (e.g. positive affect and negative affect) and cognitive (e.g. satisfaction with life) measurement components (Diener, 1984, Diener et al., 1985, Guyatt et al., 1989, Lawton et al., 1991, Kerce, 1992, Felce, 1997, Haas, 1999, Galloway et al., 2005). The connections between an event and subjective QoL appraisal is therefore mediated by affect and the pleasing effect of these states (Lawton, 1996).

In evaluating subjective QoL, any individual response to an item is therefore a function of an appraisal process which can evoke a range of issues and concerns which are particular to the person being assessed (Rapkin and Schwartz, 2004). Emotions are the central driving force of human thoughts and actions, giving meaning to individuals' lives and relationships. Happiness is an individual appraisal of immediate emotional experience, whereas satisfaction with life involves comparisons between objective conditions against internal expectations, standards, and values (Cheng, 1988). People can be happy but not necessarily satisfied with their lives, and vice versa, suggesting that happiness and satisfaction are different components of QoL.

3.3.2. Aspects related to changes in subjective appraisal of quality of life in later life

Several factors play a role as predictors or mediators of subjective QoL in older adults, such as level of adaptation, social values and social comparisons, coping strategies, beliefs, and aspirations (Bowling et al., 2002). Personality traits are unlikely to change in later life, whereas attitudes, behaviours, and their underlying cognitions and emotions are transformed as a response to environmental and biological changes, with the extent and quality of these changes suggesting that these are particular to developmental changes, rather than cohort effects (Coleman, 1992).

Even though developmental psychology is mostly focused on individual aspects of ageing and coping with adversities throughout the life span (Spiro, 2007), theories such as adaptation and plasticity (Baltes, 1987), socioemotional selectivity (Carstensen, 1995), control (Heckhausen and Schultz, 1995), and resilience (Greve and Staudinger, 2006) have gained wider acceptance in health-related fields (Spiro, 2007) and have been used to justify the need for age-specific QoL measures (O'Boyle, 1997, Hyde et al., 2003, Bowling, 2005a, Hickey et al., 2005). This socio-psychological approach is considered pluralistic (multidisciplinary and multidimensional) and recognizes that development is variable, and both particular and universal (Spiro, 2007).

Such theories have explained the idea that, even though cognitive and physical abilities decline in later life, older adults appear to show high levels of affective well-being, emotional stability, and satisfaction with life into their 70s and 80s (Schilling, 2006, Scheibe and Carstensen, 2010). Even though some studies show that subjective well-being tends to decline after the 80s (Smith and Planck, 2002, Hansen and Slagsvold, 2012, Jivraj et al., 2014), an Italian research study showed that individuals in their 100s have higher levels of satisfaction with life than young adults (Buono et al., 1998). Participants in this study also complained less spontaneously about their health, even though they declared greater functional disability. Older individuals showed lower levels of anxiety and depression when compared to groups of young adults, were satisfied with their financial situation and with social and family relations, and had greater satisfaction with life than did younger individuals (Buono et al., 1998).

This 'contradiction' between cognitive decline and physical ageing (which generates decreased physical reserves) and the maintenance or even improvement of emotional well-being (improved self-regulation) has been referred to as the "positive effect" (Carstensen, 2006), "paradox of ageing" (Reker et al., 1987, Carstensen et al., 2000, Zautra et al., 2002, Carstensen and Mikels, 2005, Davis et al., 2007), or "well-being paradox" (Greve and Staudinger, 2006, Hansen and Slagsvold, 2012). This phenomenon appears to have a protective role in health maintenance, with higher levels of eudemonic well-being associated with increased survival in older adults, even though this pattern may differ in low-income countries (Steptoe et al., 2015a).

Baltes (1987) explained this phenomenon by theorizing that older people adapt themselves to their living situations throughout their lives, in order to maintain their well-being when facing limitations. According to this author, older adults narrow or select the range of activities that are essential to their lives (selection), replace losses or limitations in order to achieve their goals (compensation), and maximize available resources (optimization). This cycle is closely related to the concept of "response shift", which maintains that changes occur in individuals' internal standards, values, and conceptualization of QoL as people experience life and adapt themselves to different situations. This means that someone's self-evaluation of QoL will change across their lifetime, following a range of lived experiences (Sprangers and Schwartz, 1999, Rapkin and Schwartz, 2004). Individuals pass through a process of reconceptualization (redefinition of meanings), reprioritization (change of the importance of some aspects of life), and recalibration (a change in the individual's internal standards) of how they perceive their QoL, which may explain why QoL scores of some individuals can be stabilized despite severe changes in health status (Sprangers and Schwartz, 1999).

Research has also demonstrated that older people have different goal representations, which are considered driving forces in the self-regulation of behaviour (Bandura, 1997), influencing attention, cognition, and affect (Penningroth and Scott, 2012). For example, healthy young people will invest their time focusing on goals related to knowledge acquisition or novelty (e.g. to learn a new language) and on a social network that goes beyond their close relationships. Older individuals, however, often have more motivation to engage with emotionally meaningful aspects of life, focusing on emotions and emotional regulation, valuing close relationships (e.g. spouse) as opposed to broader and uncertain social relations (Medley, 1976, Carstensen et al., 2000).

Social networks are narrowed in later life, and social roles change quantitatively and qualitatively, which is also likely to be affected by sensory losses affecting older adults (e.g. limiting conversations) (Carstensen, 1992, Charles and Piazza, 2010). On the other hand, it is well established that social support in old age, and the positive emotions derived from it, account for a stronger sense of meaning in life, greater emotional well-being, delay in cognitive decline, and preservation of health status (Charles and Piazza, 2010). Research demonstrates that supportive relations may play an important role in facilitating adaptation to internal and external sources of stress. In addition, high-quality social relations are strongly related to higher QoL levels and resilience in older people, which allow them to overcome chronic illnesses and other limitations in favour of well-being (Netuveli et al., 2006).

3.3.3. The well-being paradox and family caregiving in later life

The well-being paradox maintains that when life is controllable, with strong available and accessible social support, older people have far more satisfaction in life than young people. While benefits of social networks exist for older people when the relationship experiences are emotionally meaningful and positive (Rook et al., 2007), negative social interactions can have greater impact on older adults than positive relations do, generating higher levels of depression, lower positive emotional well-being, and poor self-rated health (Newsom et al., 2008). In the presence of inevitable and prolonged stress, such as experiencing a negative situation as a carer, this psychological regulation suffers, and these individuals may struggle to cope. As a consequence, these carers may have considerably reduced well-being when compared with older people who are non-carers (Charles and Piazza, 2010), as evidenced by a number of studies discussed in Chapter 2.

Other psychological mechanisms, such as selective social engagement with positive interactions, are not always possible in older carers, with unpleasant or stressful situations being unavoidable for these individuals (Rook et al., 2007). Caregiving becomes a negative source of social stress, which affects the relationship with the person being cared for (often a close family member) and may also generate a conflictual relationship with other family members. Also, older carers are often forced to forfeit their social experiences and are more likely to suffer with the negative psychological impact of an unavoidable demand for caring for a family member as they are rarely able to disengage from their carer role (e.g. spouses).

A socially restricted life and often unsupported caregiving role will also invariably affect how much older carers can maintain their protective psychological mechanisms, and conflictual relationships with other close family members may restrict the benefits of social relations even further. As an example, a meta-analysis has shown that stressors affecting the relationship with the cared for, such as the behavioural problems of the cared for (often present in dementia), have a stronger association with burden for spousal carers than for adult children. Overall stronger associations between caregiving stressors and psychological outcomes were found in spouses than in adult children (Pinquart and Sörensen, 2004).

In summary, older people appear to experience emotion differently from young people, with greater selectivity in responding to stimulus and increased control, as a result of a lifetime transformation and psychological adaptation. The emphasis on health state and physical capacity noticed in HRQoL scales developed for use with the general population of all age groups may undermine these individuals' QoL. Considering that individuals' responses to questions related to QoL are a function of an appraisal process that evokes a range of issues and concerns idiosyncratic to the person being assessed (Rapkin and Schwartz, 2004), any approach to QoL of older people should therefore consider the advances in knowledge of the psychological adaptation to ageing (O'Boyle, 1997). With regards to the current study, specific measures of QoL in caregiving developed for and used with these people should consider the particular views and domains that are important to older individuals in order to obtain valid and reliable results.

3.3.4. Relevant quality of life concept and domains for older people

Considering the biological, social, and psychological changes that occur in later life, it can be expected that ageing will affect QoL directly or indirectly (Netuveli and Blane, 2008). Even though the need for an age-focused approach to QoL has been established by WHO (The WHOQOL-OLD Group, 2011), investigation of the QoL of older people still lacks clarity regarding conceptualization and operationalization of the construct. Halvorsrud and Kalfoss (2007) conducted a review of empirical studies published in the period 1994-2006 in order to identify patterns of conceptualization and measurement of QoL in older adults. The authors identified that from the 47 references included, 40 different QoL measurements were applied, most frequently assessing functional status and symptoms, with minimal empirical evidence given for other psychometric properties. Perhaps more importantly, about 87% of the studies lacked a conceptual framework, and 55% did not report any methodological considerations related to older adults.

Arnold (1991) proposes that the QoL assessment of frail older people should include physical function and symptoms; emotional, behavioural, cognitive and intellectual function; social function and support network; satisfaction with life; health perception; economic status; ability to maintain interests and recreation; sexual function; energy; and vitality. Powell Lawton (1991 p.6) describes the QoL of frail older adults as being "the multidimensional evaluation, by both intrapersonal and socio-normative criteria, of the person-environment system of an individual in past time, current and anticipated". In saying this, Lawton considers objective (socio-normative approach) and subjective (individualistic approach) aspects of QoL which are relevant for these individuals, with objective aspects preceding subjective ones. However, one criticism of this model is that antecedents and consequences of QoL outcomes are mixed, with indicator variables as effect indicators, possibly affecting the reliability of the measurement (Fayers et al., 1997).

Even though both authors agree that QoL in later life should reflect a multidimensional concept, including physical, emotional, and social domains, it has been argued that QoL conceptualizations for older people have rarely been developed by older people themselves (Gabriel and Bowling, 2004, Netuveli and Blane, 2008). Also, by investigating only frail older people's QoL, the QoL perception of healthier older adults has been neglected, and therefore these findings may not be generalizable to a wider older population. Although individuals have a common set of variables that influence their QoL, the domains that are particularly relevant to each person are likely to vary. As such, it has been argued that any attempt to define and measure QoL should be based on lay views, reflecting individuals' subjectivity and variation, while also considering wider general social accounts (Gabriel and Bowling, 2004).

To date, two studies stand out in UK literature for having asked lay older people living in the community about what QoL means for them. The first was carried out by Farquhar (1995), who questioned the validity of operationalization of QoL simply in terms of health status and functional ability with older people. The author aimed to identify older individuals' views of the quality of their lives in a series of qualitative investigations and also to test the relevance of various scales used to measure QoL in community-dwelling older people. A high proportion of the sample in this study evaluated their QoL positively, either solely based on themselves or based on comparisons between themselves and other people. Also, participants judged that social contacts, health, material resources, and activities improved life quality. On the other hand, poor QoL was associated with dependency and functional limitations, and unhappiness, as well as reduction of their social contacts due to the death of loved ones.

Farquhar (1995) highlighted the need for a clearer definition of QoL for older people and the importance of social contacts as a component of good QoL, rather than just focusing on health or functionality. It was thus concluded that measures of QoL for older people living at home should only be selected if they include measures of social contacts and activities, emotional well-being (including life satisfaction), adequacy of material circumstances, and suitability of the environment, as well as health and functional ability. Farquhar's study also showed the importance of both age- and context-sensitive policies aimed at maintaining or improving the QoL of older people living at home. Differing aspects were considered to have different levels of importance for participants, according to the area where they lived (rural vs urban) and their age group (old vs very old).

The second study was carried out by Bowling et al. (2003) with 999 older people (aged 65+) living in the UK. The authors identified the following constituents of QoL in order of the frequency with which they were mentioned: social relationships, social roles and activities, solo activities, health, psychological health, home and neighbourhood, financial situation, independence, society/politics, and miscellaneous. QoL was improved by the same aspects, in the same order of importance, while health, home, and neighbourhood were more often associated with poor QoL in this population.

This study provided a model of QoL based on the following concepts: having good social relations and support; living in a home and neighbourhood that gives pleasure, where they can feel safe, with access to local facilities and services, including transport; being able to engage in hobbies and leisure activities (also solo), as well as maintain social activities and a role in society; having a positive psychological attitude and acceptance of circumstances that cannot be changed; having good health and mobility, and enough money to meet basic needs, participate in society, and enjoy life; and being able to maintain independence and control. Above all, the study showed that people of different ages have different priorities, with older people prioritizing health and independence, whereas young people are more concerned with work and finance (Bowling et al., 2002).

3.3.5. Measuring quality of life in later life

As QoL appraisal relies strongly on how people perceive their social interactions, as well as how they adapt their own expectations, QoL outcomes are likely to be affected by psychological mechanisms (Charles and Piazza, 2010, Isaacowitz and Blanchard-Fields, 2012, Reed and Carstensen, 2012, Wang et al., 2015). The literature systematically demonstrates how people change their goals, expectations, standards, and concerns as they grow older and how this has a direct impact on older people’s perceptions of their physical health, mental health, social relationships, and levels of independence, which are important domains of QoL. In addition, adaptation to life changes and everyday stress is differentiated in later life (Lazarus and DeLongis, 1983, Folkman et al., 1987, Cummings et al., 1991, Skinner and Edge, 1998, Amirkhan and Auyeung, 2007), which is particularly relevant to this research. The association of stress and coping strategies may ultimately be different in advanced age, and this may have an impact on the subjective views and appraisal of QoL domains in older carers.

As older people in various social, cultural, and demographic groups emphasize and prioritize QoL in different ways, there is a need for measures to be more sensitive to their particular needs, attending to specific values and priorities in the conceptualization and measurement of QoL, as well as distinguishing variables which influence, constitute, and mediate QoL of the older group being studied (Bowling, 2005a). It is necessary to take into consideration the specific aspects that are relevant to them, either when conceptualizing the QoL construct, or when measuring it (Farquhar, 1995, O'Boyle, 1997, Fleck et al., 2003, Higgs et al., 2003, Hyde et al., 2003, Gabriel and Bowling, 2004, Bowling, 2005a, Hickey et al., 2005, The WHOQoL Group, 2005, Netuveli and Blane, 2008, Caballero et al., 2013). Non-age-specific QoL scales are unlikely to represent the true nature of older people’s QoL (Iwarsson and Isacsson, 1997) and therefore could lead to methodological and interpretative errors, failing to meet a diverse set of older people’s needs. Moreover, these tools may not be sensitive to differing values of people or to the way that priorities may change with increasing age, and the items may have little relevance to an individual in a particular context and point in time (Hickey et al., 2005). In studying older adults’ QoL, a broader and relevant model for the specific target population is necessary (Bowling, 2005). Nevertheless, much of the research evaluating older people’s QoL has used instruments developed with a wider younger population or specific disease groups rather than with the older target population (Hickey et al., 2005).

A common and erroneous practice in QoL research with older people, for instance, is to equate poor health with poor QoL, which neglects the ability of individuals to overcome a disease and have a good life (Hyde et al., 2003, Halvorsrud and Kalfoss, 2007). Making assumptions about the QoL of older people, as per using population samples, can potentially reduce older individuals to medical or social policy categories. This neglects a range of life experiences and abilities that this particular group has, and does not consider the clear disproportion of the prevalence of morbidities between young and older population groups (Hyde et al., 2003).

As Hyde et al. (2003 p.187) suggest, symptom-focused scales (as is the case with many HRQoL scales) used with older people should be considered "age-blind and disease-specific measures rather than QoL measures". However, it has also been argued that the use of generic QoL scales to measure QoL in some disease contexts might lack content validity regarding fundamental aspects of QoL for people in specific situations, such as individuals in moderate to advanced stages of dementia or those fully involved with caregiving (Netuveli and Blane, 2008).

Furthermore, the specific psychometric properties of HRQoL instruments used with older people have also not been established, and it is unclear to what extent the available scores relate to an older person's overall perceptions of their HRQoL (Bowling et al., 2002, Gabriel and Bowling, 2004, Hickey et al., 2005). The validity and reliability of the generic and specific scales commonly utilized to evaluate the HRQoL of older populations have been increasingly questioned, as these have been developed not with older people, but with younger and more physically able adults. This may lead to an underestimation of older people's HRQoL due to an over-emphasis on physical functioning, commonly affected in old age (O'Boyle, 1997, Hickey et al., 2005).

Another consequence is the already-mentioned "well-being paradox", in which older people with limitations report high levels of well-being due to a higher level of resilience and adaptation (Greve and Staudinger, 2006). Because older people are more likely to have their health affected by diseases and chronic impairments, using these instruments in older and younger populations together may inadvertently discriminate against the older group, as they may report low levels of QoL due to an over-emphasis on health aspects. Indeed, a literature review focused on studies measuring the HRQoL of older people found that none of the instruments were old-age specific. This may have serious consequences for matters of validity and reliability of those outcomes (Hickey et al., 2005).

As an attempt to reduce these disparities, instruments developed specifically for use with the older population have been created, and four of these stand out in the literature for the quality of their thorough development and validation processes (Terweea et al., 2007). Two were created by WHO: the WHOQOL-OLD (The WHOQoL Group, 2005, The WHOQOL-OLD Group, 2011) and the WHOQOL-AGE (Caballero et al., 2013). In addition, other researchers have proposed a needs satisfaction model in early old age ‘Control’, ‘Autonomy’, Self-realization’, ‘Pleasure’ (CASP-19) (Hyde et al., 2003) and a multidimensional model of QoL in old age Older People’s Quality of Life Questionnaire (OPQOL-35) (Bowling, 2009, Bowling and Stenner, 2011, Bowling et al., 2013). The domains of QoL represented in each of these models and their respective psychometric properties are shown in Table 5.

Table 5. Domains of QoL and psychometric properties of QoL scales developed for use with the general older population

Scale	Domains	Sample	Cronbach's α	Convergent validity	
				Instrument	**Coefficient**
WHOQOL-AGE (Caballero et al., 2013) 13 items	Sensory abilities; health; life overall; self; autonomy; relationships; environment; leisure/activities; energy/vigour; control; self-realization; financial situation; intimacy	Nationally representative European sample (developmental sample n=6993; validation sample n=2994) aged ≥50	Factor 1: α=0.88 Factor 2: α=0.84 Entire scale: α=0.91	SWLS	r=0.75
WHOQOL-OLD (The WHOQoL Group, 2005, The WHOQOL-OLD Group, 2011) 24 items (module)	Sensory abilities; autonomy; past, present and future activities; social participation; death and dying; intimacy	n=7400 respondents from 22 centres around the world aged ≥60, plus a second field test with n=5500 respondents aged ≥60	Six facts: α=0.72 to 0.88	-	-
CASP-19 (Hyde et al., 2003) 29 items	Control; autonomy; pleasure; self-realization	n=286 English people aged 65-75	Four domains: α=0.6 to 0.8	Satisfaction Index – well-being scale (James, 1986)	r=0.63
OPQOL-35 (Bowling et al., 2013) 13 items	Life overall; health; social relationships/leisure and social activities; independence, control over life, freedom; home and neighbourhood; psychological and emotional well-being; financial circumstances; religion/culture	n= 589 National English survey people aged ≥65	α=0.86	CASP-19 WHOQOL-OLD	r=0.66 r=0.64

In addition, some individual approaches to QoL of older people have been established, such as the SEIQoL (O'Boyle, 1994). This model was developed based on the assumption that standard QoL questionnaires may not reflect the particular priorities of each respondent, as the domains and questions are anticipated by those who developed the scale and do not consider the relative importance of each item to the life quality of the individual. This model entails a phenomenological approach to QoL (O'Boyle, 1997) and has been able to discriminate between a sample of healthy community-dwelling older adults and a sample of young adults (Browne et al., 1994).

Although individual approaches to QoL tend to be more responsive to changes than questionnaires containing previously established items, some limitations may affect the suitability of these measures for the purposes of clinical assessment and the development of appropriate interventions and policies. First of all, it has been argued that individual approaches are labour-intensive and time-consuming, which makes them difficult to apply in larger populations and also in day-to-day clinical practice. Secondly, because this is effectively a phenomenological approach, its very nature does not allow meaningful comparisons of individuals' QoL against an external measure, which can have major implications for the type of analysis employed. Finally, and perhaps most importantly, because respondents are asked to rank or weight aspects that are important to their own QoL, it may focus on the influences on QoL and leave the actual QoL untheorized (Hyde et al., 2003).

3.3.6. Measuring the quality of life of older family carers of people with dementia

According to the last European consensus on outcome measures for psychosocial intervention research in dementia care, more research needs to be carried out to investigate the QoL of family carers of people with dementia (Moniz-Cook et al., 2008). This letter stated that more robust QoL tools are needed for use with these people. It has also been pointed out elsewhere that measurement tools within the dementia context (either with patients or carers) should be face valid, construct valid, practical, and acceptable for use with these individuals (Sheehan, 2012). Nevertheless, as discussed in Chapter 2, the instruments used to measure the QoL of older family carers in previous studies lack robust psychometric evaluation, are not age specific, and have limited scope.

The existing scales developed for use with dementia family carers from any age group, and others developed for use with family carers from different disease contexts, are outlined in Table 6. The Caregiver Quality of Life questionnaire (CGQOL) (Vickrey et al., 2009) is a dementia-specific tool but lacks construct validity against a gold standard measure, has a large number of items, and was developed in a USA context, thus it may not be applicable in the UK without appropriate adaptation. The PIXEL questionnaire (named after the PIXEL study) (Thomas et al., 2006) is dementia-specific but was developed in France and also lacks construct validity. The CarerQoL (Brouwer et al., 2006) is a non-disease-specific caregiving scale which does not have information about the internal consistency of its items, neither does it have construct validity against a gold standard measure, and is limited to the dimensions of happiness and burden of care. Even though evidence of construct validity has been provided for the Adult Carers Quality of Life (AC-QoL) (Joseph et al., 2012), another non-disease-specific caregiving scale, this was established against a scale developed by the researchers themselves, which calls into question the extent of this psychometric evidence. In addition, this scale has a large number of items, which may compromise its acceptability in clinical practice and research.

Table 6. DQoL-OC reliability and validity coefficients compared with quality of life scales developed for use with family carers of people with dementia and general family carers

Type	Instrument	Sample for psychometric study	Cronbach's α	Construct validity against a gold standard measure	
				Instrument	Coefficient*
Dementia-specific	CGQOL – 80 items, divided into 10 scales (Vickrey et al., 2009)	n=200 informal carers from English and Spanish speakers in the USA	α=0.78 to 0.94	-	-
	PIXEL questionnaire – 20 items (Thomas et al., 2006)	n=100 French informal carers	α=0.72	-	-
Non-disease-specific	CarerQoL – 8 items evaluating burden and happiness (Brouwer et al., 2006)	n=175 German family carers	-	• Caregiver Strain Index (Robinson, 1983) • Self-Rated Burden (Van Exel et al., 2004) • Process Utility (Brouwer et al., 2005)	r=-0.50 r=0.43 r=0.64
	ICUB97 (Gallego et al., 2001)	n=227 Spanish informal carers	-	-	-
	AC-QoL – 40 items, 8 subscales (Joseph et al., 2012)	n=385 English adult carers	α=0.94	• Psychosocial functioning checklist (Joseph et al., 2012)	r=0.33

-: not available; *p<0.05

It has been suggested in the literature that effective age-specific methods for reducing stress, anxiety, and depression are needed for the population of older carers in order to improve their QoL (Carers Trust, 2011, Luchesi et al., 2015, NICE, 2015). Examples of such interventions are outlined in Table 7. Because developing effective interventions also entails gathering accurate and consistent evidence of their efficacy (Craig et al., 2014), such as measuring their impact on QoL, any attempt to create and implement interventions to improve older carers' QoL will need a more robust measurement tool to assess the impact.

Table 7. Interventions for older family carers of people with dementia suggested in the literature

Intervention	Authors
• Behavioural management therapy • Physical activity reduces depression in older adults in general and may also be effective for older carers	(Lautenschlager et al., 2014)
• Targeting problematic behaviours in dementia • Addressing risk factors for role captivity	(Givens et al., 2014)
• Strengthening social support systems	(Ahn et al., 2012)
• Improving the social functioning of the person with dementia, the older carer's perceptions about caregiving, and giving older carers more breaks from caregiving	(Van Den Wijngaart et al., 2007)
• Carers of more advanced ages who are relatively poor may benefit from reducing the physical burden	(Kim and Spillers, 2010)
• Breaks should include access to high-quality alternative care	(Carers Trust, 2011)
• Help for older carers to integrate back into their communities	(Steptoe et al., 2015b)
• Treating depression, decreasing burden, and focusing on the positive aspects of caring	(Loi et al., 2015)

Even though the use of generic QoL scales allows comparison of results with other population groups, these tend to be less sensitive to the needs of the population under investigation and to changes in QoL over time (Hyde et al., 2003). The creation of a short and acceptable tool, with robust psychometric properties, is thus necessary for better-quality studies with this population. While benefiting research, such a tool would also be useful to apply in clinical practice, clinical audits, service evaluations, and self-rating by older family carers.

3.4. STUDY RATIONALE

Dementia is a chronic and progressive disease with no available cure, which reduces affected individuals to a complete state of dependence on care. Family members are arguably the most important resource available for and the preferred source of care by people with dementia. Therefore, family carers have the right to an assessment of their needs and access to appropriate support to meet these needs. Even though older individuals are often in need of care themselves, these people are currently responsible for providing care to a significant portion of the population with dementia in the UK. Older carers are at considerably higher risk for physical and mental morbidities, and lack of social support and financial resources, which may have a significant impact on their QoL.

To date, few measures have been developed for use with family carers. Mostly, caregiving research is focused on specific negative aspects of being a carer (such as stress, strain, or burden). These outcomes provide information about how caregiving may be impacting specifically on carers' mental or physical health. However, they do not provide a multidimensional view on how carers perceive this impact on a range of domains that are important in their lives, or what internal/external factors are associated with or mediate this impact, which could be useful information for the purposes of health and social intervention. Even though single-domain scales may be more easily integrated into practice, these are likely to provide limited evidence about the complexity of the impact of dementia caregiving on areas of life that are particularly important for family carers.

WHO has established the importance of measuring individuals' QoL for the purpose of evaluating interventions, services, and impact of diseases and has guided the development of new policies and health economics. QoL is a multidimensional and broad construct; disease-specific QoL tools have the benefit of focusing on the aspects of the disease which mostly affect the individual being assessed, and they are responsive to changes in QoL. This can be particularly useful, for example, for the measurement of how much QoL has been improved as a result of specific health or social interventions. Even though measuring and maintaining the QoL of family carers of people with dementia is a public priority, this construct is still under-researched with this group of people. In particular, the QoL of older family carers of people with dementia has received very little attention.

WHO has also established that QoL perceptions and appraisal change in later life, making it necessary to develop and use age-specific scales according to each population group. This aims to improve the validity and reliability of QoL outcomes and to identify appropriate interventions focused on the specific needs of each age group. Even though age-specific scales have already been developed to measure the QoL of the general older population, these do not consider the specific impact of caregiving on older people who are carers. QoL scales created for use with the general older population may offer the benefit of comparison of QoL outcomes from older people in different circumstances of life (older carers vs older people who are not carers). However, older carers may find the items on a caregiving-specific scale much more meaningful to their current situation than the former would. Therefore, even though general QoL scales may well provide reliable and valid QoL outcomes in older carers, the QoL scores from these scales are likely to be less responsive to changes and do not provide information about what aspect of caregiving is affecting QoL domains, offering less meaningful information for clinicians and researchers who are interested in reducing the negative impact of caregiving in older carers.

To date, no age- and dementia-specific measurement tool has been developed to measure the specific impact of dementia caregiving on older family carers. Such an instrument is needed in order to bring together the aspects of life quality which are particularly affected in older people who are carers and will provide reliable and valid outcomes about the QoL of this population in order to develop appropriate interventions and support to improve their life quality.

3.5. AIMS AND OBJECTIVES

This PhD study aimed to develop and evaluate the psychometric properties of a new scale entitled ‘Dementia Quality of Life Scale for Older Family Carers’ (DQoL-OC). This is a unique dementia- and age-specific tool for the evaluation of the QoL of older family carers. This sequential exploratory mixed-methods research had the following objectives:

3.5.1. Qualitative strand (focus groups)

- To identify the variables underlying the QoL of older family carers of people with dementia by:
    - Exploring how these older family carers make sense of their own QoL through their experiences and understanding of what QoL means to them;
    - Exploring the factors that enhance or compromise older family carers’ QoL; and
    - Exploring older family carers’ opinions about the relevance of the items of an existing carers’ QoL measure to their experience.

3.5.2. Quantitative strand (expert panel and psychometric study)

- To develop a measure of QoL for older family carers of people with dementia (the DQoL-OC); and
- To evaluate the validity, reliability, and practicality of the DQoL-OC.

Chapter 4

CHAPTER 4. METHODOLOGY AND METHODS

4.1. OVERVIEW

The preceding chapters present the literature review that led to the development of the aim and objectives of this research. This chapter presents the research methodology and methods employed to reach these research aims and objectives. It explores the relationships between the chosen methodology, philosophical assumptions, and theoretical frameworks adopted in this study, providing a rationale for the chosen research design and the methods of data collection and analysis. An overview of the study design and the literature around scale development is provided first. Subsequently, the research process is detailed in five subsections: 1) philosophical assumptions, 2) theoretical framework, 3) methodological approach, 4) methods, and 5) ethical considerations. Section 4 is subdivided into qualitative and quantitative strands, with a description and rationale for the methods employed in each.

4.2. OVERVIEW OF THE STUDY DESIGN

This study was approved by the Research and Ethics Committee (REC) of the Faculty of Medicine and Health Sciences (The University of Nottingham) and of the National Health Service (NHS). Research was carried out through a quantitatively focused, sequential and exploratory mixed-methods design (Figure 4), justified by the need to create and validate a relevant and psychometrically sound QoL measure (Creswell and Clark, 2011). This research was underpinned by a pluralist ontology, in which subjective and objective approaches are considered. The subjective approach to QoL was underpinned by an interpretivist epistemology, looking closer and in depth at the personal and shared experiences of older family carers' QoL. An objective approach then followed the premises of post-positivist epistemology in order to create a measure that produced valid and reliable outcomes (Creswell and Clark, 2011).

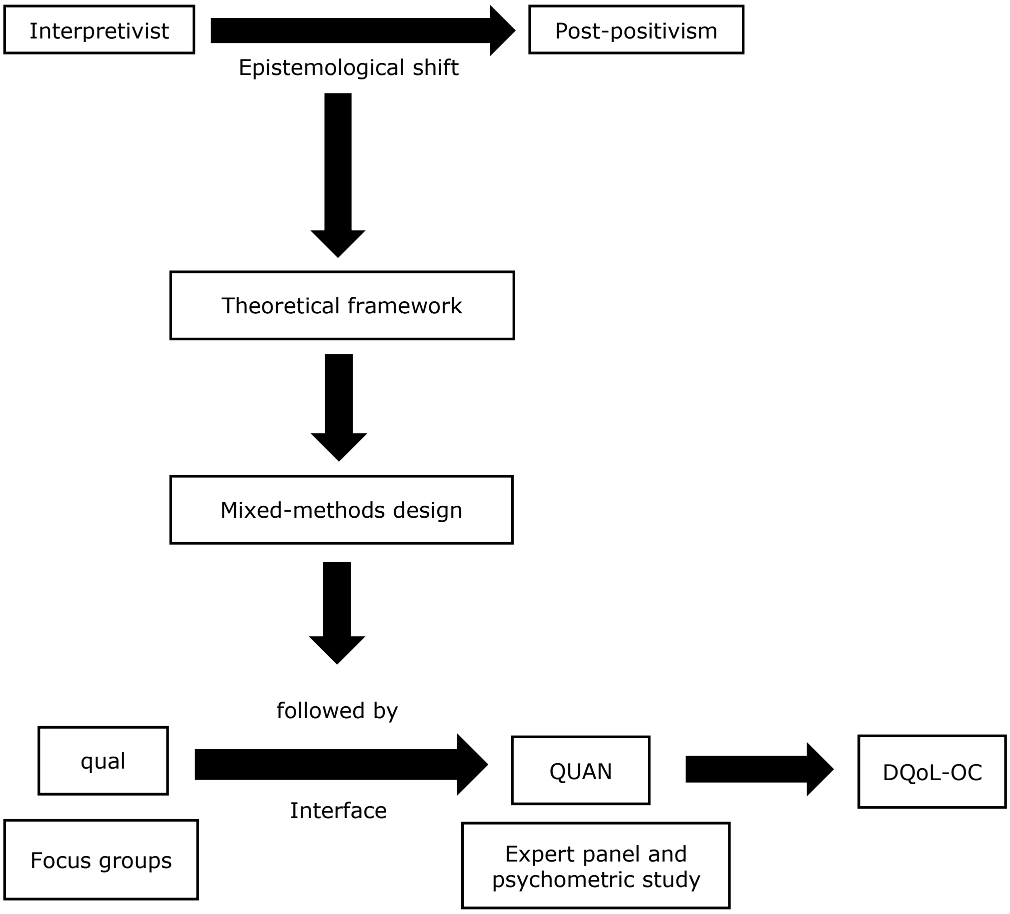

Figure 4. Flowchart presenting the research design

The qualitative phase was carried out through purposively sampled focus groups with older carers in the community of Nottinghamshire (UK), in order to explore their experiences, interpretation and understanding about QoL and the relevance of the items of an existing carers' QoL scale. The qualitative data gathered were transcribed verbatim and analysed using IPA independently by two researchers. Inter-coder reliability was established. The interface between qualitative and quantitative phase studies was reached at the end of the qualitative data analysis and beginning of quantitative data collection. The themes and superordinate themes generated in the data analysis informed the content of the items of the DQoL-OC and its format.

The preliminary version of the DQoL-OC was then submitted to experts (researchers and family carers) who evaluated the relevance and word clarity of the items. The modified version of the DQoL-OC was then applied to a larger sample of participants, through psychometric and retest studies. Data were collected in support groups in the voluntary sector (e.g.

Alzheimer’s Society), as well as in the NHS (e.g. memory clinics, General Practice services, home care services). Participants completed the newly developed DQoL-OC alongside other validated scales from the existing literature (The WHOQOL-AGE; the Satisfaction with Life Scale: SWLS; Perceived Health Status Visual Analogue Scale: PHS-VAS; Overall Perceived QoL: OPHRQoL-VAS). The data were then analysed in order to provide evidence of the validity and reliability of the new tool.

4.3. SCALE DEVELOPMENT

With the increasing need for adequate patient-centred outcome measurements, especially disease- or population-specific scales, the literature on the methodological features for the development and validation of new tools has also increased significantly over the last few decades. At the same time, however, this has raised a concern over the extent to which these new assessment devices measure the constructs that they are intended to measure, as well as their appropriateness to the population being studied, which may threaten the validity of research findings and clinical decisions (Marshall et al., 2000, Streiner and Norman, 2003, Vogt et al., 2004). Several authors have thus engaged with the study of scale development and application by proposing a wide range of methods and techniques aimed at generating tools that produce valid and reliable scores and that truly and accurately reflect the underlying construct of interest (Clark and Watson, 1995, Streiner and Norman, 2003).

The different techniques and study designs utilized in the development and validation of new scales and the appropriateness and relevance of each may depend on the type of scale being developed or variables being measured (Urbina, 2014). The choice of one or some of these methods and study designs when one intends to adapt or validate a scale may also depend on the purposes of the new instrument, the construct being measured, the target population, time frame, or resources, for example. The rigour and transparency in the use of the chosen methods will contribute to the development of a sound and robust tool (Vogt et al., 2004, Fayers and Machin, 2016).

Despite the wide range of available techniques, there are some key elements that must be considered for the development of good-quality scales. Essentially, it is recommended that the process of scale development should have at least four phases (Furr, 2011): 1) to articulate the construct and the context; 2) to choose the response format and pilot/psychometric study; 3) to collect data from respondents; and 4) to examine the scale's psychometric properties and quality. Reliability and validity are paramount aspects of psychometric quality, and the study must provide sufficient transparent information with regard to the nature and strength of the reliability and validity and evaluate the impact that these psychometric properties have for analysis and psychological implications (Furr, 2011).

The term validity has received many definitions over the past years (Coaley, 2014) but is roughly defined as the extent to which scores from a test measure what they are supposed to measure (Thompson, 2003). It concerns the nature of the construct being measured (Coaley, 2014) and is considered the most fundamental aspect regarding scales and their use, as it "hinges on the evidence we can bring to bear to support any inference that is to be made on the basis of test results" (Urbina, 2014 p.165). Validity needs to be determined in relation to a purpose or a target group, and it is desirable that the test users themselves judge whether or not the instrument is appropriate to their own situation (Coaley, 2014).

Reliability refers to the accuracy of an inference made upon the results of a test. It is intimately linked with validity, in the sense that the results from a test need to be accurate (reliable) and truly valid (Coaley, 2014). In other words, it can be defined as an estimated value of whether the new instrument consistently measures what it is intended to measure (McDowell, 2006). It refers to the trustworthiness of the scores of a test and the extent to which decisions can be made on the basis of it, implying consistency and precision (Coaley, 2014, Urbina, 2014). The results from reliability tests therefore refer indirectly to the amount of error in the results of a test, both random and systematic (Streiner and Norman, 2003).

Reliable results of a measure are not necessarily valid, as it is possible to have accurate and consistent scores of a measure that do not necessarily reflect the construct that one intends to measure (Coaley, 2014). It is also important to clarify that there is no 'reliable or unreliable test', nor 'valid or invalid test', as the reliability and validity coefficients refer to the scores of a test, and not to the test itself (Thompson, 2003). In addition, results from validity and reliability coefficients of a new scale are supported by accumulated evidence about the test, regarding its interpretation and uses, meaning that the construction of a psychometrically sound test does not terminate at its development, but there is also a responsibility for its future users to build up its psychometrical profile (American Educational Research Association et al., 2014).

In practice, the most important criterion for selecting an appropriate QoL scale is to carefully examine to what extent the items match the requirements of the research that is to be carried out, the population being studied, and the type of improvement that one expects from a treatment. Coefficients resulting from validity and reliability evaluation and the scale design will also interfere with the researcher’s choice of a specific QoL scale. For example, a good QoL scale for a cross-sectional study is the one that discriminates well between the severities of QoL deficit between patients. In RCTs, however, a good QoL scale is one that is good at detecting expected changes in patients’ QoL resulting from the treatment being studied and has items measuring all aspects of QoL important to the target population. The item relevance in this case can be highly population specific and is particularly important when comparing disease-specific with generic scales, as generic scales are less responsive to change than disease-specific scales, even though generic scales can be particularly suitable to detect iatrogenic effects in RCTs (Hyland, 2003).

Accordingly, this PhD research aims to generate a scale that provides valid and reliable scores which truly and accurately reflect the QoL levels of older family carers of people with dementia being cared for at home in the UK. It is hoped that the transparency and rigour in selecting and reporting the study design, methodological approach, and sampling strategies, together with the results from the development and validation process, will provide researchers and the clinical community with a psychometrically sound measurement tool that can be used for the purposes of investigating older family carers’ QoL and measuring how much QoL is added by interventions that are focused on this population. In doing this, it is hoped that researchers and clinicians will have enough information to decide the best QoL scale to use in their studies or clinical practice with this population. Table 8 outlines the validation process applied in this PhD thesis, based on DeVellis (2012). This process is summarized in Figure 5.

Table 8. Steps carried out for scale development and corresponding methods and outcomes, based on DeVellis (2012)

Research steps	Methods	Aims/Outcomes
Step 1. To determine clearly what it is you want to measure	• Literature review of dementia, QoL and family caregiving in older age	• Identification of research gap • Research scoping and rationale • QoL operationally defined for guidance in qualitative investigation and scale development
Step 2. To generate an item pool	• Focus groups with older family carers of people with dementia	• Transcription of focus groups and IPA analysis of the data • Identification of recurrent themes in the data • Organisation of themes into superordinate and sub themes and examination of relationships between them • Selection of QoL domains and facets to be included within a conceptual framework • Conceptual framework for subjective QoL of older family carers of people with dementia • Generation of preliminary item pool
Step 3. To determine the format for measurement	• Evaluation of existing QoL scales for older people and family carers and the literature on scale development	• To decide on the best scale design for the target population and construct being accessed • Likert response format selected and items collated together in a questionnaire
Step 4. To have initial item pool reviewed by experts	• Questionnaire development and expert evaluation	• Initial draft of the DQoL-OC (89 items) • Assessment of adequacy of conceptual framework • Verify content, language, and format of items (content and face validity) • Reduction of item pool through rejection of poor or redundant items
Step 5. To consider the inclusion of validation items	• Literature on scale development and QoL	• Convergent measures for a separate validation study selected
Step 6. To administer items to a development sample	• Psychometric study	• 100 items questionnaire administered to 182 older carers, from which 18 took part in the retest sample
Step 7. To evaluate the items	• Evaluation of psychometric properties	• Examination of scale structure (incorporating factor analysis) • Statistical analysis conducted to evaluate items and identify a latent factor model • Assessment of validity and reliability
Step 8. To optimize scale length	• Evaluation of psychometric outcomes	• 22 items retained and interpreted in relation to the factor model • Factors labelled (if more than 1) and final items presented as the DQoL-OC • Final scale structure of 22 items.

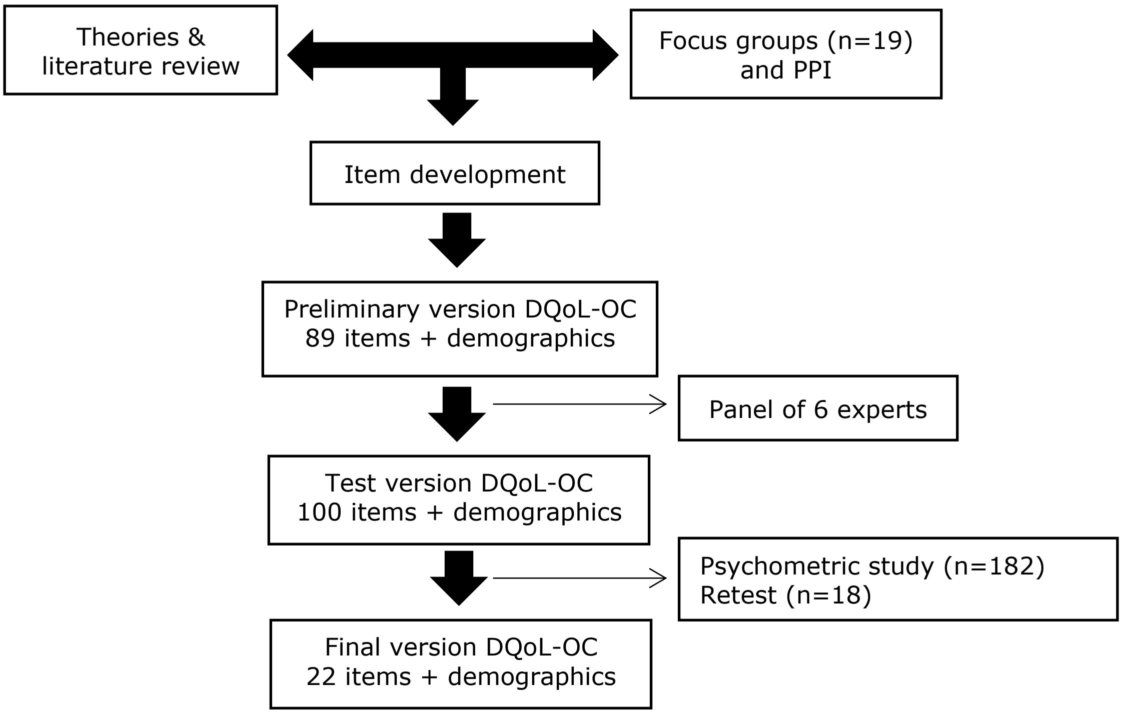

Figure 5. Operational flowchart of scale development

4.4. THE RESEARCH PROCESS

The research process adopted in this study will be presented according to the four essential elements proposed by Crotty (1998) for the development of research. First, (1) the ontological and epistemological assumptions, as well as (2) the theoretical perspective adopted, guided by the research questions and the nature of the phenomenon being studied will be presented. Then (3) the methodological approach and (4) methods of data collection employed will be detailed and the rationale for these choices and their use described. Finally, ethical considerations will be presented.

4.4.1. Philosophical assumptions

In the social sciences, the human world is seen as composed of many and multiple worldviews, embracing subjective and objective perspectives (Johnson and Onwegbuzie, 2004). Philosophical underpinnings in research consist of a basic set of beliefs or assumptions that guide the enquiry under study (Guba and Lincoln, 2005). These are often called as 'worldviews' or 'paradigms' (Creswell and Clark, 2011) and are defined are a "shared belief system that influences the kinds of knowledge researchers seek and how they interpret the evidence they collect" (Morgan, 2007 p.50). Worldviews differ particularly in their nature (ontology) and how knowledge is gained according to them (epistemology), having a major influence on how researchers investigate and report their inquiries (Creswell and Clark, 2011).

As this PhD research aims to produce a valid and reliable instrument for the purposes of measuring older family carers' QoL, this should be constructed based on the views of older family carers themselves, in a way that means their views can be truly represented in the set of items proposed. Older family carers' sense-making of their own QoL is considered in this research as subjectively related to each individual's standpoint, embedded in emotional issues, life history, culture, and age, and varying according to daily experiences and expectations. Each family carer lives in a different situation, in relation to the social economic environment, age, social support, family relations, and disease stage, which can lead them to experience their caregiving activity and make sense of their own QoL in a different way. Their perceptions about negative feelings, such as stress and burden, and positive aspects, such as satisfaction and well-being, are quite specific and need to first be investigated through an in-depth qualitative enquiry. The need for listening to older family carers' views reflects a subjective ontology that calls for a subjective research approach. However, this study also aims to translate these perceptions in measurable items, in a way to generalize its results, by developing a scale that provides valid and reliable QoL scores for clinical and research purposes, thereby assuming an associated objective and universal ontology.

As this research seeks to investigate the phenomenon of interest both subjectively (qualitatively) and objectively (quantitatively), it assumes an ontological position of pluralism (Johnson and Onwegbuzie, 2004). A pluralist ontology makes the core assumption that

> "reality is socially constructed and that subjective meaning is a critical component of knowledge building", in which "the qualitative tradition recognizes the importance of the subjective human creation of meaning but does not reject outright some notion of objectivity" (Hesse-Biber, 2010 p.63).

Creswell and Clark (2011) posit that the epistemological assumptions within a study with multiple ontologies depend on how the researcher intends to "mix" subjective and objective realities in order to answer the proposed research questions. As will be discussed later in this chapter, the mixed-methods approach that best fits this study is a sequential exploratory mixed-methods research (qual -> QUAN) (Hesse-Biber, 2010), in which a qualitative approach is used to generate the QoL theoretical constructs of the DQoL-OC, with the results from this investigation tested through quantitative methods, enabling the validation and generalization of the qualitative results (Howe, 2003).

Accordingly, Creswell and Clark (2011) and Onwuegbuzie et al. (2010) propose that for a sequential exploratory research, subjective (research phase 1) and objective (research phase 2) worldviews should be considered, with each following its own epistemological approaches. When moving from the subjective to the objective worldviews, "the underlining assumptions may shift" (Creswell, 2011 p.87), for example from interpreting the world to carrying out statistical tests and mathematical models, aiming to prove or refute a hypothesis and come up with a universal truth. If the researcher had decided to carry out both qualitative and quantitative studies at the same time instead of a sequential study, and merged two sets of data, then an "all-encompassing" worldview would be more appropriate for the investigation (such as pragmatism, for example). This study was therefore underpinned by an 'interpretivist' epistemology, when subjectively investigating the QoL of participants, followed by a 'post-positivist' epistemology, when dealing with statistical interpretations of the QoL model being tested.

In interpretivism, people and their institutions are central and they are "fundamentally different from that of the natural sciences" (Bryman, 2006 p.13). Knowledge is constituted through each person's lived experience and cultural and historical interpretations. Interpretivists believe that researchers and participants are singular, interdependent, and mutually interactive, and seek to understand motives, meanings, reasons, and other subjective experiences that are time and context bounded (Neuman, 2000). On the other hand, post-positivists make claims of knowledge based on cause-and-effect thinking, by being reductionists, conducting detailed observations and measures of variables, as well as testing theories that are continually refined (Slife and Williams, 1995). A post-positivist epistemological perspective follows the methods utilized in natural sciences, not considering external and individual issues, but seeking to identify, by observation, universal features in human nature and in the society, leading to explanations, control, and predictability (Creswell and Clark, 2011). Because post-positivism posits that observations may contain errors and that all theories are revisable, this offers a suitable approach to scale development, which is in constant revision and re-evaluation.

Even though mixing methods can enable a better understanding of social phenomena, some authors consider the mixed-methods approach as incommensurable or incompatible, arguing that different epistemologies cannot be combined in the same research (Carter and Little, 2007, Johnson and Gray, 2010). Despite the criticisms of mixed-methods research, Mesel (2013) stresses that the transparency of the researcher with regard to these philosophical assumptions is what will actually impact on its validity and consistency, as well as on the success in integrating or establishing a relationship between qualitative and quantitative methods, subjective and objective realities.

Researchers have suggested some strategies to deal with the potential epistemological incompatibility in sequential mixed-methods studies. Creswell and Clark (2011), for example, stress that the researcher needs to tie together the two worldviews in each of the study phases and base the research process and data analysis according to the underpinning epistemological assumptions of each worldview. It is necessary to be explicit and write about each paradigm in use in each study phase, also acknowledging the 'shift point' of the two different epistemologies and how one informs the other. In order to improve the transparency and trustworthiness of this research, as well as to overcome possible methodological and epistemological incompatibilities, such recommendations were followed and are detailed in each research step throughout this thesis.

4.4.2. Theoretical frameworks

This research follows the literature of QoL and HRQoL in old age, particularly that based on older people's views about their life quality (Farquhar, 1995, Bowling et al., 2002). It is grounded in some of the key principles of developmental psychology in old age, theories of stress and coping in later life, plus the available literature on caregiving to widen the scope of the investigation. It considers QoL as being a subjective, broad, and multidimensional construct, meeting WHO's definition of QoL (WHO, 1995 p.1405).

4.4.3. Methodological approach

Mixed-methods research has been considered the "third research paradigm" (Johnson and Onwegbuzie, 2004 p.15) and has received numerous definitions in past years (Streiner and Norman, 2003). Because they encompass multiple epistemological and ontological views, mixed-methods studies offer a diverse range of means by which to address profoundly complicated conditions, such as dementia and caregiving (Robinson et al., 2011).

Aiming at a definition that embraced both methodological and philosophical orientation, Creswell and Clark stated that mixed-methods is

> "a research design with philosophical assumptions as well as methods of inquiry. As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis and the mixture of qualitative and quantitative approaches in many phases of the research process. As a method, it focuses on collecting, analysing and mixing both quantitative and qualitative data in a single study or series of studies. Its central premise is that the use of quantitative and qualitative approaches, in combination, provides a better understanding of research problems than either approach alone" (Creswell and Clark, 2007 p.5).

Later on, the authors built on this statement, by incorporating multiple viewpoints, combining methods, a philosophy, and a research design orientation (Creswell and Clark, 2011 p.5). They generate a practical and guiding definition that aims to bring solutions to the ongoing debate regarding the ontological and epistemological tensions in mixing qualitative and quantitative enquiries, and to improve the validity and reliability of results from mixed-methods studies. For this reason, this definition was used as a methodological framework within this study.

The authors state that "in mixed methods, the researcher

- collects and analyses persuasively and rigorously both qualitative and quantitative data (based on research questions);
- mixes (or integrates or links) the two forms of data concurrently by combining them (or merging them), sequentially by having one build on the other, or embedding one within the other;

- gives priority to one or to both forms of data (in terms of what the research emphasizes);
- uses these procedures in a single study or in multiple phases of a program of study;
- frames these procedures within philosophical worldviews and theoretical lenses; and
- combines the procedures into specific research designs that direct the plan for conducting the study" (Creswell and Clark, 2011 p.5).

4.4.3.1 Mixed-methods approach to scale development

A mixed-methods approach is commonly used for the purpose of developing and testing new instruments (Bryman, 2006, Onwuegbuzie et al., 2010, Creswell and Clark, 2011), especially health and psychological scales (see, for example: Brod et al., 1999, Younossi et al., 1999, Chen et al., 2001, Atlas et al., 2005, The WHOQoL Group, 2005, Aubeeluck and Buchanan, 2006, Aubeeluck and Buchanan, 2007, Wittenberg et al., 2007, Dunning et al., 2008, Zeldenryk et al., 2014, Wassef et al., 2014).

The items of a QoL scale need to reflect important aspects of QoL for the population the scale is designed for so that the validity and reliability of the scores produced by the new tool are improved and the research and clinical community are able to make decisions based on the content of the scale, its format, and psychometric properties (Streiner and Norman, 2003). In this research, an investigation of older family carers' views and perceptions about their QoL was carried out through a qualitative study, a method of enquiry aimed at gaining an in-depth understanding of human behaviour, by listening to people's own views, feelings, and perceptions about their social reality (Vogt et al., 2004). Results from this qualitative investigation were considered the base for the development of the scale items and were tested in a quantitative study (Creswell and Clark, 2011), which is a method of enquiry aimed at creating or making use of statistical models, theories, and hypotheses to explain a phenomenon, in which the process of measurement is central (Clark and Watson, 1995).

This research thus follows a deductive approach. The qualitative enquiry was placed at the core of scientific quantitative enquiry through a fixed, typology-based, sequential, and exploratory mixed-methods study (qual-> QUAN) (Hesse-Biber, 2010). The qualitative approach was used to generate the QoL theoretical constructs of the DQoL-OC, the two paradigms were integrated after the qualitative data analysis and interpretation, and the results of this integration tested using quantitative methods, enabling the generalization of the qualitative results (Creswell and Clark, 2011).

The choice of this type of mixed-methods research was also guided by the research questions and objectives proposed in this study, since for achieving objectives 2 and 3 it was necessary to have achieved objective 1, and that the knowledge produced in each phase be interdependent. Also classified as an instrument-development variant (Creswell and Clark, 2011), this sequential exploratory mixed-methods research has the emphasis or priority given to the quantitative strand, as the qualitative phase takes a secondary role on the prioritized quantitative strand. The point of interface between the two paradigms is at the end of the qualitative data analysis and beginning of quantitative data collection. The qualitative results were used to make decisions about quantitative questions, sampling, and data collection as part of the quantitative strand (Morse and Niehaus, 2009).

4.4.4. Methods

4.4.4.1 Qualitative strand

In research aimed at the development and validation of a new scale, focus groups are considered a viable method for both enriching and extending the knowledge about a concept, informing the item development, and improving the relevance and representativeness of its items (Streiner and Norman, 2003, Vogt et al., 2004). As such, this method has been used for the construction of a wide variety of QoL instruments in different cultures and diseases (Brod et al., 1999, Younossi et al., 1999, Chen et al., 2001, Willgerodt, 2003, Atlas et al., 2005, The WHOQoL Group, 2005, Wittenberg et al., 2007, Zeldenryk et al., 2014, Wassef et al., 2014).

Focus groups have the potential to allow the capture of dynamic interactions of people who share commonalities (Loeb et al., 2006). Such interactions are considered as part of the method as people are encouraged to talk to each other, rather than to the researcher. This method is particularly useful for exploring people’s knowledge and experiences, what people think, and how and why they think that way (Kitzinger, 1995). The groups can help people to explore and clarify their views, and this is particularly appropriate when the interviewer wants the participants to explore the issues in their own vocabulary, generating their own questions and priorities, as well as for the interaction and conversation in opinion formation (Seymour et al., 2002).

In addition, focus group is a widely used method to assess people's experiences of disease and health, effective in exploring the group's feelings, attitudes, and needs (Rabiee, 2004, Kitzinger, 2013). They have been used to discuss particularly sensitive topics with older adults, such as end of life (Seymour et al., 2002), dignity (Bayer et al., 2005), and dementia care (Sutcliffe et al., 2012). In this sense, by proposing a conversation, much more can be discerned about what people know or experience, touching on points and revealing dimensions of understanding that other qualitative methods, such as in individual interviews, would not be able to do (Kitzinger, 2013).

Some of the limitations of the focus group method are known in the literature. For example, the quality of the data depends directly on the moderator's skills in leading the group (Leung and Savithiri, 2009), as some people who have more confidence than others may try to dominate the group, intimidating other participants, for example. In addition, the data derived from the audiotaped group conversations can be difficult to analyse due to the cross-conversations and sounds produced by the group, which may prejudice the identification of the participants and the quality of the results (Barbour, 2007). However, by being aware of these possible limitations the researcher can be prepared and prepare the participants, proposing some 'ground rules', such as to wait in turn to talk, and to speak clearly and at an audible volume, in order to optimize the quality of the data collected.

Another criticism of focus groups is related to the idea that the group dynamic and social constructions are prioritized, rather than the 'self' of each participant or the personal accounts. However, focus groups do not aim to reach a consensus on the topic being discussed, but to "encourage a range of responses which provide a greater understanding of the attitudes, behaviour, opinions or perceptions of participants on the research issues" (Hennink, 2007 p.6). They provide more than a sum of separate and individual accounts, and elicit a more in-depth discussion of events and experiences (Morgan, 1997). In this sense, another view of the reality of the participants is gained, not necessarily ‘individual’ or ‘self’ excluding.

Much of the quality of the results from focus groups and how much the personal accounts are revealed are dependent on the capacity of the moderator to allow people to talk and feel comfortable in sharing their personal thoughts. In a group of people that shares common characteristics, such as being an older person and a family carer, a more open and honest discussion may happen, rather than with just the researcher, who doesn’t share the same reality, experiences, or culture (Basch, 1987). Basch (1987) stresses that the group situation might indeed inhibit participants from providing irrelevant information.

In this study, besides attempting to generate a more open and honest discussion among the participants, other strategies were used at the data analysis level to create a picture of the comfortable environment in which the participants shared their feelings and experiences, for example by acknowledging evidence from the findings or behavioural signs of how comfortable they felt about sharing their thoughts in the group; by highlighting participants’ different opinions (disagreement), or when they introduced different ideas without being asked to; moments in which the researcher became an irrelevant figure in the group, because the participants created a more carers’-focused discussion, rather than a research discussion; and so on.

The discussions were aimed at 1) exploring how older family carers make sense of their own QoL; 2) investigating their experiences, interpretation, and understandings of QoL; 3) investigating the factors that enhance or compromise their QoL; and 4) exploring their opinions about the relevance of the items of an existing QoL measure. Focus groups were guided by the following research questions: 1) How do older family carers of people with dementia make sense of their own QoL?; 2) What are their experiences, interpretation, and understandings of QoL?; 3) What factors enhance or and what factors compromise their QoL?; 4) What are their opinions about the relevance of the items of an existing QoL tool?

In order to benchmark the discussions and ground them in existing QoL research, it was felt important to gain carers’ perceptions of an already validated QoL tool. When choosing a validated QoL scale to use, priority was given to those developed for carers in the UK. By doing this, it was hoped that the dimensions of QoL represented in the items of the chosen scale could contribute to the discussions about aspects of QoL related to caregiving. After consulting the existing measures, it was decided to adopt the Huntington's Disease Quality of Life Battery for Carers (HDQoL-C) (Aubeeluck and Buchanan, 2006, Aubeeluck and Buchanan, 2007, Aubeeluck et al., 2010). Huntington's disease is a rare genetic subcortical dementia that causes progressive dementia symptoms, such as affective, movement, and cognitive disorders, mainly in middle-aged to older individuals (Folstein, 1989). As such, the scale was considered to have relevance to older carers of dementia patients. It is a disease-specific, multidimensional, validated, and well-documented instrument for the assessment of subjective and objective aspects of QoL. It has 34 items that incorporate measures of individual's health, psychological state and level of independence, social relationships, and personal beliefs and is based on WHO's contemporary construct of QoL. It is brief, easy to understand, and has been translated into a number of languages, demonstrating multi-lingual and multi-cultural consistency (Aubeeluck et al., 2013).

Setting

Considering the purposes of this study and its time frame, and also the time constraints which family carers often have, participants were mainly invited from support groups in the Nottinghamshire community. This strategy would enable the simultaneous identification of multiple participants who would be able to take part in the study at a common venue. Local groups led by members of the community, as well as those led by Alzheimer's Society and the Carers Federation, were first invited to help with the study.

Prior to the Ethics application being made, support group leaders were approached and the research proposal introduced. Considering the cultural and language gap between the researcher and the members of these groups, it was considered important to make early contact with the target population and get to know their experiences before data collection started. The researcher tried to attend support meetings as often as possible, as well as local conferences and health-care meetings. Support meetings usually took place every fortnight or once a month, at churches, health services, or day centres, and had a variable number of participants. Some attendants were no longer carers but felt they still benefited from the support of the group even after the loss of their cared for. Living locally to support group venues was not part of their eligibility criteria, so potential participants were from different parts of Nottinghamshire. Some groups also accepted people with dementia, so that carer and cared for could attend the support meeting together.

Participants

Qualitative studies are aimed at reflecting a wider range of diversity within the population being investigated, seeking to capitalize on 'outliers' and incorporate them in the study (Barbour, 2007). Specifically when the purpose of the qualitative study is to gather relevant themes for a new measurement tool, a purposively selected sample, rather than a randomly designed one, is necessary in order to have the widest representation of the target population as part of the instrument development process, aiming to balance the range and diversity of the people with whom the instrument will be used (Creswell and Clark, 2011, Fayers and Machin, 2016).

As such, the literature on the methodological guidance for scale development is not prescriptive about the best sample size. Instead it advises recruiting a sample that represents the population characteristics for which the new scale is designed. Morgan (1997) advises that three to five focus groups are necessary in order to cover a sufficient range of experiences and opinions about a topic. Streiner and Norman (2003), however, suggest that when devising the items of a new health scale, no more than two or three focus groups are necessary. Advice regarding the number of participants per group varies from three to a dozen individuals, with five to six being considered an ideal number (Fayers and Machin, 2016).

Considering that the qualitative data gathered in this study would be analysed using IPA (see 'Data analysis', page 95), studies using this method of analysis tend to have small, purposively selected, and carefully situated samples, as IPA is concerned with an in-depth and detailed exploration of the human experience. Because IPA analysis requires time, reflection, and dialogue, larger datasets tend to inhibit these processes (Smith et al., 2009). As time and resources were limited, it was therefore decided to carry out a minimum of four focus groups with six to eight participants in each group. Even though this sample size is considered large for an IPA study, it would allow for the gathering of enough data to answer the research questions and to achieve the aims of this research (Kitzinger, 2013).

Participants were approached in local community support groups provided either by community leaders or voluntary organizations, such as Alzheimer's Society. In order to identify the views of those older carers who did not have access to such services, individuals who were not currently taking part in any support group but who were registered within these centres were also invited to take part in the study.

Eligibility criteria

Participants needed to meet the same criteria as the population to whom the new scale will be applicable in order to form a purposive sample (Creswell and Clark, 2011, Fayers and Machin, 2016). The individuals invited to take part in this research were:

- Older people (≥60 years of age) currently providing unpaid care for a family member with diagnosis of dementia (carers' report) in the UK; and
- English speaking.

Procedure

Focus group procedures followed guidance from various experts in focus group methodology (see for example: Kitzinger, 1995, Willgerodt, 2003, Loeb et al., 2006, Barbour, 2007, Kitzinger, 2013). The researcher also attended training courses within and outside the University in order to gather key information on how to conduct and analyse focus group data. After Ethics Approval had been obtained (Appendix 1), community leaders gave a formal invitation letter to older family carers attending support groups. Those who were interested in taking part in the study gave their permission to be formally contacted by the researcher. The best day and time to carry out the focus groups were then arranged, which was often at the same time as the normal support group meeting. This guaranteed that relatives with dementia would be safely cared for by the support leaders. All the groups were moderated by the researcher, with the help of a co-moderator (trained psychologist) in the first two groups. The co-moderators listened to the groups and made notes on the discussions and other issues that could not be otherwise recorded, such as facial and corporal expressions or parallel comments.

At the start of the focus group meeting, the researcher read the Participant Information Sheet (PIS) and the Consent Form (CF) with the participants and answered their questions about the study. After giving their consent, the older family carers were taken to a private room, and they were invited to answer the sociodemographic, health, and caring questionnaire created for the purposes of this research based on the literature (first section of Appendix 2). After making sure that participants had no questions about the study, the voice recorder was turned on, and the group discussions were carried out in three sequential parts:

1) Warm-up session: The ethical issues involved in the study and the objectives of the group session were reinforced. Participants were reminded to keep all the information that they shared in the groups anonymous, to respect the other participants' confidentiality and opinions. They were asked to speak one by one, avoiding cross or parallel conversations, in order to improve the quality of the data and facilitate data transcription. The researcher and the co-moderator introduced themselves to the group, giving their names, background, and role in the focus group. All participants were invited to introduce themselves, giving their name, age, how long they had been carers, who they cared for, and whether they knew anyone else in the group.

2) QoL discussions: After the warm-up session, the researcher introduced the WHO definition of QoL (WHO, 1995) to participants. She explained that QoL could mean different things to each individual, giving examples of what could be a good or a poor QoL, in order to assist and motivate the discussion. Participants were then invited to discuss meanings and understanding of QoL in the context of caring for a family member with dementia at home, particularly the feelings associated with the experience of being family carers, in a manner similar to the procedures that Farquhar (1995) used to investigate the important domains of QoL for older people in his research. Discussion was guided by the following questions:

- Could you tell me what does QoL mean for you as a carer?
- Could you tell me what compromises your QoL while being a carer of a family member with dementia?
- Could you tell me what enhances your QoL while being a carer of a family member with dementia?

All participants were encouraged to contribute with their opinions at least once for each topic in order to identify the personal accounts of all the participants. After that, they were handed a copy of the HDQoL-C and asked to give their opinions about the relevance of each question and the overall instrument to their QoL:

- Based on the HDQoL-C, do you think these questions are relevant to evaluate your QoL?

3) Summary session: At the end of the discussion, results were summarized and the family carers asked whether they had any questions. The voice recorder was turned off at this point, and participants were given time for debriefing. They were also encouraged to contact the researcher after the group had finished in case of any remaining questions, distress, or any other discomfort associated with the group discussions. The researcher and co-moderator then met, discussed, and wrote down their own impressions about each session.

The entire processes of recruitment, data collection, and data transcription took four months and were carried out in parallel. The focus groups' recordings were transcribed verbatim by the researcher and each participant given a code (P1, P2, P3, etc.) in order to maintain the anonymity of data. As a consideration of the language gap between the (non-native-English speaking) researcher and participants, the recordings and transcriptions were compared by the supervisors of this study in order to make sure that they were reliable.

Data analysis

Data generated in the focus groups were analysed for the purposes of producing themes that expressed relevant aspects of QoL and to inform the content of the DQoL-OC. Given the exploratory nature of this qualitative study, as well as its research questions and epistemological assumptions, it was decided to carry out the focus groups analysis using IPA (Smith and Osborn, 2004). This aimed to identify the older family carers' own and shared lived experiences and what QoL meant to them. Derived from phenomenology, hermeneutics, and idiography, IPA enables the capture of subjective experience from the perspective of the individual, with a certain level of interpretivism in trying to make sense of what they think and feel about their own experiences, allowing the exploration and understanding of subjective meanings, experiences, opinions, and needs (Smith and Osborn, 2004).

Phenomenology is a philosophical movement concerned with lived experiences and provides a detailed examination of the participants' accounts (Smith et al., 2009). Phenomenologists believe that experience should be examined in the way it occurred, on its own terms, through a careful investigation of the participants' contributions, focusing on what is experienced in the consciousness of the individual. In embracing phenomenology, IPA engages with a detailed description of a person's experiences, revealed during the detailed and analytic search for patterns across the data, pointing out personal and shared accounts. The difference between phenomenology and IPA, however, is that IPA assumes no "direct route" to someone else's experience; the researcher is actually attempting to get as close as possible to how it feels to have that experience. This requires a process of "engagement and interpretation" that is embedded within hermeneutics (Smith, 2011 p.10).

Hermeneutics is therefore the second pillar of IPA (Smith et al., 2009). In hermeneutics, the lived time and engagement with the world are primary features of a lived experience, but access to these is always through interpretation. As such, IPA recognizes that the researcher's understanding of an individual's thoughts is influenced by his or her own assumptions and conceptions, and that this is a necessary process for making sense of another person's experiences. Rather than considering this as problematic to the data analysis, the researcher is invited to reflect upon it.

IPA also assumes that when revealing meanings and experiences, individuals are in a process of trying to make sense of them. At the same time, the researcher is trying to make sense of the individuals trying to make sense of what is happening to them, through a "hermeneutic circle". This is concerned with the dynamic relationship between the part and the whole, in a series of levels that are interdependently analysed (Smith et al., 2009 p.27). Within this study, for example, IPA helped to understand the older family carers' cognitive and affective reaction to the impact of caring on their QoL. The understanding of the phenomenon was associated with interpretative accounts from both the researcher and older family carers.

Finally, the third influence upon IPA is idiographic (Smith et al., 2009). It reflects the IPA commitment to the particular, and this is achieved by carrying out a detailed, thorough, and systematic investigation of the phenomenon under study, by situating participants in their particular contexts, exploring their personal experiences, and starting with a more detailed individual examination before moving on to make general claims. Because the objectives of this qualitative research (within a mixed-methods study) were to provide content for the new scale, less time was therefore allocated for this qualitative investigation, as a larger sample size than IPA normally requires to allow detailed examination of each personal account would be needed. Even though the idiographic component of analysing specific accounts of each participant was less evident, the researcher attempted to produce a detailed, thorough, and systematic investigation of the participants' accounts by using group and personal verbatim quotes, and reflecting upon individual and shared experiences.

The phenomenon of family caregiving in old age and how older family carers make sense of their experience and of their own QoL was considered in this research within a phenomenological perspective, but also emphasizing the role of the researcher's interpretation in accessing and making sense of the participants' making sense of their reality (Smith et al., 2009). Even though IPA is an in-depth exploration and interpretation of a described phenomenon, the levels of interpretation of personal and shared accounts can vary (Smith et al., 2009). The analysis was transparent in its assumptions, and the interpretations were bounded by the ability of the participants to articulate their thoughts and experiences and by the researcher's ability to analyse (Wooleet, 1996).

IPA is also originated from symbolic interactionism, which conceptualizes that individuals do not perceive their objective reality passively, but that they come to interpret and understand their world by formulating their experiences in a way that makes sense to them, and these meanings are constructed by individuals within both a social and a personal world (Denzin, 1995). Accordingly, it makes sense to use IPA within focus groups, as the complexity of the shared experiences in the group dynamics and the multiple voices that are embodied within a set of complex social and relationships contexts provide experiential and interactional elements that can be analysed with IPA in a way that develops a meaningful examination of the participants' experiences and perspectives, while considering social and cultural factors involved in the group constructions (Palmer et al., 2010). In the Palmer et al. (2010 p.101) study, for example, personal experiences were "clearly embedded in a complex set of dynamics" and needed to be studied in the light of phenomenology, rather than in a discursive analysis as this would miss the central experiential meanings of the participants.

The epistemological compatibility between IPA and focus groups is not without controversy, due to the idea that this approach requires an in-depth understanding of individual meanings with regard to the phenomenon being studied and it can be problematic in a group conversation to capture personal phenomenological accounts (Webb and Kevern, 2001, Smith, 2004, Brocki and Wearden, 2006). However, some researchers have been presenting strategies to manage these tensions (Palmer et al., 2010, Tomkins and Eatough, 2010). For example, in using IPA with focus groups, the researcher must bring individual experiences to light during all stages of the research, rather than just analysing the group interactions and constructions (Palmer et al., 2010, Tomkins and Eatough, 2010).

The sense-making of the participant is often explicitly grounded in the iterative group context and must be explored, both the whole and the part with equal importance, from a multiple hermeneutic and idiographic perspective. IPA therefore allows the capture of the most meaningful thoughts and experiences of groups of older family carers presented as shared lived experiences, which would not be possible using other types of analysis (Starks and Trinidad, 2007), and its suitability to the data collected was constantly reviewed along the process of analysis. This study attempted to bring the personal and shared experiences of the participants to the surface, arriving at a shared agreement among the participants about what enhances and what worsens their QoL, while also considering each participant's particular contribution to be unique and as important as the common experiences.

Procedure

After transcription, the researcher carried out the steps proposed by Smith et al. (2009) for effective IPA (Table 9), in accordance with what is proposed for focus group data analysis (see for example: Kitzinger, 1995, Morgan, 1997, Barbour, 2007, Kitzinger, 2013). Data analysis was carried out using the NVivo® package. Considering the cultural and language gap between the participants and the researcher, one of the supervisors of this study carried out the same analysis process in order to improve the trustworthiness and the content validity of the new scale. She randomly selected one of the focus group transcriptions and coded it according to, but not restricted to, the previously selected themes, meaning that she could create her own themes if she felt the need to. Inter-coder reliability was then established by correlating the two sets of analysis using kappa coefficient (Streiner and Norman, 2003).

The literature suggests that, for the purposes of developing a new measurement tool, the researcher can make use of "significant statements or quotes to help write specific items for the instrument" (Creswell and Clark, 2007 p.145). Quotes or themes can be transformed into variables or scale items, and the superordinate themes or clusters can be the constructs or concepts which the new scale aims to measure. Accordingly, the quotes from each theme were read carefully and questions drawn from them. The superordinate themes were considered as QoL domains within the scale.

It was attempted wherever possible to preserve the participants' own words in order to create a meaningful set of questions that related to their own experiences as family carers. Besides considering their quotes, the available literature on scale development, QoL of older people, and family caregiving was revisited in order to make sure the scale was relevant, clear, and focused on QoL measurement. Participants' comments about the relevance of the items and scale format of the HDQoL-C, as well as the Patients and Public Involvement (PPI) members' comments (more details about the Patient and Public Involvement (PPI) advice can be found in the section 'Ethical considerations') were also revisited at this point. The newly developed scale items were exhaustively checked by the researcher, with input from supervisors and postgraduate research (PGR) colleagues, before being submitted to an expert panel (more details about the item development process can be found in Chapter 6).

Table 9. IPA procedure

Stage	Description of analysis
1) Getting close to the data	Writing and reflecting about feelings and experiences in each group. Reading and rereading the transcript to become familiar with the content and to get an overall sense of meaning. Frequent discussion about the data and research experience with supervisors.
2) Making descriptive notes, writing down interesting findings/data/groups' connexions	Initial notes were made in the right-hand margin of the transcript following a phenomenological strategy (descriptive comments, interesting findings, language highlights, possible ideas/connections between the comments and participants in the group, connections between different aspects of the transcript, group agreement/disagreement, personal accounts, emphatic sentences, emotional moments, core definitions, conceptual comments, and questions about how the participant understands caregiving and QoL). Specific group conclusions were drawn on the left-hand side of the transcript.
3) Developing emergent themes	The transcript and initial notes were exhaustively and reflexively re-examined in order to identify themes from participants and group accounts in NVivo®. The process of generating themes and superordinate themes followed the literature of HRQoL in order to identify relevant HRQoL concepts to be represented in the questions of the new scale. Ninety-five initial themes emerged from interpretative accounts, capturing what had been found in the text, while drawing upon knowledge and theory from caregiving and QoL literature and assuming a reflexive position regarding the researcher's own views. The themes were re-examined and compared with the associated references in order to make sure that they were representative and to identify thematic relations between them. During this process, the 95 themes were re-aggregated and reduced to a total of 33.
4) Identifying connections across emergent themes; identifying superordinate themes	Emergent themes were mapped out in NVivo® and using Post-it® notes to explore possible connections between them. Scrutiny of the references of each theme revealed a high degree of concordance, and these were finally allocated into 3 superordinate themes.

Rigour

Aiming to produce a trustworthy qualitative investigation, certain strategies were adopted to establish the rigour and quality of this study. In particular, the following aspects were addressed (Guba, 1981, Shenton, 2004): credibility (or internal validity); transferability (or external validity); dependability (or reliability); and confirmability (or objectivity).

Credibility

The concept of credibility refers to how congruent the findings are with the reality studied, addressed in this research by the following strategies:

- By adopting research methods that are well established.
- By developing an early familiarity with the culture of participants;
- By triangulating: Alzheimer's Society groups, community groups, participants that did not regularly participate in support groups – focus group 1 (FG1), PPI, expert panel, inter-coder reliability.
- By having strategies to help ensure honesty in informants when contributing to the study, so that the data collection sessions involved only those genuinely willing to take part and prepared to offer data freely: in the first instance, potential participants were approached by the support group leaders, rather than by the researcher, giving them the opportunity to decline to participate. In addition, participants were encouraged to be frank in each session of the group, with the researcher indicating that there were no right answers to the questions asked. Confidentiality and anonymity were frequently emphasized to participants throughout the research process. It was made clear to participants that they had the right to withdraw from the study at any point, with no explanation to the investigator needed.
- By having debrief sessions between the researcher and supervisors, as well as with the organization managers: sharing feelings, experiences, hypotheses, theories, always maintaining the anonymity of the information.
- By having a research diary for reflexive accounts.
- By having supervisor checks.
- By examining previous research findings to assess the degree to which the project's results were congruent with those of past studies.

Transferability

This concept is concerned with the extent to which the findings of a study can be applied to other situations. It was addressed in this research by making sure that sufficient description of the phenomenon under investigation was provided to allow readers to have a proper and transparent understanding of it, enabling them to compare the phenomenon described and conclusions drawn with their own views and research experiences.

Dependability

This concept refers to the consistency and replicability of the findings, by making sure that the entire study process is described sufficiently, enabling others to repeat the same study and have the same results and to develop a thorough understanding of the methods and their effectiveness (Guba, 1981). In order to address the dependability issue in this qualitative research, the processes in the study were reported in detail, providing the reader with in-depth coverage, enabling assessment of the extent to which correct research practices have been followed.

Confirmability

The concept of confirmability is comparable to objectivity in quantitative studies. Strategies must be adopted in order to make sure that the findings represent the participants’ accounts, rather than the researcher’s own beliefs or worldviews. Even though IPA implies that researchers’ own beliefs and assumptions will influence how they interpret and make sense of a participant’s accounts, researchers need to reflect upon their own views during the data gathering and analysis stages in order to increase awareness of possible sources of personal inference that may affect analysis (Smith et al., 2009).

Here again, a detailed methodological description may enable the reader to determine how far the data and QoL constructs emerging from it may be relied upon. The triangulation strategies followed in this study have important impact here, by reducing the effects of the researcher influences. The decisions underpinning the data analysis and methods adopted were acknowledged throughout the research. It was endeavoured to present a rationale for decisions made during the data analysis, as well as taking a critical stance on the individual’s position as a researcher reflected during the research process, aiming to establish clear boundaries between interpretation and influence on the data (Elder and William, 1995, Malterud, 2001, Tong et al., 2007).

Before starting the group sessions, the researcher reflected, discussed, and wrote down her own concepts about QoL, together with choices and assumptions about the possible results. She reflected upon the possible influences of her gender, identity, previous training, experiences, profession, and age, as well as the role and attitudes of the moderator and co-moderator during the focus groups in the interpretation and analysis of the data.

After developing the DQoL-C items, the quantitative study strand aimed at measuring the psychometric properties of the DQoL-OC and validating it for use with older family carers of people with dementia.

4.4.4.2 Quantitative strand

The validation process has been previously summarized in Table 8 (page 81) and was carried out in two sequential steps: 1) consultation of an expert panel; and 2) psychometric study.

Step 1 – Expert panel

Having generated the items of the new scale and chosen the scale format that was most appropriate to the older family carers’ population, experts by training (researchers) in the fields of dementia, psychometrics, QoL, and family caregiving, and experts by experience (older carers) were invited independently to evaluate each item and the entire tool with regard to clarity of language, relevance to the QoL of the target population, and how much the items appeared to measure the QoL construct. This procedure is considered good practice in scale development as it helps to ensure content and face validity of the new tool (Rubio et al., 2003, Streiner and Norman, 2003, Leung et al., 2005, Polit and Beck, 2006, Nagpal et al., 2010, Wassef et al., 2014).

Eleven researchers from the aforementioned fields of expertise were approached, four of whom agreed to take part. Two older family carers were also invited to provide expert opinion. This group of six experts was e-mailed a cover letter explaining details about the study, the aim of the evaluation, and their role as assessors, and giving instructions about how to carry out this assessment. They also received a brief explanation of how the DQoL-OC was developed and how the items were organized and scored. They were asked about their past/current academic/caregiving experience, as well as any previous experience as a member of an expert panel.

The literature around expert panel as a method for the evaluation of face and content validity of new questionnaires is variable, offering different judgmental procedures and approaches (Rubio et al., 2003, Hardestya and Beardenb, 2004). After consulting several studies on this topic, it was decided to invite the experts to evaluate the DQoL-OC items and entire measure using two sequential steps. Firstly, the relevance of the items for the target population and its congruence with the WHO's QoL construct was evaluated using 1 to 10 point Visual Analogue Scales (VAS). They were asked: "In your opinion, how relevant is this item/measure for the purposes of evaluating the QoL of older family carers of people with dementia?" Experts were given examples of questions that they were expected to reflect upon (e.g. Does the scale cover relevant domains of QoL? Is the construct of QoL being covered by these questions? Do you have any suggestions about item inclusion/exclusion?). Secondly, clarity of language was assessed again for the entire measure and for each question, by using the following question: "In your opinion, how clear is this item/entire measure for the purposes of evaluating the QoL of older family carers of people with dementia?" Results from all members were compared and discussed with the researcher's supervisors.

The literature suggests that a kappa coefficient is the best method for measuring agreement of results of each member of the panel and should guide item removal (Rubio et al., 2003). In this particular study, however, all members of the panel judged all items as being relevant. They proposed modifications in wording for clarity and the inclusion of some caregiving aspects which were missing. Therefore, a 'qualitative' approach was taken to the experts' comments to improve the quality of the preliminary version of the DQoL-OC and no item was removed at this stage. This is discussed in length in Chapter 6.

Step 2 – Psychometric study

The aim of the psychometric study was to explore the latent factor structure of the newly developed QoL model represented within a set of items. It also aimed to evaluate the preliminary psychometric properties of the DQoL-OC and its practicality, as well as to refine and reduce the instrument while preserving its relevance and clarity (Summers, 1993, Polit and Hungler, 2000, Rubio et al., 2003, Streiner and Norman, 2003, Carretero-Dios and Pérez, 2007, Kimberlin and Winterstein, 2008). Because of the exploratory nature of this study, Exploratory Factor Analysis (EFA) was the method chosen to investigate the latent factor structure of the QoL model. EFA is composed of a series of statistical methods which are broadly used and applied in social science research and are appropriate when a new scale being developed is not based on a clearly defined construct (Costello and Osborne, 2005, Beavers et al., 2013). Current best practices for carrying out EFA were followed and are described below.

Participants and procedure

There is no agreement in the literature regarding appropriate sample size when conducting EFA (Mundfrom et al., 2005). Even though large sample sizes (n>500) are indicative of better factor discrimination (Costello and Osborne, 2005), several studies show that adequate sample size is partly determined by the nature of the data and not just by the number of participants, meaning that the stronger the data, the smaller the sample necessary for an accurate analysis (Fabrigar et al., 1999, MacCallum et al., 1999).

Although an absolute minimum sample size is not often presented in the literature, in general small sample sizes are accepted for higher levels of communality within the data and a higher ratio of number of variables to number of factors (Mundfrom et al., 2005). For low communality factors within the matrix under study, the literature suggests a minimum acceptable sample size of 150 to 200 participants. Accordingly, a maximum convenience sample of 300 participants was set for this psychometric study. A sample size of around 20 participants was invited for the retest reliability study. These participants were invited to complete the same questionnaires a second time in order to identify whether the scale provided stable outcomes after a two-week interval (Streiner and Norman, 2003).

Participants were recruited from a variety of voluntary organizations (Alzheimer's Society, Carers Trust, Carers Federation) and community-based carers' groups. Information about the study was also publicized in public areas, such as supermarkets, churches, and local community centres. Online advertisements were placed on social media (e.g. Facebook, Twitter, and blogs from Alzheimer's Society). In order to reach the target sample size and include a wider variety of carer demographics and levels of support, Ethical Approval was sought from the NHS in order to access older carers from General Practice services, memory clinics and home care providers. Individuals needed to fit the following inclusion criteria:

- To be aged ≥ 60;
- To be currently providing care for a family member with dementia (carers' self-report) at home in the UK; and
- To understand English.

As shown in Figure 6, older carers were recruited directly by the researcher or by the services involved with the study. All Alzheimer's Society support groups located in the Nottinghamshire area were visited by the researcher, who distributed leaflets and envelopes containing the research material. Research material was also distributed by support workers from support groups located in other areas of the East Midlands (Leicestershire, Lincolnshire, and Northamptonshire). Envelopes from each area received a different colour stamp in order to allow creation of a research report for each of these areas and to help support workers to identify areas of priority.

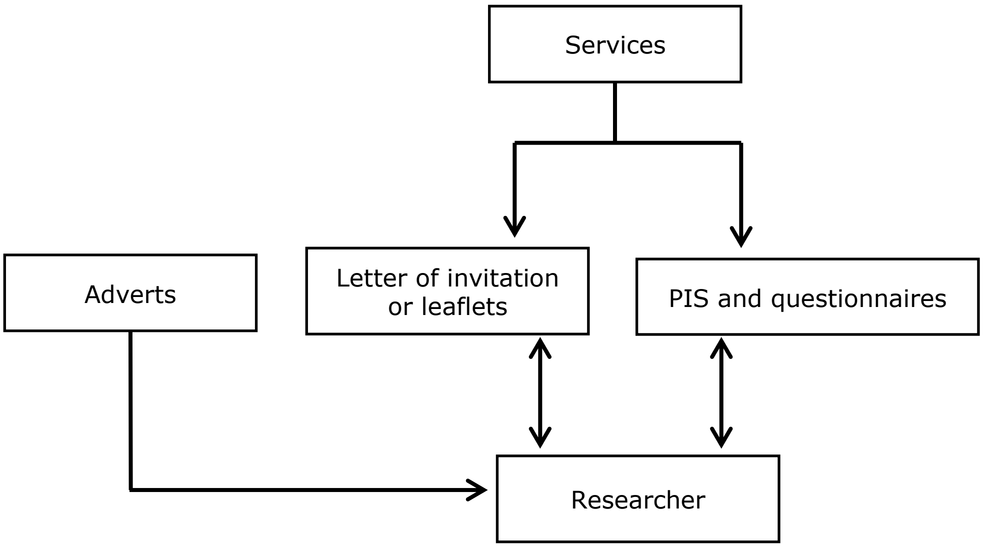

Figure 6. Recruitment strategy

In the GP services, a letter of invitation for the study was sent by each service from the Nottingham West area to carers who were registered with them and met the inclusion criteria of the study. Those who were interested in taking part contacted the researcher directly, and an envelope with the research material was sent to their address, with a pre-paid return envelope. All participants who agreed to take part in the psychometric study were also invited to take part in the retest sample until the required sample size was reached. In addition to the test version of the DQoL-OC, other existing validated scales were used to assess the convergent construct validity of the new scale (Streiner and Norman, 1995, Polit and Hungler, 2000, Furr, 2011, Fayers and Machin, 2016). By correlating the results of the final version of the DQoL-OC and these previous validated scales, it is possible to provide evidence that the new scale taps into the same construct as already-established and well-used measures. A brief explanation of each scale is given below.

The World Health Organization Quality of Life Scale for Aging Population (WHOQOL-AGE)

This is a QoL scale developed by WHO for use with older people (Caballero et al., 2013). It contains 13 Likert scale items (1 to 5) derived from the WHOQOL Older Adults Module Short Form 1 (The WHOQOL-OLD SF1) (The WHOQoL Group, 2005, The WHOQOL-OLD Group, 2011) and the EUROHIS-QOL index (Schmidt et al., 2006). This tool was validated with a large sample of older adults living in European countries and is considered a short, easily completed, and robust QoL instrument. It is highly reliable (Cronbach's ɑ=0.88 for factor 1, 0.84 for factor 2, 0.91 for the entire scale) and contains areas of QoL that are specific to older adults. The higher the total QoL score, the better is the individual's QoL.

The Satisfaction with Life Scale (SWLS)

This is a well-established scale to measure the global cognitive judgments of satisfaction with one's life (Cronbach's ɑ=0.87) (Diener et al., 1985). It contains five items and usually requires only about a minute of a respondent's time. It has been translated into various languages and validated in a number of cultures, and is often used with older populations

(Pavot and Diener, 1993). The higher the SWLS score, the better is the individual's satisfaction with life.

Perceived Health Status and Overall Perceived Health-Related Quality of Life – Visual Analogue Scales

The Perceived Health Status Visual Analogue Scale (PHS-VAS) (Weinman et al., 1995) and Overall Perceived Health-Related Quality of Life Visual Analogue Scale (OPHRQOL-VAS) (Torrance, 1978, Carlsson, 1983, EuroQol Group, 1990, Bleichrodt and Johannesson, 1997, Lundberg et al., 1999, Shmueli, 1999, Boer et al., 2004, Shmueli, 2005) were used to evaluate participants' perception about their state and quality of health. VASs have been proved to be valid and reliable in providing a single overall score of people's state of health and QoL (Bowling, 2005b) and were thus used in the current study to provide further evidence of the convergent construct validity of the DQoL-OC. For the PHS-VAS, participants were asked to indicate on a vertical scale of 1 (poor) to 100 (perfect) how good they felt their current state of health was. For the OPHRQOL-VAS, participants were asked to indicate on a vertical scale of 1 (worst imaginable quality of health) to 100 (best imaginable quality of health) how good they felt the current quality of their health was. The higher the scores of both VASs, the better the individual's perception of his/her state/quality of health.

Questions investigating face validity, content validity, and practicality

The literature does not provide clear guidance for assessing face validity and practicality in developing new questionnaires (Hardestya and Beardenb, 2004). These two assessments are related to the degree to which test respondents view the content of a test and its items as relevant to the context in which the test is being administered, as well as the extent to which the items are clearly written, easy to understand, and can be completed in a timely manner. For the current study, it was decided to invite participants to give their opinions about the DQoL-OC, by answering 1 to 5 Likert scales for relevance, length, difficulty, and language clarity, similarly to the procedures employed in the expert panel. Family carers were also asked about the presence of any upsetting/distressing questions. They were asked to record both the time taken to complete the DQoL-OC and to complete all the scales being used.

Data analysis

During the psychometric study, after the first 20 questionnaires had been received by the researcher, these were checked in order to identify any discrepancies or strongly problematic items (e.g. ceiling or floor effects, distressing items, high number of missing) that appeared to affect the overall quality of the study.

After the psychometric study was finished, the data collected were uploaded in SPSS® 22, and a confidence interval (CI) of 95%, $p \leq 0.05$ was considered for all calculations. Data analyses were carried out through an iterative process, in which a number of statistical tests were performed for data screening, data cleaning, item reduction, factor analysis, and validity and reliability measurements. All variables first had their univariate descriptive statistics checked for accuracy of data input (out-of-range values, plausible median and standard deviations) (Tabachnick and Fidel, 2014). About 10% of all questionnaires (n=18) were randomly selected to have all their data input checked for accuracy in SPSS®. After that, inspection of the complete dataset was then carried out to check the pattern of missing data and to decide what statistical technique was required to handle this.

After missing data were corrected appropriately, descriptive statistics were calculated for all variables in order to identify any ceiling or floor effects (≤15%) (Terweea et al., 2007), and normality of each variable was checked using kurtosis and Shapiro-Wilk statistics (Ghasemi and Zahediasl, 2012). As suggested by Tabachnick and Fidel (2014), about 10% of the whole dataset was randomly selected for inspection in relation to the presence of univariate (z scores) and multivariate outliers (Mahalanobis distance), and for multicollinearity (multiple linear regressions). In addition, a new variable was then created with the sum of the total scores of the DQoL-OC. Item–total correlation was calculated for the 100 items, and the results of each item were checked prior to item removal (Tabachnick and Fidel, 2014).

Item removal and exploratory investigation of the new QoL model

After cleaning the dataset and checking the statistical properties of each variable, EFA was carried out in order to explore the latent structure of the new QoL model and to reduce the number of items (DeVellis, 2012). This was performed using Principal Axis Factoring (PAF), as it does not make any distributional assumptions and therefore is suitable for ordinal data (Fabrigar et al., 1999, Costello and Osborne, 2005, DeVellis, 2012). The suitability of the data for factor analysis was checked by inspecting the significance of the Bartlett Test of Sphericity (Bartlett, 1954), which indicates the strength of the inter-correlations between the items, and by inspecting the extent of Kaiser-Meyer-Olkin (KMO) (≥ 0.60) (Kaiser and Caffey, 1965, Kaiser, 1970, Dziuban and Shirkey, 1974), which provides evidence of sampling adequacy.

EFA was carried out using PAF and promax rotation (PR) (Costello and Osborne, 2005). The decision about the number of factors to be extracted was taken based on two approaches (Ledesma and Valero-Mora, 2007). First, the scree plot was visually inspected in order to identify the point where there was a clear decline in the group of eigenvalues (Cattell, 1966). After that, the eigenvalues generated in the EFA were compared to a set of random eigenvalues created via Monte Carlo simulation, using parallel analysis (PA) (Horn, 1965) and the 95th percentile criteria (Glorfeld, 1995). This test was performed using the software 'Monte Carlo Principal Component Analysis (PCA) for PA' (Watkins, 2000).

PA, scree plot inspection, and EFA were carried out several times, and items were removed based on their item–total correlations (<0.3), communality scores (<0.32), and pattern matrix loading scores (<0.4) (Tabachnick and Fidel, 2014). Items were removed and re-inserted many times in the analysis in order to be sure of their performance before the final decision to keep or remove them, based on their performance within the overall scale. This iterative process aimed to retain a small but robust and meaningful set of items for the measurement of QoL of older family carers.

Convergent construct validity

Other previously validated scales were administered during the study for the purposes of providing evidence of convergent validity. The sum of the total scores of the WHOQOL-AGE, and the SWLS, and the measurements of the OPHRQOL-VAS and the PHS-VAS were therefore correlated with the sum of the total scores of the final version of the DQoL-OC, using Pearson statistics. A high, positive, and significant correlation between the scales was expected in order to establish convergent validity. Correlation analysis between the total scores of the final version of the DQoL-OC and sociodemographic and caregiving variables was carried out using non-parametric statistics (Spearman’s rho). This aimed to help establish construct validity, identify patterns of QoL in the sample under investigation, and identify variables that can be further explored in future research using the DQoL-OC.

Reliability

Evidence of reliability was provided using two different tests: internal consistency and retest reliability. Internal consistency demonstrates how closely related a set of items are as a group within a scale and gives evidence of the extent to which the selected set of items is a consistent measure of a particular concept (Streiner, 2003). Cronbach’s ɑ is one of the most commonly used tests to demonstrate the strength of consistency, and scores may vary from 0 to 1 (Cronbach, 1951). Reliable scales have Cronbach scores above 0.7, but scores above 0.95 may indicate redundancy among the items (Streiner, 2003).

Retest reliability was calculated using a smaller sample of 18 participants to explore stability over time. As later demonstrated, the sum of the QoL scores (overall QoL) from both sets of measurements were normally distributed, and so this variable was considered continuous (possibly ranging from 22 to 110) for the purpose of reliability estimation. This decision was also made by considering that the DQoL-OC scale is likely to be used in the future as a measure of overall QoL, rather than its individual items or dimensions. In other words, identifying the extent of variation of changes over time in the multidimensional construct is considered more important than the variation of each item. For this reason, the two sets of measurements were compared using Intraclass Correlation coefficient (ICC), as it reflects both systematic and random differences in test scores, thus reflecting variability within the sample (Kramer and Feinstein, 1981, Guyatt et al., 1987).

Face validity, content validity, and practicality

Results from the evaluation of relevance, length, clarity of language, levels of difficulty, presence of any upsetting/distressing questions, and time to complete the questionnaire were compiled and described using a table of frequencies. Comments made by participants were summarized and provided further explanation for their general ratings on the overall scale.

4.4.5. Ethical considerations

Ethical issues must be presented in any type of research, because of the possible tensions between researcher’s interests and participants’ rights. Especially in health studies, the specificities of research must be outlined and followed, thereby anticipating, preventing, or reducing any possible harm to the participants (Orb et al., 2000). In order to adhere to good clinical practice guidance in this research, the researcher participated in the course entitled ‘Introduction to Good Clinical Practice (GCP)’, provided by the NHS. Permissions to conduct this research were sought from the Faculty of Medicine and Health Sciences in The University of Nottingham and from the NHS Research Ethics Committee. After this, other necessary approvals were sought (e.g. Alzheimer’s Society, Nottinghamshire Healthcare Trust).

In this study, older carers were treated as autonomous agents, having their decision for voluntary participation respected and being provided with as much information as necessary to understand the research, their participation role, and their rights (Orb et al., 2000, Harris, 2011). Their decisions were respected, and all efforts were made to protect them from harm. The researcher was mindful of the potential risks and benefits of the study to the older participants and paid attention to issues of fairness and equality. All the participants were treated equally, receiving the same benefits and having the same ‘opportunity’ for participation in the research (Flaskerud and Winslow, 1998).

Older family carers received an invitation letter from the support group’s leaders in order to avoid any type of coercion that could be generated by the recruitment process. Questionnaires were also all anonymized, aiming to avoid putting pressure on carers. For the qualitative investigation, PIS and CF were read together with each potential participant, giving them the amount of time they needed to decide, and the researcher was open to any questions that they had (NHS, 2001). Participants were informed of their right to decide not to participate in the research or to withdraw at any time, with no change with regard to the support that they received from services. The researcher made sure that the writing of the research documents was legible and written in layperson’s language, containing no restrictive terminology. The confidentiality and anonymity of the participants was ensured, and the data will be kept in a safe place for the next seven years, in line with the University Faculty and NHS Ethics requirements.

With focus groups specifically, the literature provides evidence of both the positive and negative impact that this method can have on participants, which should be addressed in the research design (Owen, 2001, Seymour et al., 2002, Barbour, 2007). The researcher was mindful that comments generated in the group sessions could cause distress for participants, which was mitigated by constantly making sure that participants were feeling 'OK' during and after the group session, providing time for participants to debrief, to raise their concerns and to ensure their consent. During the last focus group, for example, the researcher identified a distressed participant who raised concerns about safeguarding issues. The group discussion was terminated, and adequate support was sought from the Alzheimer's Society support worker and GP (more details about this case are available in Chapter 5).

4.4.5.1 Patients and Public Involvement

Introducing potential participants to the process of the research development is recommended research practice by ethics committees (Smith et al., 2005, NHS, 2011). This project was presented in the 'Palliative Care Studies Advisory Group' in Sheffield (on 2 June 2014) in order to gather lay views about the research. PPI members had the opportunity to read a brief overview of the research sent previously and made available on the day of the meeting. The group also received a 20-minute presentation on the research. The attendees gave opinions and advice with regard to the study protocol and possible ethical concerns for a study being developed with older family carers.

The researcher asked: "As I am planning to do research with older carers, what would be important to consider?" Discussions involved number of people per focus group; communication with participants; what is relevant to consider when carers have to leave their homes and their cared for to participate in this study; how to formulate the study questions; what would be important to ask about QoL; and relevant venues for the groups or the interviews. The group feedback was recorded and transcribed with permission. Some adaptations were made to the project based on the discussions, and these were also valuable for data collection.

4.5. SUMMARY

This chapter presents detailed aspects of research design and philosophical assumptions, as well as the methods and procedures utilized to collect, analyse, and interpret the gathered data. A rationale was provided for the development of a sequential mixed-methods research study, with focus on the quantitative strand, underpinned by interpretivist and post-positivist epistemologies. Methods used in the qualitative and quantitative study strands were described, with a rationale provided for each decision taken through each method. The use of a transparent and systematic approach helped to ensure that trustworthy qualitative data, as well as valid and reliable quantitative outcomes, were obtained. Results from this mixed-methods study are presented in the following chapters.

Chapter 5

CHAPTER 5. EMERGING QUALITY OF LIFE THEMES IN FOCUS GROUPS WITH OLDER FAMILY CARERS

5.1. OVERVIEW

The last chapter presented the methodology and methods used in this PhD research. This next chapter presents and discusses the findings from the focus groups carried out with 19 older carers in Nottinghamshire (UK). This qualitative investigation was aimed at identifying the variables underlying dementia older family carers' QoL by:

- exploring how older family carers make sense of their own QoL through their experiences and understandings of what QoL means to them;
- exploring the factors that enhance or compromise older family carers' QoL; and
- and exploring older family carers' opinions about the relevance of the items of an existing carers' QoL measure to their own QoL.

Participants were recruited via community-based support groups. Gathered data were transcribed verbatim and analysed using IPA by two researchers independently. Very good inter-coder reliability was established (kappa coefficient=0.839). The 33 themes emerging from this qualitative study were collated into three superordinate themes, namely 1) practical aspects of care and caregiving, 2) feelings and concerns, and 3) satisfaction with life and caregiving. These findings were then discussed against the current literature. Findings from this qualitative study formed the basis for the item development process of the DQoL-OC, described in Chapter 6.

5.2. PARTICIPANTS

A total of four focus groups carried out with 19 participants took place in different areas of Nottinghamshire, each with 50 to 112 minutes of duration. It was considered difficult for some older carers to take part in the focus groups, predominantly due to the fact that they were mostly full-time carers and had no other available source of support. Other reasons for declining participation or not attending the scheduled meeting were related to their own physical health impairments, which limited their access to the venue, and difficulties in sharing their caregiving-related feelings in a group. Other individuals had issues with travel costs and difficulties in allocating a common day and time for their participation in the groups (due to caregiving). Some carers referred to not being allowed by their cared for to leave for that length of time or because their relatives with dementia felt insecure staying with the other support group members while their carers were taking part in the study. After contacting the first potential participants, the best strategy to offset these issues seemed to be to arrange the groups on the same day and time as the support groups, in which case the person being cared for could stay with the support group coordinators, and carers were able to take part in the focus groups in a private room in the same building.

Table 10 shows the sociodemographic characteristics of the participant group, collected prior to group discussions using the questionnaire described in Chapter 4. Participants' age ranged from 60 to 81 years old. The majority were women (n=13), married (n=18), who attended school for from nine to 12 years (n=16) and did not have a job outside caregiving (n=16).

Table 10. Sociodemographic characteristics of participants (n=19).

Group	Participant code	Age	Gender	Relationship state	Schooling (years)	Work
FG1	1	81	M	Married	9-12	No
	2	63	F	Married	9-12	Yes
	3	60	M	Single	5-8	Yes
	4	72	F	Married	University	No
	5	79	F	Married	9-12	No
	6	72	M	Married	9-12	No
FG2	7	63	M	Married	9-12	No
	9	64	F	Married	9-12	No
	10	76	M	Married	9-12	No
	12	77	F	Married	9-12	No
	13	67	F	Married	9-12	No
	15	78	M	Married	9-12	No
FG3	16	65	F	Married	9-12	No
	17	75	F	Married	9-12	No
FG4	18	67	F	Married	9-12	No
	19	70	F	Married	9-12	No
	20	63	F	Married	9-12	No
	21	80	F	Married	9-12	Yes
	22	71	F	Married	5-8	No

Moreover, participants reported being a carer since dementia diagnosis, and some of them declared having started their carer role some years before the diagnosis, when the first symptoms of dementia actually appeared. Carers were co-residing spouses (n=16) or children living in different houses (n=2), mostly providing care to their family members 24 hours a day (n=15), seven days a week (n=18). Their relatives were diagnosed with dementia for up to three years (n=7), from four to six years (n=7) or more than seven years ago (n=5), mostly with AD or VD, or both (n=12). Six older family carers did not receive help from any other family member or friend and only six participants were receiving formal support. Two female participants were carers of other family members with dementia in the past, and a female participant was also providing care to an adolescent son with mental health illness at the time of the study.

5.2.1. Reflexive notes

The researcher's reflexive notes include a description of my experience as a focus group researcher, my feelings about participants' accounts, and perceptions as a researcher interested in older carers' QoL. A few of these thoughts are hereafter presented prior to study findings in order to provide some contextual information about the focus groups.

As expected, my first experience as a focus groups researcher was challenging, and having the support of a co-moderator in the first two groups was important. The first group was co-moderated by another PhD student, who is a psychologist by background and mental health researcher, and the second group was co-moderated by one of the supervisors of this PhD study. They supported me by helping to prepare the setting, check questionnaire responses, and make relevant notes.

As mostly full-time carers, participants' attendance in the focus groups was at times affected by their caregiving demands. For example, a few participants in FG1 arrived late because they were making sure their cared for was settled, the third group had a smaller number of participants because five carers had difficulties attending the group, and P20 from group four was called by the support worker to see her husband, who was agitated without her, and she did not return to the research room.

Carers had long narratives embedded within their experiences. Discussions were intense, with carers speaking one by one at the beginning of the sessions. As they were progressively engaging with the discussion and getting to know each other's stories, little space was left for me to intervene, demonstrating strong group identity and a sense of freedom to expose their ideas. Carers seemed to need to talk and report their feelings and experiences, particularly those in advanced stages of dementia caregiving. In order to cover all the research questions, I had to interrupt participants every time it was necessary to move on with the discussion or to include some quieter participant in the conversations.

As I had previous contact with some of the participants, I noted that family carers seemed to be in a much more difficult situation than they appeared to be outside the research setting, as if they had been hiding their negative feelings and frustrations during informal chats. This may be due to the fact that previous contact with participants took place during the support groups, which were carried out together with their relatives with dementia. For this reason, carers might not have felt that they could share their needs and experiences of caregiving in front of their relatives. The confidentiality of the study setting may have allowed carers to disclose their most intimate feelings, which they would not have had otherwise. I wonder whether this may reflect how much of the carers' needs are actually identified by health and social supporters and how much these professionals are able to offer support at this level.

Caregiving accounted for a large part of the older carers' lives. In general, the aspects related to participants' QoL or their definition of what it means to have QoL were very close to how they were experiencing their family caregiving. It was also closely related to their perception about their family members' current state of well-being. Particularly in the fourth group, I noticed that carers often asked the permission of the person who they cared for to leave them for that period of time. They also had concerns about their relative's reaction to it, constantly asking their family members whether they would feel OK by themselves, even though their relatives were being taken care of by volunteers and support workers during that time. As a result, two potential participants did not participate in the research because their family members refused to stay without them. I wondered during my debrief session if this was an aspect associated with their full-time caregiving, which did not allow them to disconnect their lives from their relatives' and also impacted on their sense of identity.

Finally, one participant from group four disclosed some safeguarding issues about herself and her cared for. Other participants were so worried about one of these carers that the group discussion needed to be terminated. I then decided to seek her permission to ask for the help of the support worker, who took the case further. All the proposed research topics were discussed, apart from the relevance of the existing QoL scale to their reality. I felt a bit disempowered as a researcher at times, unable to change the situation that those carers were in.

5.3. FINDINGS

Thirty-three themes emerged from the data analysis and were collated into three superordinate themes, as outlined in Table 11. In order to improve the trustworthiness of the findings, a random proportion of the data was analysed by the second PhD supervisor. Very good inter-coder reliability was established (kappa coefficient=0.839). The most frequent themes across all focus groups were ‘daily conflicts’ (n=111), ‘sense of burden of care and responsibility’ (n=97), and ‘living a limited and restricted life’ (n=102). Themes were highly interrelated, and therefore results from each superordinate theme are presented as a unit.

Table 11. Superordinate themes and their respective subthemes

Superordinate themes	Subthemes	Quotes
Practical aspects of care and caregiving	1. Appropriate support from health and social services	64
	2. Daily conflicts	111
	3. Disease stability or stage	25
	4. Family and friends	61
	5. Financial situation	28
	6. Information about dementia and caregiving	23
	7. Own health, ageing, and illness	63
	8. Physical demands	16
Feelings and concerns	9. Accepting support	38
	10. Accepting losses	66
	11. Being positive	27
	12. Burden of care and responsibility	97
	13. Constant worry	14
	14. Concerns about the future	36
	15. Duty of care and marital commitment	28
	16. Faith, religion, or spiritual beliefs	3
	17. Identity of the cared for	44
	18. Resentment	29
	19. Sadness or depression	32
	20. Sense of control and safety	59
	21. The happiness of the cared for	34
	22. The health of the cared for	22
	23. The overall quality of life of the cared for	14
	24. The safety of the cared for	12
	25. Tiredness	16
Satisfaction with life and with caregiving	26. Adapting life (quality) and expectations	84
	27. Life is worthless	9
	28. Living a limited and restricted life	102
	29. Providing good care	20
	30. Relationship with the cared for	63
	31. Satisfaction with or trust for health and social services	26
	32. Self-identity	28
	33. Sleep quality	13

5.3.1. Practical aspects of care and caregiving

This superordinate theme represents the day-to-day caregiving factors affecting these individuals' feelings, concerns, satisfaction, and QoL. More important than receiving support from health and social services was the extent to which this help was appropriate or adequate for older carers' needs. Carers had to face battles with the system to get a dementia diagnosis, with professionals who did not seem prepared to help, meaning that older carers' QoL may had been affected some time before the diagnosis.

> *P17: And, I told my daughters [about her husband's unusual swearing behaviour] and we went to the doctor, and he said 'I'll put sticky-tapes over your ears'. (Husband)'s got a neurol., ahm, a neurologist, at (hospital's name), for his brain haemorrhage. And I*

> *asked if I could go and see him, and he said 'no', he [husband] didn't need it.*

It was important for older carers that health and social services professionals gave immediate responses to their requests, as it helped to reduce their burden.

> *P12: He [husband] used to be going to the hospital, when he got an infection. But now we just phone the district nurse, and they come, as soon as they can, and they'll change the catheter straight away now; they don't mess about.*

As some participants were frail and had their own physical limitations, they found it very difficult to provide care. In this scenario, inadequate support from Social Services became an added source of stress and burden to their already difficult situation.

> *P4: Well, for me, what, what would improve my quality of life mostly is to have better support from health-care professionals, because (husband) is a very big man, a very heavy man, and just keeping him clean is extremely challenging, I can't clean his groins and his private parts, because I can't bend down. I can't do it. I can't kneel on the floor; I'll never get up if I kneel down. And the [formal] carers, just don't do that sort of thing, you know?*

Some older carers had serious health problems themselves, such as Parkinson's disease, AD, cancer, and stroke, and being a carer precluded their looking after their own health.

> *P3: I had to go to having two operations [cancer], one to diagnose and the second time, to have it out and then go through [inhale] various treatments […] and I didn't feel there was a time for me to truly recover, I had to keep trucking in.*

In addition, because the older person affected by dementia often had other co-morbidities, older carers' demands were significantly increased. They felt unsupported by the public system and frustrated for not being able to provide good care.

> *P4: I want to look after him myself, but I can't. I, physically, I can't. I can't bend down. I can't kneel down, so, dressing him and*

> *undressing him, he is a very heavy man, you've seen him (P4 points to someone in the group). I find it physical. My arms are wrecked, this elbow in this harm, from helping him up from chair, and, in and out of car, ahm […] Those stories, it is the relentlessness of it, I am 72, (husband) is a very strong man, and, he has diabetes, he has hypertension, he has glaucoma, he has AF, he has all sorts of things, but he is actually a very strong man. […] I do all of his, well I call the medical caring. I have to crush up his tablets, I have to give him his insulin, I have to apply, make sure he has his warfarin, I have to look after his feet, his legs, and there is very, very little help from the NHS for doing that.*

They acknowledged that receiving support for their own health would help to improve their QoL and would invariably help them to continue being carers.

> *P4: If I could get more help with my own problems, which are real problems with my elbows, with my arms, from lifting and moving, that would be make a huge difference to me, but that help is just not, is just not there!*

They were also worried about the fact that their health issues would eventually prevent them from caring for their relatives, and this was a constant worry for some of them.

> *P13: You can't be able to be ill when you're looking after someone with dementia […] Because who is going to look after the person you're looking after?*

It was difficult for some participants to separate the disease from the person that they knew before dementia, which generated a lot of anger and resentment.

> *P3: Ahm, and, I felt resentment. Resentment. Because, it was a black hole just sucking you dry [mother/dementia/caregiving].*

Daily conflicts and symptoms also appeared to be hugely stressful and caused feelings of helplessness, frustration, and sadness to older carers, which significantly affected their overall QoL. Daily conflicts were mostly associated with the need for people with dementia to attend day centres or to accept paid carers in the home environment, as well as with all the day-to-day care needs (e.g. getting up in time, showering, etc.).

> *P4: He has day care two days a week in (day centre's name), which sounds great, but, 'a' is getting him organized, because he doesn't want to get up in the morning, and this morning was a nightmare!*

The disease stages also impacted on the older family carers' QoL, as it often indicated how much they were limited to the daily care routine or how much burden they were under. While some carers of people in the early stages of dementia whose relatives only had memory problems appeared to have good QoL, carers of people in advanced stages of dementia demonstrated having their psychological well-being impacted by the disease stage. However, for some of them this situation was actually easier, because their relatives with advanced dementia were much more passive and less conflicting, which reduced their stress.

> *P6: Because she is so far gone, she can't do anything. She doesn't argue, she doesn't, she doesn't get nasty, she doesn't. In fact, she doesn't do anything! She just sits in the chair and gazes into free air.*
>
> ---
>
> *P13: He's on the advanced stages now. But, you still have a laugh, and if you don't have a laugh, you cry.*

Particularly for those who had no other source of support with caregiving and had to carry out a full-time caring role, having regular respite support was important to maintain their own mental and physical health, and helped them to continue providing care at home for their family members.

> *P17: Ahm, (husband) goes to [day centre's name] two, two days a week, which gives me five hours each day; that's great! I can do things I want to do in those five hours.*

They also appreciated the help provided by children and other relatives with practical care, especially at the advanced stages of the disease, when the physical care needs were more intense.

> *P13: If your daughters aren't there to help you, when they get as advanced as (husband), you're shot!*

Having someone to contact if they needed, and who they could trust, helped them to cope and to continue providing care at home on their own.

> *P2: If I didn't have a sister to ring in the evenings and download to, and, ahm, if I didn't have the carers coming in, I'm… not sure if I would be coping. I don't think I would be coping, to be honest. I wouldn't be working now; my mum would probably be in care now.*

Because older carers were often frail themselves, they did not feel safe leaving the home environment without some support. They felt no longer able to cope with emergencies or physically demanding situations (e.g. moving the wheelchair). Receiving support in these situations helped them to feel less worried and gave them a sense of safety and control over the situation.

> *P17: But because my family was with me, it was a combined effort to help me with him. And that's why you sort of aren't too ready to go on this type of weekends or days [away], because you know you might need the help.*
>
> *P17: Well, I feel more relaxed, if I've got somebody with me.*

In particular, this support was beneficial when the older carer felt that the family member or friend understood the situation that the carer and the cared for were in and was aware about dementia and its symptoms.

> *P16: He [friend] is very good with (husband), so, and she is as well, and so if they can see I am getting a bit stressed, they take over. [friend says] 'Come on (husband), let's go and do this'. Because, you know, the sort of thing. And, we feel better, don't we?*

Participants also emphasised the importance of maintaining their friendships while being carers. Their social networks were generally reduced, either because of the limitations imposed by the caregiving needs, or by society, which isolated the carer and their cared for. This brought feelings of loneliness and sadness to participants.

> *P7: I had a group of friends, you've got this camaraderie at work, and I am leaving all that, to be a full-time carer. I… I mean, friends have gone, the acquaintance has gone, it so seems; I get very bored. You know? Especially in the winter time.*
>
> *---*
>
> *P17: Do you find your friends sort of dwindle (to P16)? You are left with a few good friends, just a handful. And the others sort of… They don't like the atmosphere, so they keep away, don't they?*

Another concern and source of stress for participants was getting access to carers' services and the impact of caregiving on their financial situation. The social care system was quite complicated for the older carers and often did not provide the support that these people needed to have access to their benefits.

> *P17: They [social services] gave all these forms for you to fill in, knowing, how old you are, and knowing what sort of stupid questions they ask, and you've got to fill them in! And, the older you get, the worse it is to try!*

Carers' Allowance was usually used to pay care costs, and as they were mostly pensioners, they were no longer entitled to receive this benefit, even though they were still providing care.

> *P13: Whatever money I get for Attendance Allowance, pays for his days' care [tearful].*
>
> *---*
>
> *P7: I get Carers' Allowance, and I'll finish it in a year's time. I am still a carer! Really! It's the money side that worries you as well.*

Some older carers providing care for their spouses with dementia also had disabled children, which generated more costs, but they did not have the right to claim this benefit twice.

> *P9: He [son] claims the carers for his dad, because I already claim for the carers for my [other] son, and you can't claim for two.*

Another factor that helped to improve the older carers' QoL was receiving information about dementia and caregiving. This helped to enhance their QoL and the quality of the care that they provided to their relatives. Having enough information about the disease and its symptoms helped them to not attribute dementia symptoms to the person, which helped to maintain their mental health and ability to cope, and to preserve their spousal/parental relationship. It also enabled them to identify the sources of support that they could access whenever they found themselves in a difficult situation, preventing further distress.

> *P2: I've got a bit of knowledge of, of that, and, obviously that impacts on my caring […] and because I understood those [symptoms] they didn't confuse me or make me frustrated or angry.*

Information was mostly gathered at support group meetings. Attending these groups also gave them the opportunity to interact and share their experiences with other people in the same situation.

> *P5: It helped me to go on [name]'s course. No doubts at all, just learning something about it. And, well, what happened and talking to the others, talking to the others is marvellous…*

5.3.2. Feelings and concerns

This superordinate theme relates to older carers' feelings and concerns related to caregiving, which were closely related to their satisfaction with life and to their overall QoL. One of the main challenges for the older carers was to allow someone else to care for their relatives. This represented an important decision and often involved considerable emotional distress and strain. Barriers to accepting support were imposed either by the carers themselves, or by their relatives with dementia, which was often associated with some level of stigma in the use of these care services.

> *P3: I take the responsibility. I know it sounds we've got a bit out of these care things, but we've set all alone. There is some satisfactory thing that you are doing the right thing.*
>
> ---

> *P22: I mean, (support worker) from social services rung me up and asked me if I'd persuaded him to go in or not and what's his attitude now, 'cause he turns round, you know, he gets so vicious about it, as if I'm trying to shove him away. I'm not trying to shove him away!*

For others this difficulty in accepting support was due to views on love and marital commitment, which caring for each other should be part of. For this reason, accepting care from services did not feel right for them.

> *P12: He's… I didn't know he [husband] was going with the carers, because, when you've done, same as P13 said, when you've been married that long, when you've done everything…*

In cases where the difficulty in accepting formal care came from the person with dementia, carers had to face extremely stressful situations. This represented an added burden and distress, as they felt guilty in forcing their relatives to stay in a place where they did not wish to be.

> *P22: I'm in such a state now, and he won't go; he just threatens me and he gets nasty tempered. I don't know what to do! I don't know what to do anymore. My daughters said it's up to me [sighs]. I just need help and I don't know how.*

Participants perceived the use of formal services as being "a trade-off", because even though they may get some respite, their emotional health could be extremely affected by guilt and distress.

> *P2: And it doesn't feel good, bringing, strangers in to care for Mum, and there is an emotional journey there. […] And there is a trade-off […] you get guilt. So you share the care, with, ah, in this case, the agencies, ah, but then you feel guilty because you are, sharing it and giving it to strangers and not doing it all yourself.*

Those individuals who were struggling with this decision often preferred to provide care for their relatives at all times in order to avoid the anxiety and guilt arising from this situation.

> *P6: I've never(.) Well, I've had (wife) for respite home for one week. Never again. I've taken (wife) to a, a day centre for two or three days. Never again. All sitting round like [sad face, open*

> *mouth]). And then I thought: this is not for her, you know, it's terrible. And so, that's the way, you know?*

Older carers also suffered with anticipated grief. They struggled to cope with the memory loss of their loved ones, especially the older spouses.

> *P4: He's not, he's lost all his perception of what his grandchildren meant to him. […] I find it extremely hard to say to (husband): 'Look, here is a picture of (grandchild) on a Shetland pony'. And he says 'Oh, good for her'. That's very hard to take; it really is.*

Especially for older spouses, the feeling of loss also means loss of lifelong companionship, as they will no longer be able to enjoy activities together or share their past memories.

> *P12: What do I miss? What I was saying, as I say, doing things, a lot of things together and doing things, you know? I mean, (husband), we always did everything together.*

Much of the sense of loss that older carers felt was accounted for by the loss of identity of their relatives, particularly in spouses. They felt that their relatives had become strangers to them, which often generated emotional distress. For cohabiting spouses, this sense of loss had a severe impact on their marital relationship and identity as a couple, as well as on their own self-identity, causing feelings of loneliness, sadness, and helplessness.

> *P5: He was 'the most gentle' considerate gentleman. And he is suddenly, or gradually, is becoming a very obstreperous, cantankerous, difficult man! Nothing like the man I married!*
>
> ---
>
> *P17: But that [memories] slowly goes out of your mind, and you forget the person as well because it's so dominant the person that you've got now, he is so full in in your mind, and in your thinking, that it's hard to go back and pick that up all those years ago.*

Some carers justified their current good levels of QoL with the fact that they were able to identify their spouse in the person that they were caring for.

> *P19: Although it was four years ago [diagnosis], it's been a very gradual change, and he's still, he's still (husband). He still enjoys doing certain things, his physical fitness is really good.*

One method some older carers found to cope with losses was to focus on positive memories from the past. These individuals were often those who reported better levels of QoL. They tried to reassert the activities that they were still able to do together and sometimes even started doing new ones in a way that both could still enjoy life together.

> *P18: You've got to think about all the good times you had. I mean, and if the bad times come up, you've got to deal with them. You want to be thankful to what you've had, and not what you've missed. You know? You've got to look on the positive side.*

Others found meaning or a purpose in life through caregiving. By reframing how they saw their everyday problems, they were able to benefit from being carers.

> *P6: I don't look at any problems as problems; I look at problems as a challenge. When you successfully complete a challenge, you feel good.*

Caregiving also meant a constant worry about their relatives with dementia. Being apart from their cared for made them feel anxious, which impacted on a range of aspects of their lives, such as sleep quality and psychological well-being.

> *P2: When I wasn't there [with the cared for], I was just so worried. And calls in the night, and jumping over, at two o'clock in the morning…*

Carers, and particularly spousal carers, also felt responsible for making their relatives happy and enabling them to have a high QoL, as it seemed to be part of their marital commitment.

> *P10: I mean, we do things together, and my wife is happy, and she'll laugh, and she's not sad. So that's good; I mean, I forfeit my bits and bobs to keep going as it is. […] That's all, that's all my task is, to keep her happy.*

Advances in dementia meant lower levels of reciprocity in spousal relationships. Feeling unable to make their cared for happy generated frustration and a sense of failure as carers or partners.

> *P4: And you just, is such a sense of, just, failure, to, to look after him properly in the sense of making him happy. But I… I… I can't make him happy.*

Older carers were also constantly worried about keeping their relatives healthy and felt that they did not receive enough support with that.

> *P4: My concerns are about everything, but (husband)'s health, that I find it very hard to keep him healthy and that I am unable to get what is the support that I feel that I need. […] because I want him to be healthy; I don't want him to have soreness and infections…*

The older carers also demonstrated feeling concerned and responsible for their family members' safety, which was intimately associated with how satisfied they were and how much they could trust Social Services to care for their relatives. Feeling that their relatives were in a safe environment gave them a sense of psychological well-being.

> *P3: So I would say that quality of life […] is having that confidence that she is safe in the setting she is in […] just made us, I think, far more in peace.*

This sense of responsibility towards their relatives' well-being also made participants feel that caregiving became dominant and that they lost control over their own lives, as they felt subjected to their relatives' needs.

> *P4: I… I can't take (husband) with me to see him [grandson] because (husband) doesn't want me looking at other people or talking, he wants me looking after him […] (husband) dominates my whole life […]*

Because participants felt that they had to preserve their relatives' independence as much as possible, they felt obliged to do what this relative wanted to do all the time, putting aside their own expectations and wishes in life in order to keep their relatives active for longer.

> *P19: I mean, as far as, you know, on the whole, quality of life isn't too bad, at the moment, 'cause we can still go out and, you know? But it's all about what he wants to do. I feel as I should be, doing things that he likes to do, while he can still enjoy it, you know?*

Sense of control was also associated with feeling safe. If carers were able to have control over caregiving and over their lives, they felt safe.

> *P6: I think if you feel in control, you feel safe. If you don't feel in control, you'll be wobbly.*

The older carers also had negative expectations about the future not only related to the disease progression, which is uncertain, but also about their own QoL prospects. Participants referred to not being able to envisage any QoL for the future.

> *P15: Note what quality of life we are going to have for the next years or whatever it is. I don't; you can't have a quality of life. We don't know what's going to happen.*

Other concerns about the future were related to a sense of duty, as carers felt that there was no one else to care for their partners in the case that they eventually died or were no longer able to care.

> *P16: But I think, you don't think about yourself, do you? If you're ill yourself, you can't be, because, you have to look after. You feel like that? Because I feel. There is nobody else to look after, is it?*

Because most participants were spouses, they felt that they had a duty of marriage, which implied being a carer for their spouses with dementia.

> *P4: Obviously part of that is that you married some one that, for better or for worse… And you, that's something that you just have to take on board.*

In other cases, this duty of care came from their cared for, especially in parental care. P2 explained how her mother expected her daughters to provide full-time care for her, not accepting other sources of support. This feeling of duty may explain why some carers struggled to accept support with caregiving or felt guilty for doing so.

> *P2: She [mother] did actually say to one of the carers, in front of my sister, 'You shouldn't be here. I have daughters; they should be doing this. That's why I have daughters for!'*

The older carers reported a huge amount of burden generated by several factors related to caregiving. This was expressed in several parts of the focus groups by their inability to cope, increased family and house responsibilities as a result of dementia progression, and feeling divided because they were forced to choose between their own lives and their relative's needs and provision of intensive physical care. These situations led participants to feel extremely exhausted (such as P5 below), having a dramatic impact on their mental and physical health, as well as social relations, which will invariably affect the quality of their lives.

> *P5: I feel that I can't manage, I ca... I can't, you know, there is [sighs deeply] there is just so much that I just can't do it.*

One aspect impacting specifically on spouses' QoL, which may be particular to this generation of older carers, is the fact that they found themselves having to take over their partner's role. Male carers found themselves having to cook and clean their houses, which in the past had been their wives' role, and older women had to deal with finances and fix their house problems, which used to be their husbands' role.

> *P19: I've got to make all the decisions now, you know, and (husband) can't make a decision. You make the decision for everything and you take over everything.*

When the level of responsibilities or the family roles were maintained after dementia, carers felt less burdened. For example, P6 attributes his ability to cope when compared with other participants in the focus groups to the fact that he did not have to change much of his routine when his wife became dependent on care.

> *P6: I must have been in charge for seventy percent of the time and she [wife] was in charge for thirty percent of the time, because, we, we did a balance. We did a balancing trick.*

While some of the participants found ways of coping, such as appealing to faith, religion, or spiritual beliefs, others felt resentment and anger towards their situation.

> *P17: Well, I sort of pull on to my religion […]*
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> *P3: Ahm, and, it felt resent. Resentment. Because, it was a black hole just sucking you dry [mother/dementia].*

5.3.3. Satisfaction with life and with caregiving

This superordinate theme describes the factors associated with carers' satisfaction with life and caregiving, which were intimately related to older family carers' perception of their own QoL. One of the major challenges for the older carers was the limited and restricted life that they had resulting from the need to adapt their lives to their caregiving. Some participants adapted to limitation in order to cope; others did not feel that they had any choice and therefore felt very sad and frustrated. These older individuals had their own physical impairments but had arrived at later life with relative independence and energy. Nevertheless, they felt forced to limit their expectations because of their relatives' limitations, thus gradually becoming less active.

> *P10: Well, it changes, it changes your quality of life, your own quality of life […] I used to walk, I used to do a lot of garden, I used to do all these, but you have to pack it up because it takes too much time up, 'cause she cannot cope with me being away to long […] You can't leave them. So you've got to accept; you've got to say you've packed up.*

Some carers had to end their working life early in order to adapt to their relatives' caregiving needs and to reduce their own burden. This meant living a less active life and with less social interaction, which affected their QoL greatly.

> *P4: I care for him [husband], ahm, probably for seven years, working for some of that time but, by last October I just had to retire; I couldn't cope anymore with caring, and working.*

Mostly, older carers felt that their expectations for retirement had not been achieved. They felt unable to travel and enjoy their pension, to share memories with their partners, and be part of their grandchildren's lives.

Participants who struggled to accept these changes suffered living a life that they did not wish to live and were very dissatisfied with it.

> *P4: I… I would say I have actually no quality of life, at all. I… I… In terms of the expectations that I had of my retirement, none of that is, is available to me. I can't see my grandchildren, I can't go anywhere, in particular, I can't do anything […] This is not what I expected and, to be honest, it's not what I want. I do want to look after (husband), but I want to… It isn't what I wanted in my old age, to be, tied 24 hours a day into the house, not able to do the things that I wanted to do, and above all, not being able to see my grandchildren and see them grow.*

Considering their present situation, they did not have hope or expectations for the future regarding their independence. They believed that the aspects of their lives which they had had to forfeit would not be recovered, and therefore they did not envisage any goals or future beyond caregiving.

> *P10: I don't expect to do anything of my life anymore.*

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> *P22: I… I've… I feel as if I come to a standstill in life. And I think what's the point of getting up in the morning? That's how I feel! I can't even wash my hair because I haven't got the interest in it.*

Because their interests were limited by their caregiving needs, the older carers' self-identify was also affected. In addition, the loss of identity of the cared for is also intimately related to the identity of their carers, especially in spouses. Their identity as a couple and as life partners slowly became substituted by their identity as carer and cared for. This was quite sad for carers, having great impact on their psychological well-being.

> *P17: […] and who is me? And who is (husband)? Who is (husband)?! And, you slowly forget what they've been, 40 years ago to you, because it's taken out of your mind by what you are doing now!*

Particularly for female spousal carers, perceiving their husbands becoming dependent and their role as spouses being slowly substituted by their role as carers caused anger and frustration.

> *P22: [QoL is] Not to be treated as a mum all the time. That's what I am, just his mum. Nothing else. Washing him, dressing him, every morning.*

Participants perceived their own selves and those of their relatives with dementia as a unit, and so the limitations caused by dementia not only affected the person with the disease but also limited how much the older carer felt he or she was able to accomplish. The more dependent the person with dementia became, the less the older carers perceived themselves as able to do or learn. When asked about her own QoL, P18 answered the question as if her husband's QoL was part of her own QoL.

> *P18: We like dancing. We go dancing two or three times a week, but we don't learn; we only learn what we can cope with.*

Others feel that forfeiting their own interests was part of their duty as carers to provide QoL for their relatives with dementia. As a result, participants felt forced to stop pursuing these activities.

> *P7: Well, as I say, personally, as well, as a personal thing, I mean, I used to like to go fishing, but I can't do it anymore. You know, that's like, forget it.*

Those who were able to preserve their own interests and keep their own identity acknowledged that this enhanced their QoL.

> *P2: [I] separate my sense of well-being as a carer, as opposed to my sense of well-being in the rest of my life. […] So, there is the other side of that which I try to put all on a separate shelf; otherwise, I just get totally, I get lost in, in, in negativity […] that's how I cope with it.*

Apparently, this loss of self is not a temporary consequence from caregiving; the older carers feel that the loss of their own identity is permanent.

> *P17: Do you know, that they [people in general] always say they kill the carer off, and, in soooo many cases, it's the carer that is gone, isn't it? […] And the person that you're caring for 'bats on', and they usually end up, you know, somewhere, but you've gone! And this really does happen such a lot!*

Some spousal carers even acknowledged that their own QoL was intimately associated with their partner's QoL.

> *P5: I am going down and he is going down. So quality of life is going down, at this moment […] I think I am changing. I am not coping like I was coping, so there is a big change.*

Especially for older couples, because of a shifting of identities, their closeness was also gradually eroded and their intimacy was largely affected. For this reason, older carers felt very lonely, even though they did not live alone.

> *P17: But, at the end of the day, it sounds really awful for me to say this, you really lose the person that you knew! And they sort of become further away from you; the closeness becomes further way.*
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> *P4: It's, it's been very, very difficult […] so, there is no conversation; there is no interaction.*

Co-residing older spouses were also more likely to have their sleep quality affected, as they were greatly affected by their relatives' sleep disruptions. This affected how much carers could recover from a stressful day, rest mentally and physically, and preserve their health and well-being.

> *P4: I get no sleep because I have to have a buzzer that wakes me up when he gets out of bed, and, ahm, because he can't manage toileting on his own, so, it's fine; he gets up, and I take him back into bed and [pretends to be snoring]. Then I'm awake for hours now and everything is going around… [thinking]*

Another large part of how satisfied the older carers were with their life and their caregiving is related to how satisfied they were with the care they were able to provide for their family members.

> *P1: [my quality of life] depends upon how satisfied I am with what I do and how I do it. Feeling that whatever I'm doing, I've done it, to the best of my ability.*
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> *P5: I don't feel to be doing anything to the best of my ability (laugh)! I always thought I was a very practical, ahm, sensible sort of person, and, ahm, I am, now, a bit like you [points to P4], going downhill.*

Providing good care also meant finding appropriate services to look after their loved ones. Participants reported that trusting in care services helped them to accept this extra source of support to care for their relatives and therefore reduced the anxiety and guilt derived from it. Those who were satisfied with the care received from formal services reported increased overall QoL levels.

> *P2: But, now that that [care service] is established, my quality of life is good now, because I trust them, and I know there is that extra level of care.*

5.3.4. Relevance of the HDQoL-C items

Older family carers of people with dementia taking part in the focus groups were asked about the relevance of the HDQoL-C items to their own QoL. Results from this discussion are summarised in Table 12.

Table 12. Relevance of the HDQoL-C items to older family carers of people with dementia and subsequent DQoL-OC items

HDQoL-C items	Relevance	Suggestions	DQoL-OC items
1. How often are you restricted by the need to maintain a regimented daily routine?	Relevant	-	13. How often are you restricted by the need to maintain a regimented daily routine?
2. How often do you receive appropriate help from Social Services?	Relevant	To specify whether the item refers to support for the person with dementia or for the carer and whether the support is appropriate to their needs.	1. Overall, how much appropriate support is the person that you care for given by Health and/or Social Services? (refer to item 4). 88. How satisfied are you with the SUPPORT that the person you care for receives from Health and/or Social Services?
3. How often do you have access to professionals that have specialised knowledge of HD and understand its implications?	Relevant	Substitute "HD" for "dementia" and remove the word "specialised".	4. How much access do you have to health professionals that have enough knowledge of dementia and understand its implications?
4. How much support are you given by health-care professionals?	Relevant	To specify whether the item refers to support for the person with dementia or for the carer and include the word "appropriate".	7. How much appropriate health support do you receive for your own needs? 95. How satisfied are you with the support you receive from health services for YOUR OWN NEEDS?
5. How often does the inherited nature of HD dementia further complicate your caring role?	Irrelevant	Participants do not identify themselves as potentially having an inherited problem.	Item excluded.
6. How often do you have access to appropriate care facilities?	Relevant	-	3. How much access do you have to appropriate dementia care facilities?

Table 12. Relevance of the HDQoL-C items to older family carers of people with dementia and subsequent DQoL-OC items (continued)

HDQoL-C items	Relevance	Suggestions	DQoL-OC items
7. How often do you receive any practical support you need?	Relevant	This item relates to item 2, item 4 and item 6. Also it is not clear who this practical support is for: the person with dementia or the carer.	Refer to item 2, item 4 and item 6.
8. How often do you experience a conflict of interest between what you want and what your HD-affected relative wants?	Relevant	Adapted and included.	11. How often do you experience a conflict of interest between what you want and what the person you care for wants?
9. How often do you sleep well?	Relevant	It was considered more important to ask how satisfied older carers are with their sleep quality, as this may not be an issue to all the carers. Question was rephrased and included.	92. How satisfied are you with how well you can sleep?
10. How satisfied are you with your health?	Relevant	Specified to carers and included.	94. How satisfied are you with your own health?
11. How satisfied are you with what you achieve in life?	Relevant	Carers were confused about the wording. Item rephrased and included.	83. How satisfied are you with what you have achieved in life?
12. How satisfied are you with your close relationships with family or friends?	Relevant	To split this item in two separate questions.	77. How satisfied are you with your close relationships with your FAMILY? 78. How satisfied are you with your close relationships with your FRIENDS?

Table 12. Relevance of the HDQoL-C items to older family carers of people with dementia and subsequent DQoL-OC items (continued)

HDQoL-C items	Relevance	Suggestions	DQoL-OC items
13. How satisfied are you with how safe you feel?	Relevant	The word ‘safe’ was considered vague. Item was rephrased and measured in different ways.	49. I feel that I am not safe in my caring role. 97. How satisfied are you with how safe you feel in your caring role?
14. How satisfied are you with feeling part of your community?	Relevant	The word community was considered vague.	99. How satisfied are you with feeling part of your local community or groups?
15. How satisfied are you with your own happiness?	Relevant	No suggestions.	84. How satisfied are you with your own happiness?
16. How satisfied are you with the treatment that your HD-affected relative receives?	Relevant	To specify “health” treatment.	89. How satisfied are you with the TREATMENT that your family member receives from health services?
17. How satisfied are you with your overall quality of life?	Relevant	No suggestions.	100. How satisfied are you with your overall quality of life?
18. I feel guilty	Relevant	No suggestions.	74. I feel guilty
19. I feel financially disadvantaged	Relevant	Participants suggested that this is more related to their concerns about money, rather than feeling “financially disadvantaged”.	10. How often is your financial situation affected by the demands of caring? 30. I feel worried about my financial situation
20. I feel isolated	Relevant	No suggestions.	61. I feel isolated
21. I feel there is hope for the future	Irrelevant	Participants acknowledged that it is important to have hope, but they were not sure whether this is related to QoL.	This item was removed. One item related to concerns about the future was included: 31. I feel worried about the future
22. I feel exhausted	Relevant	No suggestions.	24. I feel exhausted
23. I feel supported	Relevant	No suggestions.	72. I feel supported

Table 12. Relevance of the HDQoL-C items to older family carers of people with dementia and subsequent DQoL-OC items (continued)

HDQoL-C items	Relevance	Suggestions	DQoL-OC items
24. I feel sad or depressed	Relevant	No suggestions.	60. I feel sad or depressed
25. I feel stressed	Relevant	No suggestions.	75. I feel stressed
26. I feel worried about the genetic consequences of HD	Irrelevant	Carers did not have this concern.	Item excluded
27. I feel my own needs are not important to others	Relevant	No suggestions.	27. I feel that my own needs are not important to others
28. I feel comforted by the belief that one day there will be a cure for HD	Irrelevant	No suggestions.	Item excluded
29. I feel that HD brought something positive to my life	Relevant	Participants acknowledge that for some people this experience may be positive, but not for themselves.	68. I feel that dementia has brought something positive to my life
30. I feel comforted by my beliefs	Relevant	This question was considered vague.	30. I feel that my religion or spiritual beliefs bring me comfort
31. I feel that I can cope	Relevant	No suggestions.	65. I feel able to cope
32. I feel that HD has made me a stronger person	Unsure	Participants think that there are positive aspects, but they were not sure about this item.	Positive aspects of caregiving were included, based on the literature 69. I feel rewarded for being able to care for my family member 70. I appreciate being a carer 71. I try to think positively about my caring situation
33. I feel that I have had a ‘duty of care’ forced on me	Relevant	Participants were not sure about being “forced”.	42. I feel as if I have a ‘duty of care’ placed on me
34. I feel like I don’t know who I am anymore	Relevant	Participants found the wording confusing.	91. Overall, how satisfied are you with how much you can be yourself?
Open questions: 1. What do you think would most improve your quality of life as a caregiver? 2. Anything else related to your caring role that you feel hasn’t been covered in this questionnaire?	Relevant	Rephrase it.	1. What do you think would most help to improve your quality of life as a carer? 2. Please tell us anything else that is related to your caring role or your quality of life that you feel hasn’t been covered in this questionnaire.

Participants found most of the items relevant to their own QoL, with a few items being removed and several being rephrased or adapted. Removed items were mostly those that related specifically to the inherited nature of HD. Rephrased items were mostly associated with wording and to clarify whether the item referred to the carer or cared for.

5.4. DISCUSSION OF QUALITATIVE FINDINGS

Little is known about the lived experience of older family carers of people with dementia in the UK and how these individuals make sense of their own QoL. This qualitative investigation was necessary to identify the variables underlying the QoL of these individuals in order to develop the items of the DQoL-OC and to ensure its content validity. Focus groups were used to explore how older family carers make sense of their own QoL through their experiences and understanding of what QoL means to them, and the factors that enhance or compromise their QoL. Participants were also invited to give their opinions about the relevance of the items in an existing carers' QoL measure to their own QoL.

Besides ensuring the content validity of the new scale, consulting older family carers prior to item development on what is important to their own QoL also helped to make certain that a person-centred approach was taken. A person-centred care approach establishes that the focus of care should be on the needs of the person, rather than the needs of the service (Brooker, 2004), and has recently been considered by the UK Government as being the best care model to support people with dementia and their family carers (NICE, 2016). Rather than developing a scale that meets the interests of services and health and social care professionals, a person-centred care approach to scale development therefore helped to make sure that individuals' needs, views, and priorities were considered.

Three superordinate themes emerged from focus groups, namely practical aspects of care and caregiving, feelings and concerns, and satisfaction with life and caregiving. This section discusses these qualitative findings. First, some methodological considerations are provided, detailing some of the pitfalls and benefits of using focus groups and IPA for the purposes of this study, as well as how the researcher managed to tackle some of these issues. After this, each of the superordinate themes and their respective subthemes is discussed in the context of the current literature around the

QoL of family carers. This is followed by a section that highlights the particular aspects of QoL that are relevant specifically to older people who provide care. These three superordinate themes and subthemes were the basis for the item development of the DQoL-OC.

5.4.1. Methodological considerations

Although a minimum number of focus groups was carried out in this study (Kitzinger, 1995), a range of individuals representing different genders, ages, levels of support, relationships with the cared for, times of caregiving per day/week, and years of caregiving took part in the groups. It was expected that there would be problems in allocating a suitable time and venue for all group participants due to their caregiving duties and that this would also affect having their participation throughout all the duration of the group. Having identified these issues, it was important to confirm some of the factors affecting older family carers' QoL and to understand their day-to-day challenges. This will also help future researchers understand what kind of support has to be in place to facilitate the older carers' participation in research.

Because the focus groups had an emphasis on the lived experiences of participants, the older carers taking part in the study were encouraged to disclose intimate feelings, expectations, information, experiences, and benefits from the other participants' accounts. Instead of just providing the researcher with the necessary information for scale development, participants had the chance to share experiences and identify other individuals in the same situation, which has been considered therapeutic for older people (Powers and Wisocki, 1997). Focus groups were balanced as every participant contributed to the group discussion. Experiences related to sensitive topics were shared and debated, revealing that participants felt comfortable speaking about these in a group (Morgan, 1997).

The group interaction provided a much richer account of participants' experiences than perhaps individual interviews would have done. Individuals often challenged each other's opinions, helping to build a bigger picture of what it is like to be a carer in later life and the implications for QoL. Their 'group identity' was strongly identified in all the groups, and little space was left for the researcher within the discussions (Barbour, 2007). Instead of being led by the researcher's expectations or beliefs, which would affect the trustworthiness of the data collected, participants were free to express their own views and build their own understanding around their QoL. The researcher’s reflexive annotations and the notes from co-moderators, together with the independent examination of participants’ accounts by another researcher, helped to preserve the trustworthiness of this qualitative investigation. In addition, the excellent agreement score between the two researchers’ analyses demonstrates that the data analysis carried out by the researcher was trustworthy (Creswell, 2016).

Focus groups with older family carers analysed through IPA allowed for a detailed report around the main factors associated with participants’ QoL (Smith, 2011). The use of IPA with an interpretivist epistemological underpinning also helped to provide a more in-depth exploration of what it is like to be an older carer and the interpretation of daily challenges and pleasures in relation to their QoL. Variables underlying older carers’ QoL were identified and grouped into broader caregiving related areas, which were useful for the development of the DQoL-OC. Even though IPA aims to allow an in-depth exploration and interpretation of participants’ experiences, levels of data analysis can vary (Smith et al., 2009). Considering that the objective of this qualitative investigation was the exploration of relevant QoL themes, IPA was not carried out in as much depth as it would have been in a purely qualitative PhD thesis. However, the flexibility of this method allowed for a balance between reaching the study objectives, with some degree of meaningful interpretation of the collected data. Therefore, this ‘limitation’ actually refers solely to the degree of application of this method of analysis, rather than a limitation of the study findings and analysis in relation to its objectives. Moreover, this method has been considered useful for the purpose of development of several other scales (Clare et al., 2002, Greenslade and Jimmieson, 2007, Poole et al., 2009, Gibbons et al., 2011), demonstrating its suitability for the purposes of item generation of new measurement tools.

The items of the HDQoL-C helped to benchmark and ground participants in some important key aspects of caregiving which are associated with QoL. Even though this scale has been validated with carers of people with other type of dementia, the majority of the items were also relevant to the older carers in the current study. Participants were outspoken about the importance of the HDQoL-C items for the measurement of their own QoL.

Irrelevant items were removed, and items which were not quite clear were rewritten for the DQoL-OC. Offering this scale for discussion also helped the researcher to recognize that participants were not comfortable with continuous scales, and that a Likert scale would be more appropriate for use within this population, helping to improve the acceptability of the DQoL-OC.

5.4.2. Emerging themes

As discussed in Chapter 3, the number of studies investigating the QoL of older family carers of people with dementia for comparison with the current investigation is limited. However, considering that QoL is a multidimensional construct involving several aspects of life, such as physical and mental health, and financial situation, it is possible to make some assumptions about the subthemes emerging in this qualitative study and several other studies investigating various carers' outcomes. These are discussed in the next sections of this chapter.

5.4.2.1 Practical aspects of care and caregiving

The most frequent aspect impacting negatively on the older family carers' QoL in the current study was the presence of daily conflicts with their relatives with dementia, often resulting from dementia symptoms. Neuropsychiatric symptoms have also been identified in the literature as being important causes of stress and burden in family carers (Ferri et al., 2004, Pinquart and Sörensen, 2004, García-Alberca et al., 2014, Svendsboe et al., 2016). Even though these symptoms tend to be more frequent in the early stages of dementia, as apathy tends to increase as the disease progresses (Landes et al., 2005, Wetzels et al., 2010), advanced stages of dementia are also often associated with higher levels of burden in family carers (Bell et al., 2001, Mioshi et al., 2013), perhaps due to the higher physical demands of providing care for a more dependent individual.

Focus groups participants demonstrated how physical demands may have a high impact on carers' health and well-being. This has been demonstrated by several other research studies with family carers in general (Schulz and Martire, 2004, Laks et al., 2016), as well in studies investigating only older family carers (Carers Trust, 2011, Dilworth-Anderson, 2015, Steptoe et al., 2015b). Moreover, people with dementia are likely to be affected by other diseases (McCarron et al., 2005), such as depression and diabetes, which may also demand a great amount of care. Participants of the current study reported being responsible for complex nursing tasks, such as insulin therapy and urine catheters. Apart from the physical demands that this type of care can generate, it is also an emotional burden and responsibility imposed on these people, since they become responsible for providing complex care to individuals who lack capacity (Samuelsson et al., 2001).

Several participants reported a poor state of personal physical health, which resulted in difficulty in providing care for their relatives and maintaining their own QoL. The literature has demonstrated that older family carers have a higher prevalence of chronic illnesses when compared with young adult carers or older adults who are not carers (Shahly et al., 2013). Physical demands are especially harmful to older carers, as their often compromised state of health and the presence of chronic and disabling diseases may impact greatly on their capacity to provide care. Because these individuals are mostly full-time carers, they also have limited time to look after their own health, which may cause pre-existing health conditions to deteriorate, trigger new diseases, and lead to earlier mortality (Schulz and Beach, 1999, Vitaliano et al., 2004, Schulz and Sherwood, 2008).

Due to the aforementioned challenges, participants in the focus groups demonstrated the importance of having a strong informal support network in order to maintain their QoL. Likewise, other studies have shown how support from family and friends helps to decrease depressive symptoms (Moon and Dilworth-Anderson, 2015), burden (Coen et al., 2002), and loneliness (Ekwall et al., 2005), whereas having access to extensive social ties (Berkman et al., 2004) and having a productive role (Rozario et al., 2004), strengthened social networks (Huang, 2012), and more general resources (Ahn et al., 2012, Neri et al., 2012) is associated with more favourable health and psychological outcomes.

Carers also emphasized the importance of receiving support appropriate to their needs, in the form of respite, information about dementia and caregiving, professional carers, or health support, for example. Receiving poor-quality support or support inappropriate to carers' needs was sometimes an added source of stress and burden for these individuals. The literature corroborates this by showing that the perceived quality of support is more important than the amount received for the well-being of family carers and the general older population (Barrera, 1986, Wiles, 2003, Shurgot and Knight, 2005, Oliveira et al., 2016). Together with good-quality support, older carers' financial situation may have an effect on QoL (Schneider et al., 1999). The current study has shown that caregiving demands constantly had an effect on the financial situation of these individuals. Those who felt financially disadvantaged were concerned about it and felt that this limited the quality of their lives.

5.4.2.2 Feelings and concerns

As discussed in Chapter 2, there is limited and divergent literature about levels and predictors of burden in older family carers. In the current study, perceived burden was related to almost all other themes, but predominantly to feelings and concerns resulting from being a carer. In particular, high levels of perceived burden were associated with an increase in domestic chores due to change of family roles, particularly for male carers, as identified in previous qualitative research (Egdell, 2013, Steptoe et al., 2015b).

One of the major challenges for the older carers was to deal with their sense of loss and anticipatory grief, which had a major impact on their psychological well-being and overall subjective QoL. The current literature supports this finding, by showing that loss and grief have a significant impact on the carers' ability to cope with the stressors of caregiving and are associated with more depressive symptoms and lower levels of subjective QoL (Robinson et al., 2005, Noyes et al., 2010, Garand et al., 2012, Shuter et al., 2013).

Participants also reported being constantly worried about their relatives with dementia. In multiple accounts, carers expressed that their relatives' state of health, safety, happiness, and QoL were intimately associated with their own QoL. This constant worry is probably related to a sense of duty of care and responsibility for caring for their loved ones, due to marital or parental care commitment, as identified in other studies (Arlinghaus et al., 2005, Santos et al., 2013, McDonnell and Ryan, 2014). This sense of duty was also associated with the older carers' ability to accept formal support, as they felt responsible for all the care that needed to be provided for their loved ones, as they did not feel able to cope with the guilt and worry.

Because of dementia symptoms and disease progression, carers were often disappointed in not being successful in maintaining their relative's state of health and well-being, which generated a sense of failure, guilt, frustration, distress, and resentment in participants. These are common findings in studies with older carers and general family carers (Mavall and Thorslund, 2007, Carers Trust, 2011, Steptoe et al., 2015b) and may greatly affect older carers' QoL. Older carers also reported a loss of control due to their caregiving role, their relatives' behaviour and their own lives, which at times caused them to have an overall feeling of unsafety and unbalanced marital relationship (Ross et al., 2003, Fitzpatrick and Vacha-Haase, 2010).

Considering this range of negative feelings, a major strategy used by older carers to cope with these challenges was to think positively about various aspects of caregiving and not to overthink. This coping strategy has also been identified in other qualitative investigations with family carers (Villareal-Reyna et al., 2012, Zhang et al., 2012). Another strategy identified in the current study was to maintain an active spiritual belief or religion in order to alleviate the negative impact of caregiving, which has been associated with reduced levels of burden (Spurlock, 2005) and better mental health outcomes (Hebert et al., 2007) in other research with family carers of people with dementia.

5.4.2.3 Satisfaction with life and caregiving

Another highly relevant theme relating to older family carers' QoL was the feeling of being limited in terms of their own interests, pleasures, and needs. Older carers were mostly restricted to a full-time caregiving role, which generated a sense of isolation and loneliness, as confirmed by the literature (Lavela and Ather, 2010, Dilworth-Anderson, 2015). Research has also demonstrated that changes in the ability to enjoy leisure activities can increase stress and burden and cause poor psychological well-being in family carers of people with dementia (Schuz et al., 2015). Loneliness and small or non-existent networks have been considered the strongest factor in predicting low QoL levels in older family carers (Ekwall et al., 2005). Caregiving restrictions led participants of the current study to adapt their own lives and interests around their caregiving needs, which was acceptable for some of them who were able to cope but generated a lot of frustration in others and caused them to question whether their life was worthwhile.

Considering that high levels of satisfaction are a result of high positive affect in older carers (Wilson-Genderson et al., 2009), older carers in the present study may have reported lower satisfaction with life due to their poor relationship with their spouses/parents with dementia and other family members. Since older people are more likely to value close and meaningful relationships in their lives, as opposed to general and short-term relationships (Carstensen et al., 2000), older family carers are often unable to maintain this natural psycho-social path, as close relationships are likely to be affected by dementia and caregiving. Indeed, one of the subthemes emerging from this qualitative study was the quality of the relationship with the cared for and other family members affecting the older carers' satisfaction with life/QoL.

Added to the reduced access to positive social relationships, older family carers also face a sense of loss of self-identity, which is often the result of intense caregiving demands, and which hinders their own interests and desires. Self-identity was also affected when the person with dementia no longer recognised the older carers as being their spouses or their loved children, or when the older carers needed to assume a different role in the relationship with their cared for (e.g. husband vs wife roles). This was particularly relevant in FG2 and FG4 and has been described in the literature as a factor affecting closeness between carer and cared for, as well as the quality of marriage and intimacy (for older spouses in particular) (Hayes et al., 2009).

Satisfaction with caregiving was closely related to the older carers' satisfaction with or trust in health and social services providers, as well as with satisfaction with the care that they were able to provide for their relatives. For example, P4 in particular felt unable to provide good care for her husband due to the lack of good-quality support received from health and social services. Dissatisfaction with the care received from health and social services or simply the lack of availability of any support at all led some participants to provide full-time care for their relatives themselves, which had a considerable impact on their lives (e.g. largely affecting their sleep quality).

5.4.3. Providing care in later life

Social relationships, solo activities, physical health, psychological health, home, financial situation, and independence are all important aspects of

QoL for the general older population (Farquhar, 1995, Bowling et al., 2002, Higgs et al., 2003, Hyde et al., 2003). These same aspects were reported as relevant to participants in the current study. However, these aspects were often affected by caregiving, and therefore participants were not able to foresee any benefit to their QoL. Mostly, participants suffered as a result of the symptoms of dementia exhibited by their relatives and daily conflicts arising from these, which greatly affected their psychological well-being. They also suffered from the sense of loss, the physical burden, lack of appropriate support, and the limitations and restrictions arising from a full-time carer role. These generated a lot of sadness, dissatisfaction with life, tiredness, and concerns about their own health, their future, and about the person being cared for.

As discussed in Chapter 3, higher levels of well-being in older people help to maintain life control during periods of stress (Greve and Staudinger, 2006, Hansen and Slagsvold, 2012). When external factors are ideal (e.g. strong social support, good financial situation, positive relationships) and accessible, it has been suggested that older people have greater life satisfaction than younger people. However, in the face of inevitable and prolonged stress, such as experiencing a negative situation as a carer, this psychological regulation suffers, and these individuals may struggle to cope. When compared with the general older population, older family carers may not be able to compensate for stress and daily challenges and therefore may not be able to protect themselves from them.

Participants in the present study had their well-being reduced considerably and their QoL greatly affected. Most of the older carers were not able to compensate for the negative impact of caregiving and therefore to cope and protect their well-being from this experience. Those participants with better capacity to cope (such as P1, P6, and P17) had various situations which allowed them to compensate, such as strong family support, healthy financial situation, or their cared for were at the early stages of the disease, with almost no dementia symptoms present. Older people who are carers may therefore be at higher risk for adverse outcomes if they are not able to maintain well-being and satisfaction with life and prevent such outcomes (Reisnhardt et al., 2006, Newsom et al., 2008). This may explain why several studies presented in the literature review (Chapter 2) show older carers with worse health and psychological outcomes when compared with young adult carers or older people who were not carers, even though the majority of studies still show higher life satisfaction in this population when compared with young adult carers.

Considering theories about older people's QoL, the present study was able to identify relevant aspects which are important to older carers and that can provide a much better overview of their QoL aspects than a non-age-specific QoL scale would do. With regard to caregiving experience and its impact on QoL, an age-specific QoL scale will therefore provide a much more sensitive approach to those caregiving aspects which are more likely to affect older people's life quality than is possible with a non-age-specific QoL scale for family carers: for example, the physical impact of caregiving, concerns about their own health and future, having enough energy to provide care, the role conflicts of being a spousal carer (most of the time), the higher impact of financial situations as older people mostly depend on the state to survive, confidence to provide care while being a frail older person, isolation and loneliness derived from a full-time carer role, and sleep deprivation. Including such aspects in a QoL scale is expected to enable a more sensitive and holistic view of the QoL of older family carers of people with dementia.

5.5. SUMMARY

This chapter presented and discussed the qualitative findings which emerged from focus groups with older family carers. A rationale for each of the identified subthemes and superordinate themes was provided based on the literature related to dementia family caregiving and QoL in later life. The 33 subthemes were collated in three superordinate themes, namely 1) practical aspects of care and caregiving, 2) feelings and concerns, and 3) satisfaction with life and caregiving. These will form the base of the item generation process detailed in the next chapter.

Chapter 6

CHAPTER 6. PSYCHOMETRIC EVALUATION OF THE DQOL-OC

6.1. OVERVIEW

The previous chapter presented the results and the discussion of the qualitative strand of this sequential mixed-methods research, which identified a broad group of variables to compose a QoL model for older family carers of people with dementia – the DQoL-OC. This chapter presents the results from the final process of scale development and the preliminary evaluation of the DQoL-OC. Based on the qualitative study and current literature, a large pool of items was generated. The preliminary version of the DQoL-OC containing 89 items was first evaluated for content and face validity by family carers and researchers in this area of expertise, and the results from this evaluation process are detailed here. After considering the comments of the panel, a psychometric study was carried out using a non-probabilistic sample of 182 participants. The process of item removal and factor retention are detailed. Measures of retest reliability were carried out with 18 participants. Other psychometric properties were also established and hereafter described, such as internal consistency coefficient and convergent construct validity between the final scale and other previously validated scales, and bivariate analysis between the total scores of the DQoL-OC and other sociodemographic and caregiving variables.

6.2. ITEM DEVELOPMENT

The focus groups conducted as the first phase in the development of the DQoL-OC enabled the emergence of a broad range of aspects that are particularly important for the QoL of older family carers of people with dementia. The overlapping nature of quotes and themes demonstrated how caregiving in later life is complex and multifactorial. All the 33 subthemes represent a variety of broad QoL domains that are relevant for older people in general, such as:

- Health status and function;
- Behavioural, cognitive, and emotional function;
- Ability to maintain interests and recreation and fulfil life goals;

- Social contacts, roles, and activities;
- Support network;
- Energy and vitality;
- Independence and control;
- Being able to engage in hobbies and leisure activities (also solo), being able to engage in social activities and to maintain a role in society;
- Having a positive psychological attitude and acceptance of circumstances that cannot be changed;
- Home and neighbourhood;
- Financial situation; and
- Safety.

These subthemes also reflect QoL aspects relevant to dementia caregiving, such as levels of support with care, impact of dementia symptoms, and levels of burden from caregiving, which will allow the DQoL-OC to be a HRQoL scale relevant for use within this specific population. Accordingly, older family carers of people with dementia consider their QoL as a broad and multidimensional construct, resulting from their internal subjective evaluation of both positive and negative aspects of their lives, which includes practical aspects of caregiving, and feelings and concerns, as well as satisfaction with life and caregiving. Because QoL domains from participants' accounts were often overlapping, the same aspect of QoL could be evaluated in both from the experience or from the feelings generated. For example, P4 explained the emotional strain in having her husband in day care. She struggled to accept help both because of the poor quality of the support provided and because of the guilt and distress that this situation generated for her. However, she felt forced to accept it because she was physically unable to provide good care for him.

This example illustrates that a single QoL-related aspect, namely "accepting support", can be evaluated in terms of how much the carer is able to accept formal care (more specific theme), how often the carer feels guilty (more generic theme), or about how much (quantity) or how satisfied (satisfaction) the carer is with support received from health and social care (more specific theme). Even though these aspects have different meanings, they were all considered important aspects of QoL for this population. The relationship between experience and feelings varies between individuals, according to the relative importance given to each of these factors, and according to their experiences, contexts or psychological responses.

Several psychological mechanisms, such as guilt, sense of failure, and frustration, emerged as a consequence of different themes. For example, “feeling frustrated” could be a consequence of “daily conflicts” or “adapting life and expectations”. Because these were variable according to each participant’s experience and related to multiple domains of QoL, they were too ‘generic’ to be considered as a single domain and therefore were transformed into items which were included as part of the subthemes where they were most frequently identified. In this particular example, “feeling frustrated” was considered as an aspect of “adapting life and expectations” within the scale.

Another interesting characteristic identified in this sample was the differences in the subjective evaluation of QoL according to different circumstances and how this would probably differ from an external judgment. For example, some carers had serious physical impairments or were experiencing a heavy full-time care routine. If an objective evaluation of the physical state of these carers or the quantity of care provided by these individuals was used as an indicator of QoL, these individuals would probably be rated as having very low levels. However, the same individuals demonstrated great ability to cope and signs of psychological adaptation to these difficulties, which in turn led them to refer a much more positive view of their lives.

These findings suggest that the QoL of older family carers of people with dementia is mostly accounted for by how they feel and how satisfied they are with their caregiving experience, their relationships, and their life as a whole, rather than just the frequency or quantity of events in their lives (e.g. quantity of support received vs satisfaction with the support received). Having considered that, a subjective evaluation of QoL of this population, based on their internal standards, concerns, needs, and expectations, appears to be more appropriate and may provide more reliable information about the impact of caregiving on their lives.

Nevertheless, it is important to highlight that measuring QoL in a purely hedonic way may imply that QoL should be rated as high based on feelings of happiness, and one could therefore argue that QoL could easily be improved through the use of antidepressants, for instance, even if this person was locked in a cell for 24 hours a day with no social contact or goals in life (Jennings, 2000). Moreover, assuming that feelings are directly associated with the caregiving role is to ignore the influence of factors other than older carers’ own appraisal of their QoL. In addition, evaluating QoL using only individuals’ feelings disregards such factors as sense-making, life meaning, and human flourishing.

In light of these issues, it was decided that the first draft of the DQoL-OC should incorporate different ways of assessing the same life domain. Scale items should therefore evaluate not only these older individuals’ appraisal of their context in relation to their feelings and concerns about their experience as carers but also their expectations, needs, and standards. Considering multiple ways of assessing the same QoL facet or life domain could also result in some degree of redundancy within the scale items. However, it would certainly help to ensure that the best possible way of measuring each aspect of QoL within this population is included in the scale, and overlapping items would be identified in the psychometric study and removed after a series of statistical tests (DeVellis, 2012).

According to DeVellis (2012) guideline for scale development (Table 8, page 81), after determining exactly what one wishes to measure (step 1), the next step should be to generate an item pool to be tested. The literature suggests that items should reflect the scale purposes and the latent construct being measured and these should be worded in a less specific manner. Content redundancy is also important in order to express the same idea in different ways, even though ambiguity must be avoided. A mixture of negatively and positively worded questions should be used to avoid agreement bias, and items should be worded in a short and clear manner. DeVellis (2012) suggests that multiple items are considered more reliable than single-item scales, but each question should be sensitive to the true score of the latent variable. Creating a large number of items (about three to four times larger than the final scale) is desirable at this stage of scale development because, after carrying out statistical tests, superior items can be incorporated into the final version of the scale, making sure that the most reliable set of measurement items is selected.

The items of the DQoL-OC were written in such a way as to reflect participants’ quotes, in an idiosyncratic manner. Qualitative findings were revisited several times, and new items were drawn from each participant account, using an iterative process. The literature was also revisited in order to make sure that those aspects of QoL essential for older family carers, but not mentioned in the focus groups, were reflected in the items. About 150 operational questions were generated from this process and were reviewed for repetition and grammatical redundancy. This refined pool of items was exhaustively reviewed by the researcher, supervisors, and other research colleagues, who helped to refine the set of items and clarify any ambiguity. A set of 89 items was retained following this process.

After setting wording for all the questions, the format of measurement needed to be decided upon (Table 8, page 81). Participants in the focus groups demonstrated confusion when trying to understand questions from the HDQoL-C that were measured in scalar way, e.g. 1 (never) to 10 (always). This was also a concern raised by older members of the PPI. Even though continuous variables are considered superior for measurement scales as they allow for the use of parametric tests, the literature on QoL measurement for older people and family carers has often employed a Likert scale format, as it seems easier to use with this specific population. Examples are the WHOQOL-AGE and the WHOQOL-OLD, in which each item has five possible answers, ranging from "very satisfied" (5) to "very dissatisfied" (1). The same approach was therefore used for the DQoL-OC, and the statistics applied to these types of items were chosen accordingly.

From the focus group findings, literature review, and PPI advice, using the DeVellis (2012) guideline for scale development as a basis, a QoL model containing 89 items was generated. The scale items generated for the preliminary version of the DQoL-OC, with their respective subthemes and superordinate themes, are shown in Table 13.

Table 13. Superordinate themes, subthemes, and respective items in the preliminary version of the DQoL-OC

Superordinate themes	Themes	Items
Practical aspects of care and caregiving	1. Appropriate support from health and social services	• How often does your family member receive appropriate support from health and social services? • How often are emergency requests for health and social support attended to? • How often do you have access to appropriate care facilities? • How often do you have access to professionals who have enough knowledge of dementia and understand its implications?
	2. Daily conflicts	• How often do you experience a conflict of interest between what you want and what your family member wants? • How often does your family member cooperate with you? • I feel unsure about how to deal with my family member
	3. Disease stability or stage	• How much does your family member depend on you for his/her daily activities? • How do you evaluate your family member at this moment, in terms of disease progression and symptoms?
	4. Family and friends	• How often do you receive support from other family members or friends? • How often does dementia and caregiving negatively affect your relationships with family and friends? • How satisfied are you with your close relationships with your FAMILY? • How satisfied are you with your close relationships with your FRIENDS? • How satisfied are you with the help you receive from other family members and friends?
	5. Financial situation	• How often is your financial situation affected by the demands of caring? • I worry about my financial situation
	6. Information about dementia and caregiving	• How often do you have access to information about dementia and caring?
	7. Own health, ageing, and illness	• How often do you receive appropriate health support for YOUR OWN NEEDS? • I feel worried about my health • I feel that I haven’t got the health and the strength that I used to have in the past • How satisfied are you with your health? • How satisfied are you with the support you receive from health services for your own needs? • How satisfied are you with how much you can look after yourself?
	8. Physical demands	• How often is caring physically hard for you?

Table 13. Superordinate themes, subthemes, and respective items in the preliminary version of the DQoL-OC (continued)

Superordinate themes	Themes	Items
Feelings and concerns	9. Accepting support	• I feel that accepting care services is a trade-off for me • I feel that it is difficult for me to ask for help with caregiving
	10. Accepting losses	• I feel acceptance of the situation that I am in • I feel acceptance towards the changes in my family member
	11. Burden of care and responsibility	• How often do you feel burdened by the daily hassles of caregiving? • I feel that there is simply too much to do • I feel that there are simply too many decisions to make
	12. Being positive	• I feel that dementia has had a negative impact on my life • I feel that dementia has brought something positive to my life • I try to think positively
	13. Constant worry	• I feel worried if I am away from my family member
	14. Concerns about the future	• I feel worried about the future
	15. Duty of care and marital commitment	• I feel as if I have had a ‘duty of care’ placed on me • I feel like I have no choice about being a carer • I feel that I am the only person that my family member can rely on • I feel that my family member expects me to do all the caring for him/her
	16. Faith, religion, or spiritual beliefs	• I feel comforted by my religion or beliefs • How satisfied are you with the comfort you receive from your religion/beliefs?
	17. Identity of the cared for	• I feel as if my family member has changed from who he/she used to be and this affects me negatively
	18. Resentment	• I feel that other people do not understand the situation I am now in • I feel I deserve some gratitude for everything that I do for my family member • I feel that my own needs are not important to others
	19. Sadness or depression	• I feel that nothing helps me to feel better • I feel sad or depressed • I feel that I can’t cope • How satisfied are you with your own happiness?

Table 13. Superordinate themes, subthemes, and respective items in the preliminary version of the DQoL-OC (continued)

Superordinate themes	Themes	Items
Feelings and concerns	20. Sense of control and safety	• I feel that my family member controls me and my decisions • I feel that I am not safe • I feel that I have lost the control over the everyday events and decisions in my life • How satisfied are you with how well you can cope? • How satisfied are you with how safe you feel? • How satisfied are you with the control you have over your own life?
	21. Their family member's happiness	• I feel worried about my family member's HAPPINESS
	22. Their family member's health	• I feel worried about my family member's HEALTH
	23. Their family member's overall quality of life	• I feel worried about my family member's QUALITY OF LIFE
	24. Their family member's safety	• I feel worried about my family member's SAFETY
	25. Tiredness	• How often do you have respite from caring for your family member? • I feel exhausted

Table 13. Superordinate themes, subthemes, and respective items in the preliminary version of the DQoL-OC (continued)

Superordinate themes	Themes	Items
Satisfaction with life and caregiving	26. Adapting life (quality) and expectations	• How much have you had to change YOUR OWN LIFE AND INTERESTS to fit around your family member's needs? • How much has YOUR FAMILY ROUTINE AND INTERESTS been adapted to suit your family member's needs? • How satisfied are you with what you have achieved in life?
	27. Life is worthless	• I don't expect anything of my life anymore • How satisfied are you with your own life? • How satisfied are you with your overall quality of life?
	28. Living a limited and restricted life	• How often are you restricted by the need to maintain a regimented daily routine? • How satisfied are you with how much time you can spend with other family members and friends? • How satisfied are you that you do the things you want to?
	29. Providing good care	• I feel that I have failed as a carer • I feel that my family member needs more than I can give in terms of care • I feel that I have failed as a family member • How satisfied are you with being a carer? • How satisfied are you with your confidence? • How satisfied are you with the care you provide to your family member?
	30. Relationship with the cared for	• I feel that the relationship with the person that I care for has deteriorated since the dementia started • I feel upset with my family member • How satisfied are you with your relationship with the family member you care for?
	31. Satisfaction with or trust in health and social services	• I feel that I can trust health and social services to care for my family member • How satisfied are you with the support received from health and social services for your family member?
	32. Self-identity	• I feel there has been a change of roles in my relationship with my family member • I feel like I always have to put my family member first • I feel frustrated that I am not fulfilling my own needs and aspirations • I feel that I have given up things that I enjoy because my family member needs me • I feel lost • I feel as if I have lost the boundaries between my caring role and my own life • How satisfied are you with yourself?
	33. Sleep quality	• How satisfied are you with the quality of your sleep?

The QoL model to be tested was therefore composed of 89 ordinal items measured in Likert-scale format (1 to 5 or 1 to 3), interrogated in different ways (behaviour, affective response, frequency of events). Higher scores on the scale items mean better QoL levels. A first section containing sociodemographic and caregiving questions was introduced to the DQoL-OC, based on the literature on older people, family carers, and QoL, as well as on focus group findings and PPI advice (Chapter 4). The 89 scale items formed the second (quantity and frequency of events, including carers' evaluation of their relatives' dementia state), third (frequency of feelings), and fourth sections (levels of satisfaction) of the preliminary version of the DQoL-OC (Appendix 2).

6.3. EXPERT PANEL

An expert panel was recruited to evaluate face validity and clarity of language of the preliminary version of the DQoL-OC (89 items). The panel was composed of six individuals, four of whom were researchers and two older family carers. A brief description of their background, expertise, and experience as members of a panel is given in Table 14. These experts brought knowledge from the fields of family caregiving, nursing, and psychology, providing a clinically holistic approach to the evaluation. Both carers taking part in the study had experience as members of a PPI group, even though they had no experience as members of an expert panel for the purpose of scale development.

Table 14. Characteristics of the expert panel

Member		Background and expertise	Experience as a member of an expert panel
1	RC	Psychologist, PhD Neuropsychology of dementia, differential diagnosis, carer burden, intervention, ageing and cognition	Yes
2	SG	Nurse, PhD Dementia; dementia care mapping; frail older people; family carers. Research into the hospital care of cognitively impaired older patients and their family or informal carers. Work includes RCTs, cohort studies, and non-participant observation	No
3	MP	Clinical psychologist, PhD QoL and well-being; cognition and emotion; psychotherapy	Yes
4	HB	Chartered psychologist and Registered Health Psychologist, PhD Scale development and validation; patient and carer experience; chronic illness	No
5	KS	Carer, male "I have been a carer for 7+ years. I care for my wife (name). We have been married for 50+ years. (Wife) is diagnosed with severe AD. She is being treated by the NHS (service name)"	No
6	JJ	Carer, female "[I care for] my mother, for 15 years at least"	No

6.3.1. Qualitative remarks

As described in Chapter 4, the best method to measure agreement between members of an expert panel during scale development and to guide item removal is the kappa coefficient (Rubio et al., 2003, Polit and Beck, 2006). However, considering the small number of individuals evaluating the scale items, it was decided to consider each of their comments and marks individually and for each question, rather than making decisions based solely on numerical scores. This was also decided because, overall, all members of the panel were satisfied with the content of the scale for the purposes of evaluating the QoL of older family carers of people with dementia. Experts gave suggestions to improve the clarity of the language and to reduce ambiguity in some of the items but did not suggest the removal of any of the questions. Even though they provided scores for each of the items and the overall scale (Likert scales 1 to 10), their comments mostly suggested modifications for the sake of clarity, rather than item removal.

> Carer 1: *I consider the questionnaire a quite well-balanced and constructed set of typical problems and feelings that older carers are experiencing on a regular/everyday daily basis.*

> Researcher 4: *This is a really good questionnaire […] I think the items are for the most part (almost exclusively in fact) highly relevant […] I've only made some minor suggestions on the items regarding clarity. […] I think the scale really taps into the multidimensional concept of quality of life. It is very thorough and very thought through.*

Experts who were carers often referred to their own experiences when evaluating the relevance and clarity of the items for their own QoL, which helped to also validate the inclusion of some items in the questionnaire. Carer 1, for example, highlighted the importance of including questions about feelings of isolation and exclusion from friends, as well as lack of friendship/companionship with so-called friends. He suggested including the *loss of contacts with friends/neighbours/work colleagues due to lack of understanding of the problems associated with dementia* as an important factor related to older carers' QoL.

Researcher 1 felt that the first version of the DQoL-OC had items written in a very negative way and that the content was also focused on the negative aspects of caregiving. As expected, Researcher 2 highlighted that the number of items was large and should be reduced as much as possible. However, as pointed out by Researcher 1 and discussed previously in this thesis, it is important to keep all the items during this stage of scale development in order to make sure the best items are retained in the final version of the questionnaire.

> Researcher 1: *Very good content – of course there are too many questions and not all will have value, but the next stages in the development process should help to reduce this down to a more succinct scale […] For [the] moment, I'd keep these questions in.*

Researcher 1 also considered it important to maintain the open questions so that older carers were able to express themselves according to what was mostly important for them, rather than just what is pre-determined by the researcher/clinician.

> Researcher 1: *Really good idea to include these questions to allow carers to speak openly about QoL as they see it (individualised element) as opposed to our pre-determined take on what is/isn't relevant to their QoL.*

This preliminary version of the DQoL-OC stated before each section: *"Please circle the number that best describes your situation in the last 4 weeks."* However, Researcher 1 pointed out that asking carers to assess their feelings, hopes, standards, and concerns from the past four weeks would not be reliable. These individuals may have received support or information about dementia, for example, more than four weeks ago which still had an impact on their QoL. For this reason, this sentence was modified to, for example (in section 2): "This next set of questions asks how you feel about different aspects of your life. Please choose the option that best describes how you have felt about each area of your life as a carer."

6.3.2. Summary of findings from the expert panel

Taking the comments of the panel into consideration, changes were made to scale content in terms of clarification, but all items were retained for statistical analysis. Members of the panel helped to clarify and identify those items that could possibly confuse carers and helped to identify those items that seemed ambiguous or vague. Questions were slightly modified for improved clarity, and some items asking about more positive aspects of caregiving were also included, as suggested by Researcher 1 (e.g. items 63-72). Researchers 2 and 3 provided ideas about questions which probably had duplicate content and signposted which of those were worth keeping. These additional comments were considered after the psychometric study and measurement of validity and reliability. The test version of the DQoL-OC is available in Appendix 3 and contained 100 items, plus the sociodemographic profile and two open questions related to QoL.

6.4. PSYCHOMETRIC STUDY

6.4.1. Participants

A sample of 182 older family carers was recruited through the settings described in Chapter 4, and 18 of these individuals took part in the retest reliability study. Each service chose to help with the study in a different way: some preferred to distribute questionnaires themselves and asked participants to contact the researcher if needed; others advised participants to contact the researcher to request the questionnaire. Leaflets and posters about the study were left in all GP services in the Nottingham West area, and invitation letters were sent to registered carers from 10 out of 12 of these services. All Alzheimer's Society support groups in the Nottinghamshire area were visited by the researcher, and all groups from Lincolnshire, Northamptonshire, and Leicestershire received questionnaires and leaflets for distribution. Because all questionnaires were anonymous, it was not possible to identify which service participants were from. In addition, because questionnaire distribution was organized in different ways, and the researcher wanted to avoid adding pressure on service staff, it was also not possible to track the exact response rate. A vague estimation of the response rate based on the questionnaires given to these services is about 40%.

The sociodemographic characteristics of the sample are given in Table 15. Participants' mean age was 72.15 years old (SD=8.31), with 32.2% aged 80 or above. The majority was female (64.6%), married (89.5%), white (96.1%), and had no qualifications (28.2%). It is also important to highlight that 15.5% had a job outside caregiving, and 3.3% reported having stopped work due to caregiving responsibilities. In addition, around half of the sample (48.9%) had at least one current disease diagnosed by a doctor.

Table 15. Sample demographics for the psychometric study (n=182)

Variables	Frequency (n)	Percent (%)
Age group		
60 to 69	13	11.0
70 to 79	67	56.8
80 to 89	32	27.1
≥90	6	5.1
Gender		
Female	117	64.6
Male	64	35.4
Relationship status		
Single	6	3.3
Married	162	89.5
Partnership	3	1.7
Divorced	9	5.0
Widowed	1	0.6
Maximum qualification		
No qualifications	51	28.2
Vocational	41	22.7
GCSE	31	17.1
A level	11	6.1
Diploma	16	8.8
University degree	19	10.5
Postgraduate degree	7	3.9
Missing	4	2.2
Work		
Yes	28	15.5
No	92	50.8
Stopped working to be a carer	6	3.3
Retired	55	30.4
Ethnicity		
White	174	96.1
Afro-Caribbean	2	1.1
Asian	2	1.1
Other ethnic group	1	0.6
I prefer not to say	2	1.1
Current disease(s)		
Yes	89	48.9
No	88	48.3
Missing	5	2.7

With regard to caregiving characteristics (Table 16), a high proportion of carers were spouses of their cared for (80.1%), living in the same house (83.4%), and had been providing care from one to six years (78.5%). A total of 54.7% of participants provided care for more than 12 hours a day, and 89.5% provided care six to seven days a week. In addition, 16.6% of participants were providing care for more than one person at the time of the study. Participants in the psychometric study reflected a similar profile to those taking part in the focus groups, which indicates that the qualitative study sample was representative of the quantitative investigation.

Table 16. Caregiving profile (n=182)

Variables	Frequency	Percent
Relationship with the cared for		
Spouse	145	80.1
Son or daughter	29	16.0
Other	1	0.6
Missing	6	3.3
Cohabiting with the cared for		
Yes	151	83.4
No	30	16.6
Caring for more than one person		
No	151	83.4
Yes	30	16.6
Time since started providing care		
Less than 1 year	4	2.2
1 to 3 years	80	44.2
4 to 6 years	62	34.3
7 to 10 years	18	9.9
10+ years	17	9.4
Time since dementia diagnosis		
Less than 1 year	2	1.1
1 to 3 years	70	38.7
4 to 6 years	66	36.5
7 to 10 years	24	13.3
10+ years	13	7.2
Missing	8	4.4
Hours per day of care		
Less than 3 hours	19	10.5
3 to 6 hours	30	16.6
6 to 12 hours	28	15.5
12 to 24 hours	99	54.7
Missing	5	2.8
Days per week of care		
1 day	1	0.6
2 to 3 days	9	5.0
4 to 5 days	5	2.8
6 to 7 days	162	89.5
Missing	4	2.2

6.5. DATA ANALYSIS

As detailed in Chapter 4, data analyses were carried out through an iterative process, in which a number of statistical tests were performed. Data screening of the first 20 questionnaires did not raise any concern about any of the items, so the psychometric study was continued without changes to the study questionnaires.

6.5.1. Preparing the dataset

Preliminary data screening showed no major mistakes in data input, and so the researcher proceeded with the analysis. Eighteen negatively worded questions were first reversed before calculations. Three items were removed from further analysis for the purpose of scale development as these represented questions about caregiving and cared for characteristics, rather than QoL itself (items 17-19). Statistical analysis for the purposes of developing the DQoL-OC was therefore carried out using a total of 97 variables.

6.5.1.1 Missing data

The analysis for patterns of missing data showed the presence of 1.41% of random missing data, which were replaced using multiple imputations (MI). This method uses random sampling and replacement based on complete cases from the dataset under study (Rubin, 1987). Even though MI is a parametric statistical technique, it is considered a valid option for handling missing data before factor analysis when the amount of missing data is minimum and random (Allison, 2003, Brown, 2015), in which case generating five imputed datasets is considered sufficient (Allison, 2003).

MI was carried out for all variables using the automatic method SPSS®, considering constraints from one to five, rounding to one, generating five sets of MIs. One case was removed from the dataset because of its large amount of missing data, and therefore the sample being analysed was composed of 181 individuals. All the subsequent analyses were carried out on the original data and on the multiple imputed datasets, which were compared in order to make sure that the results in each different dataset did not differ substantially. Because all results had high similarity, only the results from dataset number five are reported in this thesis, for brevity.

6.5.2. Suitability of the data for factor analysis

The first descriptive statistics showed no ceiling or floor effects for any of the investigated variables. Kurtosis and Shapiro-Wilk statistics also did not evidence any skewness. Tests on 10% of the dataset for univariate and multivariate outliers, as well as for multicollinearity, showed that the data had no such issues, and thus data analysis was continued. For brevity, the tables with these results were omitted from this thesis but are available for consultation if required. Figure 7 and 8 demonstrate a tendency to normality for the sum of the total DQoL-OC item scores.

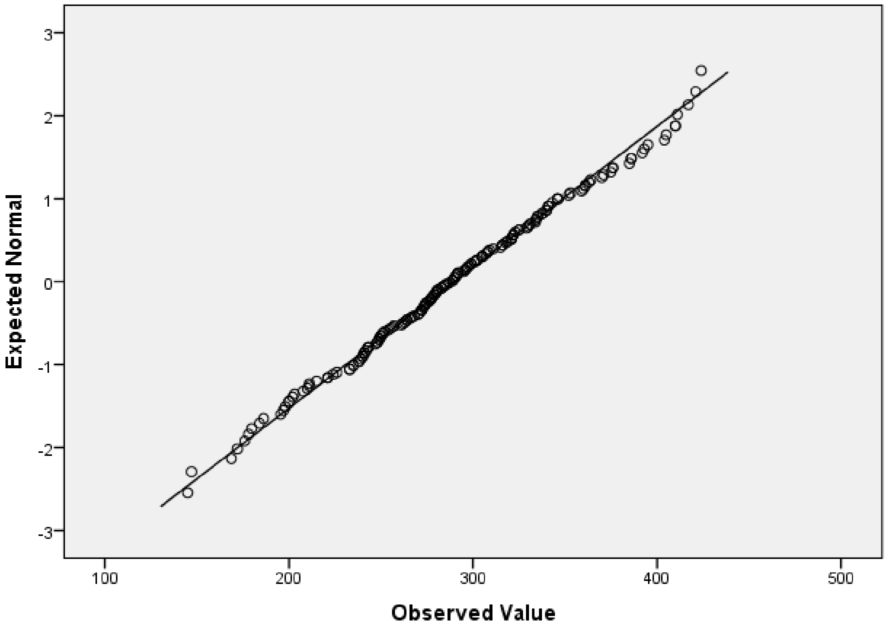

Figure 7. Normal Q-Q plot for total quality of life scores

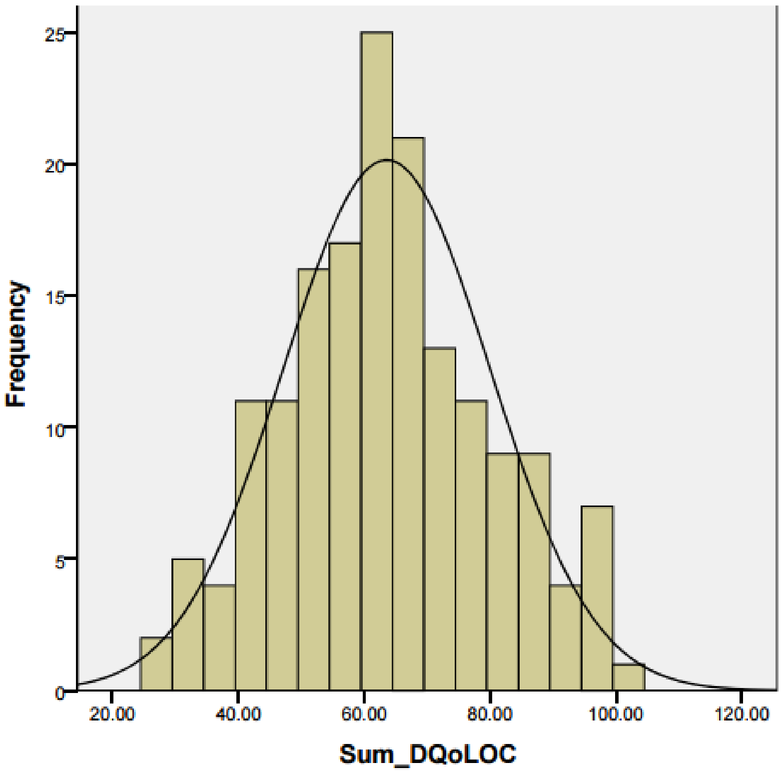

Figure 8. Distribution of total quality of life scores

Initial KMO suggested that the sample size was adequate (=0.868), as it exceeded the recommended value of 0.6 (Kaiser, 1970, Kaiser, 1974). In addition, the Bartlett’s Test of Sphericity (Bartlett, 1954) reached statistical significance (14024.523, p=<.0001), thus suggesting a strong relationship between the investigated variables and confirming the suitability of the data for factor analysis. Initial Cronbach’s α test for the 97 items was 0.974, which also demonstrated a great level of internal consistency, but some degree of redundancy within the 97 items (Cronbach, 1951) as well, which was expected due to the large amount of items at this stage of scale development.

The majority of the items showed at acceptable item–total correlation levels (>0.3) (Tabachnick and Fidel, 2014). Only seven items were below this threshold, and therefore the suitability of the data for factor analysis was confirmed (Appendix 4). None of the variables were removed at this point; those presenting low item–total correlation were further inspected during the next statistical tests to confirm their suitability or not within the scale.

6.5.3. Factor extraction and item removal

EFA was carried out using PAF. Items were excluded based on their item–total correlations (<0.3), communality scores (<0.32), and pattern matrix loading scores (<0.4) (Tabachnick and Fidel, 2014). Items were immediately excluded only if they had a poor performance in all three measurements; otherwise they were kept for the next test round.

First, the scree plot was visually inspected in order to identify the point where there was a clear decline in the group of eigenvalues. After that, the eigenvalues generated in the EFA were compared to a set of random eigenvalues created via Monte Carlo simulation, using PA and the 95th percentile criteria. Because of the large number of variables being tested, it was difficult to identify a clear slope on the eigenvalues in the scree plot (Figure 9). Results were examined with caution and suggested that three factors should be extracted. The scree plot was also analysed by the PhD supervisors, who agreed with the researcher’s interpretation.

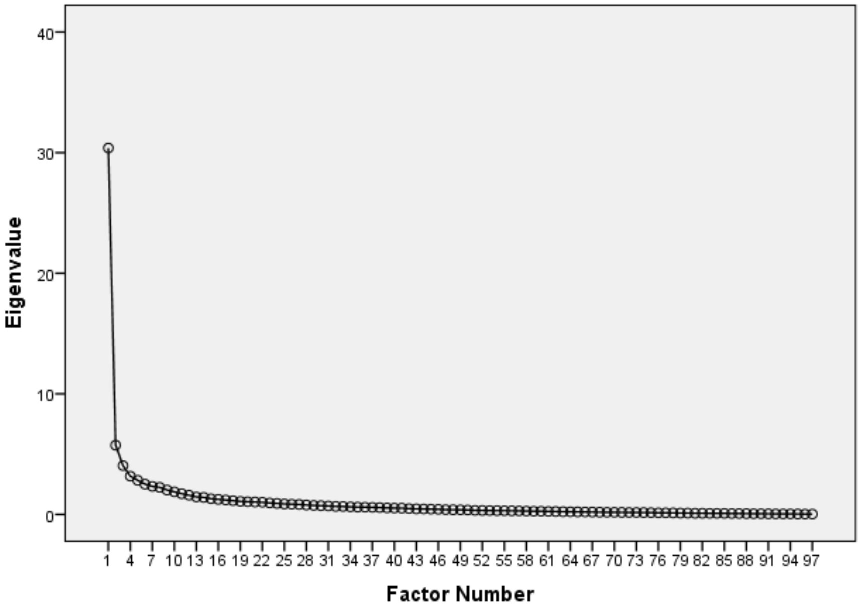

Figure 9. Scree plot from initial factor extraction

Table 17 displays all eigenvalues for the first 10 factors in the random dataset on the left side, and for the study data on the right side. PA suggested that seven factors should be extracted. The eigenvalues numbered 5 to 7 were considerably lower than the first ones and very close to each other in terms of value, suggesting that the first four eigenvalues explained a greater amount of the variances of the factors.

Table 17. Parallel analysis

Monte Carlo simulation (PA)		**Study data**		
Factor	**Eigenvalue**	**Factor**	**Eigenvalue**	**Decision**
1	2.868	1	30.384	Accept
2	2.728	2	5.739	Accept
3	2.625	3	4.050	Accept
4	2.538	4	3.171	Accept
5	2.460	5	2.830	Accept
6	2.387	6	2.507	Accept
7	2.321	7	2.329	Accept
8	2.255	8	2.247	Reject
9	2.196	9	2.027	Reject
10	2.138	10	1.872	Reject

Because of the large number of variables and potential redundancy in their meaning, the number of factors could be overestimated at this stage of investigation, regardless of the technique employed. Considering that one of the objectives of this psychometric study is to reduce the amount of questions to produce a small but meaningful scale for use in clinical practice, having a large number of factors (such as seven) with a small number of items could create a rather weak and unstable set of items and factors. For this reason, it seemed sensible to re-evaluate the appropriateness of this number of factors throughout all the item removal process, in order to make sure that the final set of factors and items were most appropriate, as well as strong enough to explain the latent construct (Tabachnick and Fidel, 2014).

EFA was therefore carried out several times through a systematic and iterative process. Results and decisions were constantly re-evaluated and justified based on both the purposes of this study and on the literature with the aim of selecting a small, but meaningful and robust number of items and factors to compose the final scale. All the steps of data analysis and evaluation of results were triangulated by the first PhD supervisor, and decisions were made based on the agreement between the two researchers, in order to make sure that content validity was also maintained after item reduction. Scree plot and PA were also re-evaluated several times throughout this process in order to make sure that the number of extracted factors was adequate for the remaining set of items.

6.5.4. Factor rotation

The first EFA with a seven-factor solution showed high initial communality scores for all the 97 variables (>0.645), and eight of them with extraction scores below 0.3 (Tabachnick and Fidel, 2014) (Appendix 5). This demonstrated that the majority of the scale items explained great proportion of variance. PR (oblique) was used to evaluate the seven-factor model as it hypothesized the factors to be correlated, which would be later confirmed by the inter-factor correlation outcomes. The rotated factor solution was examined in order to identify those items loading weakly onto the retained factors (<0.32) (Tabachnick and Fidel, 2014). This showed that factor number seven had only three acceptable items, and with low loading scores on each one. Therefore, EFA was carried out again following the aforementioned steps. After a series of EFAs, testing different number of factors and removing items with poor performance in the model, a selection of 22 items covering a wide range of life dimensions formed the final version of the DQoL-OC (Table 18).

Table 18. Means and standard deviations for retained items

Items	Mean	SD
9. How often does the caring negatively affect your relationships with family or/and friends?	2.94	1.150
10. How often is your financial situation affected by the demands of caring?	2.39	1.128
11. How often do you experience a conflict of interest between what you want and what your family member wants?	3.26	.919
14. How often have you had to change your own life and interests to fit around your family member's needs?	3.98	.884
15. How often is caring physically hard on you?	3.40	1.041
16. How often do you feel burdened by the care demands?	3.47	1.018
20. I feel worried about my health	2.86	.987
24. I feel exhausted	2.62	1.122
25. I feel as if my family member has changed from who she/he used to be and this affects me negatively	2.23	1.059
31. I feel worried about the future	2.48	1.168
43. I feel I have no choice in being a carer	2.28	1.358
46. I feel that I have lost control over the everyday events and decisions in my life	2.87	1.242
51. I feel that I have given up things that I enjoy because my family member needs me	2.48	1.118
54. I feel as if the boundaries between my own life and my caring role have become blurred	2.75	1.146
60. I feel sad or depressed	3.17	1.168
61. I feel isolated	3.40	1.269
74. I feel guilty	3.43	1.426
81. How satisfied are you with how much confidence you feel with your caring role?	3.65	.824
82. How satisfied are you with how well you can cope with your caring situation?	3.46	.956
86. How satisfied are you with the relationship with the family member you care for?	3.61	1.133
92. How satisfied are you with how well you can sleep?	2.70	1.275
100. How satisfied are you with your overall quality of life?	3.03	1.027

The KMO test and Barlett's Test of Sphericity were applied again, demonstrating sample adequacy and factorability of the 22 included items (.925 and p=.000, 2146.236). Another scree plot was created, but it was not clear whether one or four factors should be extracted. New PA suggested that two factors would ideally explain the final set of items. For this reason, it was therefore decided that EFA should be carried out and rotated in matrixes of four, three, two, and one factor, in order to identify which of these options would offer better interpretability of the selected items. Items that had previously been removed were individually re-inserted within these further analyses in order to confirm the need to remove them.

In trying to obtain high scores in all three parameters (communality, rotated matrix, and item–total correlations) with the best possible factor structure, a greater proportion of the items needed to be excluded. Because the remaining items were not clinically meaningful, it was decided to keep all the previously mentioned 22 items with acceptable parameter scores, as detailed before. Furthermore, in considering a two-factor solution, several items were cross loading and low parameter scores were obtained. After several analyses, the final decision was to select one single factor, as the other options did not offer plausible interpretations of factors, which could make it difficult for use and interpretation of QoL outcomes within clinical practice. This single-factor solution had an eigenvalue of 9.64, which explained 43.83% of total variance. Even though seven items did not have excellent communality extraction scores (Table 19), all items presented acceptable loading scores within a single-factor solution (Table 20).

Table 19. Communalities (22 items)

Items	**Initial**	**Extraction**
46. I feel that I have lost control over the everyday events and decisions in my life	.640	.624
16. How often do you feel burdened by the care demands?	.649	.595
51. I feel that I have given up things that I enjoy because my family member needs me	.655	.581
61. I feel isolated	.665	.574
54. I feel as if the boundaries between my own life and my caring role have become blurred	.596	.541
25. I feel as if my family member has changed from who she/he used to be and this affects me negatively	.508	.477
15. How often is caring physically hard on you?	.575	.388
31. I feel worried about the future	.471	.421
20. I feel worried about my health	.541	.383
10. How often is your financial situation affected by the demands of caring?	.541	.349
9. How often does the caring negatively affect your relationships with family or/and friends?	.545	.368
82. How satisfied are you with how well you can cope with your caring situation?	.619	.329
14. How often have you had to change your own life and interests to fit around your family member's needs?	.550	.313
11. How often do you experience a conflict of interest between what you want and what your family member wants?	.432	.313
86. How satisfied are you with the relationship with the family member you care for?	.498	.303
100. How satisfied are you with your overall quality of life?	.548	.505
24. I feel exhausted	.567	.450
43. I feel I have no choice in being a carer	.446	.381
92. How satisfied are you with how well you can sleep?	.306	.254
60. I feel sad or depressed	.620	.400
74. I feel guilty	.381	.284
81. How satisfied are you with how much confidence you feel with your caring role?	.576	.249

Table 20. Factor Matrix (22 items)

	Factor 1
46. I feel that I have lost control over the everyday events and decisions in my life	.790
16. How often do you feel burdened by the care demands?	.771
51. I feel that I have given up things that I enjoy because my family member needs me	.763
61. I feel isolated	.757
54. I feel as if the boundaries between my own life and my caring role have become blurred	.736
100. How satisfied are you with your overall quality of life?	.711
25. I feel as if my family member has changed from who she/he used to be and this affects me negatively	.691
24. I feel exhausted	.671
31. I feel worried about the future	.649
60. I feel sad or depressed	.633
15. How often is caring physically hard on you?	.623
20. I feel worried about my health	.619
43. I feel I have no choice in being a carer	.618
9. How often does the caring negatively affect your relationships with family or/and friends?	.607
10. How often is your financial situation affected by the demands of caring?	.591
82. How satisfied are you with how well you can cope with your caring situation?	.573
14. How often have you had to change your own life and interests to fit around your family member's needs?	.560
11. How often do you experience a conflict of interest between what you want and what your family member wants?	.559
86. How satisfied are you with the relationship with the family member you care for?	.551
74. I feel guilty	.533
92. How satisfied are you with how well you can sleep?	.504
81. How satisfied are you with how much confidence you feel with your caring role?	.499

In addition, residuals representing the difference between the original correlation matrix and reproduced matrix were very close to zero for almost all items, demonstrating that the factor extracted accounted for a great deal of the variance in the original correlation matrix and that this single factor was therefore the best choice to represent the original data (Appendix 6).

6.5.5. Face validity, content validity, and practicality

Participants had the opportunity to evaluate face validity, relevance, and practicality (length, clarity, and levels of difficulty) of the DQoL-OC items, as well as to indicate the presence of any upsetting questions. Older carers took between five and 85 minutes to answer all the 100 scale items and sociodemographic questions, with an average time of 32.43 (±15.82) minutes. As outlined in Table 21, the great majority of participants perceived the number of 100 items to be about right (73.5%). Mostly, individuals rated the test scale as being clear or very clear (79%), relevant (60.2%), and easy to complete or neither easy nor difficult (76.2%).

Table 21. Results from face validity questions

Variables	n (%)
Time to answer the DQoL-OC (minutes)	
1-15	25(13.8)
16-30	77(42.5)
31-45	38(21.0)
46-70	20(11.0)
>71	5(2.8)
Missing	16(8.8)
Length	
Too long	14(7.7)
Long	24(13.3)
About right	133(73.5)
Short	4(2.2)
Missing	6(3.3)
Clarity	
Very unclear	1 (0.6)
Unclear	4(2.2)
Neither clear nor unclear	23 (12.7)
Clear	117(64.6)
Very clear	26(14.4)
Missing	10(5.5)
Difficulty	
Very difficult	4(202)
Difficult	19(10.5)
Neither easy nor difficult	71(39.2)
Easy	67(37.0)
Very easy	13(7.2)
Missing	7(3.9)
Relevance	
Strongly irrelevant	4(2.2)
Irrelevant	9(5.0)
Neither relevant nor irrelevant	21(11.6)
Relevant	109(60.2)
Strongly relevant	21(11.6)
Missing	17(9.4)
Upsetting questions	
No	152(84.0)
Yes	17(9.4)
Missing	12(6.6)

6.5.5.1 Qualitative remarks for face validity, content validity, and practicality

Participants also made suggestions about items that they felt could be modified or removed, which helped to understand participants' evaluation of the overall scale. A total of 82 participants made comments. Several individuals felt that "faith" was not related to QoL and therefore should not be considered as part of the questionnaire. Mostly, participants found the questionnaire very thorough and that it included all relevant items for the measurement of their QoL.

> *"Very thorough in the variety of questions asked"*

> *"You know what is required"*

> *"It covered most of the areas. Can't think of any [modification]"*

As expected, most of the comments were about the fact that several questions were redundant. Some carers also struggled to report how much time exactly they took to complete all the items, as they had to do it over several days, due to caregiving commitments.

> *"Difficult to say [how much time taken to answer the questions] because I had one or two attempts at it over a number of days"*

Others reported having struggled to be able to concentrate or even to have some privacy to complete the questionnaire, as they needed to provide care at the same time.

> *"Please excuse my delay in filling in and sending questionnaire – My caree is RIGHT BESIDE ME all times and would not be happy about questions. I am currently sitting on the loo with caree calling through the door. Within ten minutes he has knocked urgently on the door, thinking he is imprisoned in the house, which he is not."*

> *"Apologies for the mistakes. He is continually asking 'what am I doing' – 'why', 'who for', etc., etc. Find it difficult to concentrate."*

Some pointed out the importance of such research and about how the simple fact of being asked about their own experience already helped them to feel better. In addition, it was encouraging for some participants to feel that results from this investigation would be taken seriously and help to guide support in the future.

> *"Keep up the good work: it [dementia caregiving] is a problem that is only going to get bigger".*

> *"Felt good to tell someone how I feel, plus [I] know it will be put in a report."*

Overall, participants who found a question upsetting explained that it was actually the situation represented in that item which was upsetting, rather than the question itself. For example, one carer pointed out that thinking about the role reversal between her and her husband was upsetting because this made her feel as if she was losing him.

> *"I feel I am losing my best friend little by little."*

Another participant found questions about support were upsetting because it was difficult for her to take over all the care needs on a daily basis.

> *"difficult to assimilate all the care into a normal daily life".*

Other carers felt sad when reflecting upon their good memories and on how their relatives had changed since dementia.

> *"Those [items] which caused reflection on how things used to be."*

> *"It brought back emotions of how helpless we can feel being a carer, knowing that you are losing a loved one. In my case, after 51 years together."*

For others, acknowledging some of the mentioned feelings associated with caregiving made it difficult for them to be truly honest, which made some of them feel guilty.

> *"Because of relationship it was sometimes hard to be truly honest because of emotional involvement."*

> *"Some [questions] made me feel guilty."*

Considering this, it became clear that it was their caregiving situation, their loved ones' disease, and their overall lack of QoL which was upsetting, rather than the questionnaire itself. Despite this, carers acknowledged that such questions are necessary to understand fully what it is like to be a carer of a relative with dementia.

> *"Not particularly [about any specific upsetting question], because the whole subject is very upsetting in any case. This research is very necessary to bring this subject more to the attention of the necessary bodies. There has always been a stigma attached to this condition and in the past it has been 'shoved under the carpet' because that was the easiest option."*

6.5.6. Open questions

A total of 150 older family carers completed at least one of the open questions. Participants' contributions were put into an Excel file and analysed using the existing subthemes identified within the focus groups. In fact, all comments fit within previous findings and therefore validated the researcher's interpretations. Carers' comments were mostly associated with the need for better and more appropriate support, the need for respite, loneliness, their own health problems, their restricted life, financial impact, and their difficulty in accepting losses. Because reporting the qualitative results from these two open questions would go beyond the scope of this study, these were omitted in this thesis but will both be explored/examined in a single publication in the future.

6.5.7. Convergent construct validity

Convergent construct validity was evaluated by correlating the DQoL-OC total scores with the total scores of other previously validated scales. In order to do this, the distribution of the sum scores of each of the variables of interest was first checked in order to decide which statistical test should be used. Table 22 outlines descriptive measures each of the variables.

Table 22. Descriptive measures for the total scores of each used scale

	Mean	SD	Median
DQoL-OC	63.55	16.42	63.00
SWLS	19.31	6.96	19.00
WHOQOL-AGE	43.36	8.42	44.00
PHS-VAS	53.65	23.26	52.00
OPHRQOL-VAS	55.57	21.16	55.50

Figures 10 to 13 show a linear and positive relationship between the DQoL-OC and the other scales' total scores.

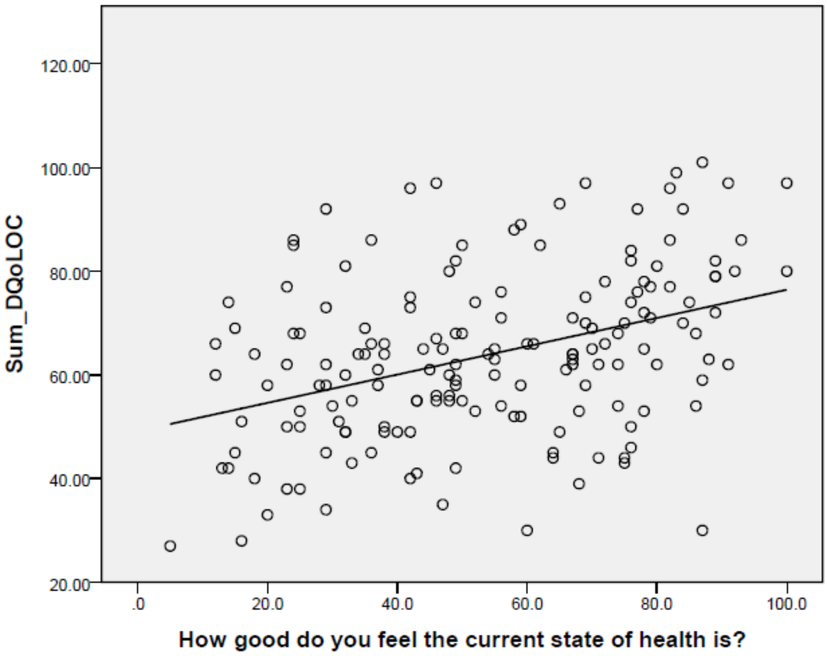

Figure 10. Relationship between the DQoL-OC and the PHS-VAS total scores

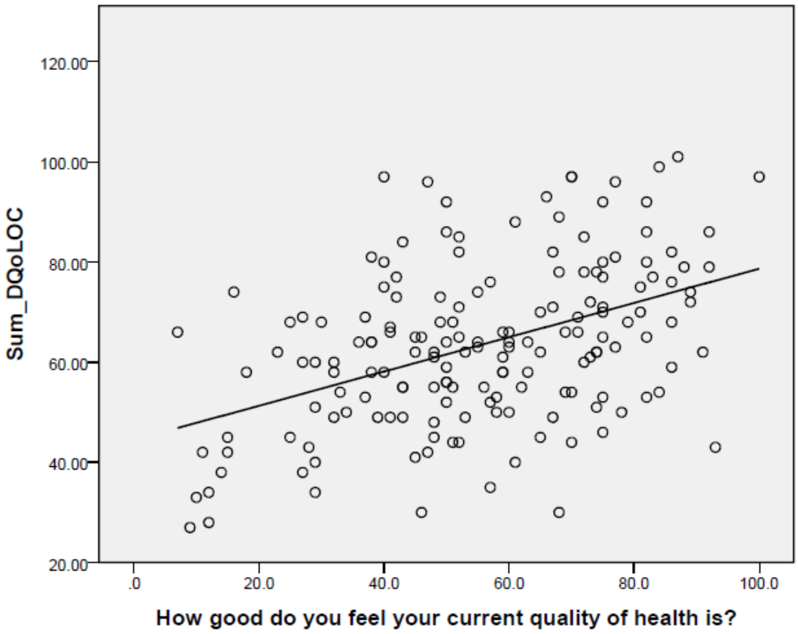

Figure 11. Relationship between the DQoL-OC and the OPHRQOL-VAS total scores

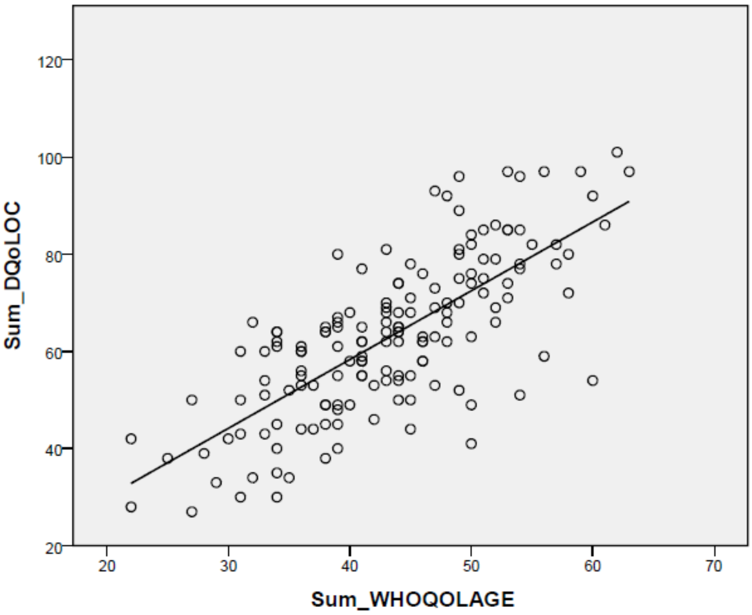

Figure 12. Relationship between the DQoL-OC and the WHOQOL-AGE total scores

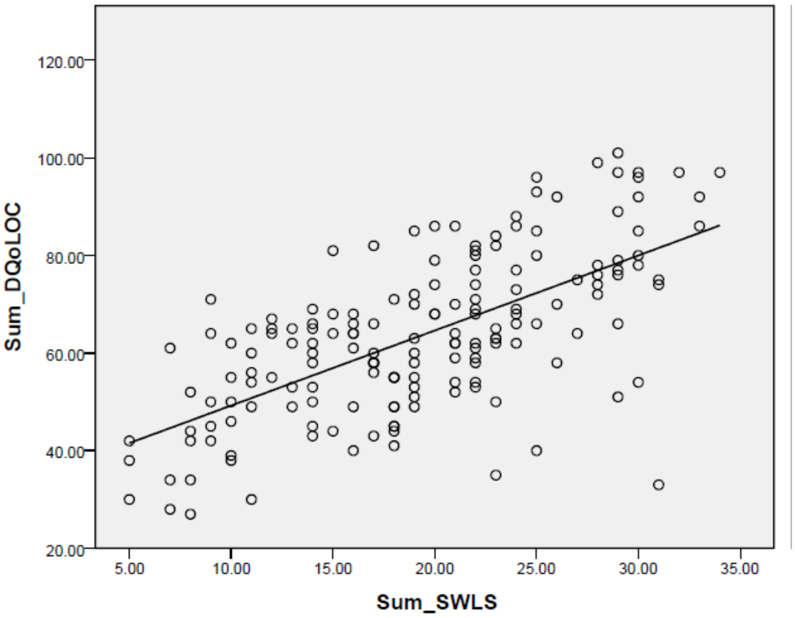

Figure 13. Relationship between the DQoL-OC and the SWLS total scores

Results from kurtosis and Shapiro-Wilk statistics showed that the curve of the sum of the total scores of all investigated questionnaires were normally distributed and had no skewness. In particular, the DQoL-OC had a mean value of 63.55 (SD=16.36; median=64.00; lower score=27; higher score=101). For this reason, it was decided to carry out parametric analysis to test construct validity (Pearson statistics). Results from these correlation statistics are in Table 23.

Table 23. Correlation coefficient between the total scores of the DQoL-OC and other previously validated tools

Scale	r	n
SWLS	.651*	166
WHOQOL-AGE	.736*	155
PHS-VAS	.389*	166
OPHRQOL-VAS	.444*	165

* p<0.001

It was hypothesized that there would be a statistically significant correlation between the newly developed QoL scale and the previously validated scales. Results confirmed that the DQoL-OC scores were strongly correlated with the other previously validated scales, particularly with the QoL scale WHOQOL-AGE (r=.736). This suggests that the DQoL-OC is a valid measurement tool to evaluate the subjective QoL in older individuals providing care for people with dementia. As expected, other measures which are considered part of the QoL construct (satisfaction with life and perceived health) also had significant correlations with the DQoL-OC, but with lower correlation scores.

Total QoL scores were divided into four groups of QoL levels, which were correlated with sociodemographic and caregiving variables to help establish construct validity. A larger number of older carers had QoL levels between 45 and 88 points (22 to 44: 12.9%; 45 to 66: 48.0%; 67 to 88: 31.6%; 89 to 110:7.6%). Non-parametric statistics (Spearman’s rho) showed that age was positively associated with QoL levels, meaning that the older the carers were, the better self-reported QoL they had (Table 24 and Table 25). In addition, female older carers, those caring for longer periods of time, and for more days a week, had significantly lower levels of QoL. Carers’ subjective evaluation of their family members’ dementia stage and symptoms also had a statistically significant relationship to their QoL. The more advanced the dementia and the less controlled the dementia symptoms, the lower the carers’ QoL. Carers’ subjective evaluation of their relatives’ levels of dependency did not correlate with their QoL appraisal.

Table 24. Bivariate analysis between the DQoL-OC total scores and sociodemographic variables

	DQoL-OC total scores n (%)						
	22 to 44	**45 to 66**	**67 to 88**	**89 to 110**	**r**	**Sig.**	**n**
Age (years)					.175	.019	179
60 to 69	1(7.7)	8(61.5)	3(23.1)	1(7.7)			
70 to 79	8(11.9)	29(43.3)	24(35.8)	6(9.0)			
80 to 89	1(3.1)	16(50.0)	11(34.4)	4(12.5)			
≥90	0(0.0)	3(50.0)	3(50.0)	0(0.0)			
Gender					.307	.000	181
Female	20(17.1)	64(54.7)	27(23.1)	6(5.1)			
Male	2(3.1)	26(40.6)	28(43.8)	8(12.5)			
Maximum qualification					-.014	.856	176
No qualifications	7(13.7)	24(47.1)	16(31.4)	4(7.8)			
Vocational	3(7.3)	21(51.2)	11(26.8)	6(14.6)			
GCSE	6(19.4)	19(61.3)	5(16.1)	1(3.2)			
A level	2(18.2)	5(45.5)	4(36.4)	0(0.0)			
Diploma	1(6.3)	9(56.3)	6(37.5)	0(0.0)			
University degree	2(10.5)	6(31.6)	9(47.4%)	2(10.5)			
Postgraduate degree	1(14.3)	4(57.1)	1(14.3)	1(14.3)			
Relationship status					-.098	.191	181
Single	0(0.0)	4(66.7)	1(16.7)	1(16.7)			
Married	19(11.7)	80(49.4)	50(30.9)	13(8.0)			
Partnership	2(66.7)	1(33.3)	0(0.0)	0(0.0)			
Divorced	1(11.1)	5(55.6)	3(33.3)	0(0.0)			
Widowed	0(0.0)	0(0.0)	1(100.0)	0(0.0)			
Currently working					.063	.397	181
Yes	3(10.7)	16(57.1)	6(21.4)	3(10.7)			
No	12(13.0)	43(46.7)	31(33.7)	6(6.5)			
Stopped working to be a carer	2(33.3)	2(33.3)	2(33.3)	0(0.0)			
Retired	5(9.1)	29(52.7)	16(29.1)	5(9.1)			

Table 24. Bivariate analysis between the DQoL-OC total scores and sociodemographic variables (continued)

	DQoL-OC total scores n (%)						
	22 to 44	**45 to 66**	**67 to 88**	**89 to 110**	**r**	**Sig.**	**n**
Providing care for more than one person					.013	.858	181
No	19(12.6)	74(49.0)	46(30.5)	12(7.9)			
Yes	3(10.0)	16(53.3)	9(30.0)	2(6.7)			
Ethnicity					.074	.323	181
White	22(12.6)	86(49.4)	53(30.5)	13(7.5)			
Afro-Caribbean	0(0.0)	1(50.0)	0(0.0)	1(50.0)			
Asian	0(0.0)	2(100.0)	0(0.0)	0(0.0)			
Other ethnic group	0(0.0)	1(100.0)	0(0.0)	0(0.0)			
I prefer not to say	0(0.0)	0(0.0)	2(100.0)	0(0.0)			
Current disease(s)					.123	.104	177
Yes	13(14.6)	48(53.9)	23(25.8)	5(5.6)			
No	8(9.1)	41(46.6)	30(34.1)	9(10.2)			
Co-habitant					.090	.227	181
Yes	19(12.6)	76(5.03)	48(31.8)	8(5.3)			
No	3(10.0)	14(46.7)	7(23.3)	6(20.0)			
Relationship with the family member					-.007	.926	179
Spouse	17(11.7)	71(49.0)	46(31.7)	11(7.6)			
Son or daughter	4(13.8)	15(51.7)	8(27.6)	2(6.9)			
Other	0(0.0)	3(60.0)	1(20.0)	1(20.0)			

Table 25. Bivariate analysis between the DQoL-OC total scores and caregiving variables

	DQoL-OC total scores n (%)						
	22 to 44	**45 to 66**	**67 to 88**	**89 to 110**	**r**	**Sig.**	**n**
Time since started providing care					-.116	.122	181
Less than 1 year	0(0.0)	2(50.0)	1(25.0)	1(25.0)			
1 to 3 years	7(8.8)	41(51.3)	26(32.5)	6(7.5)			
4 to 6 years	7(11.3)	33(53.2)	17(27.4)	5(8.1)			
7 to 10 years	4(22.2)	8(44.4)	4(22.2)	2(11.1)			
Time since dementia symptoms started					-.112	.140	175
Less than 1 year	0(0.0)	0(0.0)	2(100.0)	0(0.0)			
1 to 3 years	6(8.6)	37(52.9)	21(30)	6(8.6)			
4 to 6 years	6(9.1)	38(57.6)	18(27.3)	4(6.1)			
7 to 10 years	7(29.2)	10(41.7)	4(16.7)	3(12.5)			
10+ years	3(23.1)	3(23.1)	6(46.2)	1(7.7)			
Hours per day of care					-.285	.000	176
Less than 3 hours	0(0.0)	6(31.6)	7(36.8)	6(31.6)			
3 to 6 hours	2(6.7)	15(50.0)	9(30.0)	4(13.3)			
6 to 12 hours	3(10.7)	17(60.7)	8(28.6)	0(0.0)			
12 to 24 hours	17(17.2)	52(52.5)	28(28.3)	2(2.0)			
Days per week of care					-.091	.007	177
1 day	0(0.0)	0(0.0)	0(0.0)	1(100.0)			
2 to 3 days	0(0.0)	4(44.4)	5(55.6)	0(0.0)			
4 to 5 days	0(0.0)	4(80.0)	0(0.0)	1(20.0)			
6 to 7 days	22(13.6)	82(50.6)	47(29.0)	11(6.8)			
Dementia stage					.186	.012	181
Early stage	0(0.0)	8(36.4)	10(45.5)	4(18.2)			
Moderate stage	15(12.4)	61(50.4)	39(32.2)	6(5.0)			
Advanced stage	7(18.4)	21(55.3)	6(15.8)	4(10.5)			
Cared for independence					.131	.078	181
Totally dependent	9(21.4)	23(54.8)	6(14.3)	4(9.5)			
Mostly dependent	5(10.4)	24(50.0)	18(37.5)	1(2.1)			
Partially (in)dependent	0(0.0)	22(50.0)	17(38.6)	5(11.4)			
Mostly independent	1(4.3)	10(43.5)	9(39.1)	3(13.0)			
Totally independent	7(29.2)	11(45.8)	5(20.8)	1(4.2)			
Dementia symptoms*					.256	.001	181
Totally uncontrolled	3(17.6)	8(47.1)	5(29.4)	1(5.9)			
Mostly uncontrolled	10(20.4)	28(57.1)	9(18.4)	2(4.1)			
Partially (un)controlled	6(8.3)	41(56.9)	20(27.8)	5(6.9)			
Mostly controlled	2(4.8)	13(31.0)	21(50.0)	6(14.3)			
Totally controlled	1(100.0)	0(0.0)	0(0.0)	0(0.0)			

*e.g. memory loss, difficulty in communicating, inability to reason, disorientation

6.5.8. Reliability estimation

Reliability measures demonstrated excellent internal consistency (Cronbach's α=0.936) as a result of good levels of inter-item correlation among almost all items (Table 26), as well as acceptable levels of item–total correlations for all items (Table 27). This confirmed that the final set of 22 items reliably measures the same construct.

Table 26. Inter–item correlation matrix

Items	**46**	**16**	**51**	**61**	**54**	**100**	**25**	**24**	**31**	**60**	**15**	**20**	**43**	**9**	**10**	**82**	**14**	**11**	**86**	**74**	**92**	**81**
46	1.000	.579	.635	.635	.649	.535	.525	.481	.570	.473	.448	.447	.487	.519	.506	.406	.527	.429	.403	.403	.397	.366
16		1.000	.553	.572	.534	.531	.569	.635	.447	.539	.596	.565	.508	.425	.392	.414	.424	.427	.412	.370	.348	.360
51			1.000	.608	.697	.563	.541	.458	.467	.407	.479	.438	.522	.415	.471	.339	.578	.437	.379	.391	.398	.280
61				1.000	.592	.545	.515	.491	.445	.655	.485	.513	.435	.407	.368	.335	.430	.416	.377	.444	.399	.332
54					1.000	.514	.485	.454	.452	.415	.397	.419	.489	.417	.405	.353	.492	.449	.421	.396	.362	.327
100						1.000	.516	.435	.437	.540	.423	.436	.495	.416	.441	.494	.343	.279	.411	.351	.353	.400
25							1.000	.467	.451	.493	.381	.361	.505	.394	.357	.366	.418	.327	.443	.390	.356	.334
24								1.000	.514	.465	.576	.575	.378	.377	.396	.321	.327	.328	.269	.343	.404	.222
31									1.000	.415	.406	.438	.455	.398	.411	.418	.311	.294	.294	.366	.369	.319
60										1.000	.348	.371	.373	.293	.280	.404	.148	.291	.337	.512	.306	.354
15											1.000	.567	.298	.380	.519	.339	.449	.296	.235	.248	.229	.177
20												1.000	.354	.259	.392	.450	.258	.286	.236	.270	.346	.256
43													1.000	.308	.308	.369	.282	.332	.410	.309	.254	.354
9														1.000	.589	.298	.460	.515	.403	.364	.300	.275
10															1.000	.338	.480	.354	.185	.211	.274	.251
82																1.000	.142	.299	.453	.332	.293	.690
14																	1.000	.424	.200	.268	.300	.184
11																		1.000	.433	.333	.345	.309
86																			1.000	.381	.293	.539
74																				1.000	.243	.275
92																					1.000	.239
81																						1.000

Table 27. Item–total correlations

Items	Corrected item–total correlation	Squared multiple correlation	Cronbach's α if item deleted
46. I feel that I have lost control over the everyday events and decisions in my life	.763	.642	.930
16. How often is caring physically hard on you?	.742	.652	.930
51. I feel that I have given up things that I enjoy because my family member needs me	.729	.654	.930
61. I feel isolated	.728	.662	.930
54. I feel as if the boundaries between my own life and my caring role have become blurred	.708	.598	.931
25. I feel as if my family member has changed from who she/he used to be and this affects me negatively	.669	.505	.931
24. I feel exhausted	.647	.573	.932
31. I feel worried about the future	.621	.459	.932
60. I feel sad or depressed	.611	.621	.932
15. How often have you had to change your own life and interests to fit around your family member's needs?	.591	.574	.933
43. I feel I have no choice in being a carer	.587	.440	.933
20. I feel worried about my health	.584	.534	.933
82. How satisfied are you with how well you can cope with your caring situation?	.574	.627	.933
14. How often are you restricted by the need to maintain a regimented daily routine?	.536	.549	.934
86. How satisfied are you with the relationship with the family member you care for?	.535	.497	.934
74. I feel guilty	.497	.364	.935
81. How satisfied are you with how much confidence you feel with your caring role?	.491	.586	.934
92. How satisfied are you with how well you can sleep?	.478	.320	.935

The 18 carers who took part on the retest study had similar profiles to the total sample of the psychometric study. The overall QoL scores for the test and retest samples were compared, showing excellent and significant agreement scores among the two groups of QoL scores (lower bound r=0.835; p=<.0001), thus suggesting that the final version of the DQoL-OC provides consistent outcomes over a short period of time (Bonett, 2002).

6.6. FINAL SCALE

The previous exploratory study has identified the latent variables underlying the QoL of older family carers of people with dementia. The final version of the DQoL-OC is available in Table 28 and in Appendix 7, and instructions for users are in Appendix 8. The final version of the DQoL-OC contains two sections. Section 1 contains 12 questions related to sociodemographic and caregiving information which is considered relevant to this specific population, according to the findings of the current study and the literature review carried out as part of this investigation. The second section contains 22 items tapping into various QoL domains which have been considered relevant for older people living in the UK (Bowling et al., 2002) (Table 29). The DQoL-OC items measure the impact of dementia caregiving on the quality of older carers’ social relationships; financial situation; psychological health; independence, control over life events, and freedom; leisure, social, and solo activities; physical health; general health; energy and vitality; satisfaction with life and caregiving; identity; and life in general.

Table 28. Final version of the DQoL-OC scale

	Questions	**Always**	**Frequently**	**Occasionally**	**Rarely**	**Never**
1	How often does the caring negatively affect your relationships with family or/and friends?	1	2	3	4	5
2	How often is your financial situation affected by the demands of caring?	1	2	3	4	5
3	How often do you experience a conflict of interest between what you want and what your family member wants?	1	2	3	4	5
4	How often have you had to change your own life and interests to fit around your family member's needs?	1	2	3	4	5
5	How often is caring physically hard on you?	1	2	3	4	5
6	How often do you feel burdened by the care demands?	1	2	3	4	5
		Very frequently	**Frequently**	**Occasionally**	**Rarely**	**Never**
7	I feel worried about my health	1	2	3	4	5
8	I feel exhausted	1	2	3	4	5
9	I feel as if my family member has changed from who she/he used to be and this affects me negatively	1	2	3	4	5
10	I feel worried about the future	1	2	3	4	5
11	I feel I have no choice in being a carer	1	2	3	4	5
12	I feel that I have lost control over the everyday events and decisions in my life	1	2	3	4	5
13	I feel that I have given up things that I enjoy because my family member needs me	1	2	3	4	5
14	I feel as if the boundaries between my own life and my caring role have become blurred	1	2	3	4	5
15	I feel sad or depressed	1	2	3	4	5
16	I feel isolated	1	2	3	4	5
17	I feel guilty	1	2	3	4	5
		Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
18	How satisfied are you with how much confidence you feel with your caring role?	1	2	3	4	5
19	How satisfied are you with how well you can cope with your caring situation?	1	2	3	4	5
20	How satisfied are you with the relationship with the family member you care for?	1	2	3	4	5
21	How satisfied are you with how well you can sleep?	1	2	3	4	5
22	How satisfied are you with your overall quality of life?	1	2	3	4	5

Table 29. Final set of items for the DQoL-OC and respective quality of life domain represented

Items	General QoL domains										
	Relationships	Financial situation	Psychological health	Independence, control over life events, and freedom	Leisure, social and solo activities	Physical health	General health	Energy and vitality	Satisfaction with life and caregiving	Identity	Life in general
1. How often does the caring negatively affect your relationships with family or/and friends?	x										
2. How often is your financial situation affected by the demands of caring?		x									
3. How often do you experience a conflict of interest between what you want and what your family member wants?				x							
4. How often are you restricted by the need to maintain a regimented daily routine?				x							
5. How often have you had to change your own life and interests to fit around your family member's needs?					x						
6. How often is caring physically hard on you?						x					
7. I feel worried about my health							x				
8. I feel exhausted								x			
9. I feel as if my family member has changed from who she/he used to be and this affects me negatively			x								
10. I feel worried about the future			x								
11. I feel I have no choice in being a carer				x							

Table 30. Final set of items for the DQoL-OC and respective quality of life domain represented (continued)

	General QoL domains										
	Relationships	Financial situation	Psychological health	Independence, control over life events, and freedom	Leisure, social and solo activities	Physical health	General health	Energy and vitality	Satisfaction with life and caregiving	Identity	Life in general
12. I feel that I have lost control over the everyday events and decisions in my life				x							
13. I feel that I have given up things that I enjoy because my family member needs me				x							
14. I feel as if the boundaries between my own life and my caring role have become blurred										x	
15. I feel sad or depressed			x								
16. I feel isolated					x						
17. I feel guilty			x								
18. How satisfied are you with how much confidence you feel with your caring role?									x		
19. How satisfied are you with how well you can cope with your caring situation?			x								
20. How satisfied are you with the relationship with the family member you care for?	x										
21. How satisfied are you with how well you can sleep?								x			
22. How satisfied are you with your overall quality of life?											x

All the 22 items related to QoL are measured in 1 to 5 Likert scales, which when summed up provide an overall QoL score (22 to 110 points). The higher the final QoL score, the higher the carer's QoL. Especially for the purposes of clinical practice, the final scale scores can also be divided by five in order to graduate the QoL levels of the older carer being assessed. In doing that, the individual may be considered as having a poor (22 to 44), poor to moderate (45 to 66), good (67 to 88), or very good (89 to 110) QoL (more details in Appendix 8). Open questions were kept at the end of the DQoL-OC and are aimed at providing the opportunity for older carers to express any particular needs that they have, which might not have been covered by this scale.

6.7. SUMMARY

The aim of this exploratory study was to evaluate the psychometric properties of a latent variable model of QoL for older family carers of people with dementia in the UK. Measures of convergent construct validity against a previously validated QoL scale for older people, as well as other scales measuring psychological constructs that tap into QoL, were established. These tests confirmed that the new scale measures older people's QoL through questions related to dementia family caregiving, thus confirming its HRQoL nature. Reliability tests showed excellent internal consistency, and significant correlation was identified in the retest reliability study carried out with 18 older carers, thus suggesting that the DQoL-OC may provide consistent outcomes over time. Participants also rated the test scale for its relevance, levels of difficulty, and other practicality measures, providing positive feedback about this new measure. Two open items related to QoL also helped to identify further aspects of QoL that could potentially not have been covered by the proposed scale and gave participants the opportunity to tell the researcher more about their own QoL. Bivariate analysis between the DQoL-OC total scores and other variables demonstrated that relatively younger-old carers, females, those caring for longer periods of time and more days a week, and those providing care for people with more advanced dementia and uncontrolled dementia symptoms had significantly lower levels of QoL. The DQoL-OC represents a robust and practical measurement tool for the evaluation of the QoL of older family carers of people with dementia.

Chapter 7

CHAPTER 7. DISCUSSION AND CONCLUSIONS

7.1. OVERVIEW

Dementia has no available cure and currently represents a major problem of public health in the UK. Due to its chronic and progressive nature, research needs to focus on supporting and maintaining the QoL of people affected and their family carers (HM Government, 2010, HM Government, 2014, NICE, 2016). The literature presented in Chapters 2 and 3 showed that most of the research on family carers is focused on concepts and constructs that provide a narrow view of the impact of caregiving on these individuals, with little evidence of the impact of caregiving on the overall QoL of older family carers of people with dementia in the UK. In line with current UK policies and guidelines for scale development, the main purpose of this PhD research was to pioneer the development of the knowledge base relating to the QoL of older people providing care for their family members with dementia in the UK, an increasing and currently overlooked population of carers.

This sequential exploratory mixed-methods study provided a detailed and novel exploration of the aspects of QoL that are relevant to these individuals. A unique age- and dementia-specific QoL scale, entitled 'Dementia Quality of Life Scale for Older Family Carers' (DQoL-OC), was developed and validated for use with this population. A qualitative investigation and statistical tests confirmed the DQoL-OC to be valid and reliable, and consultation with older family carers confirmed the scale to be acceptable and relevant. The use of this tool is expected to provide more robust QoL outcomes than scales currently being used with this particular population, helping to improve the quality of the evidence resulting from studies and interventions aimed at evaluating and enhancing the QoL of these individuals. This chapter discusses the findings of the quantitative strand of this research, the purpose of which was to identify a latent variable model of QoL for older family carers of people with dementia in the UK and to evaluate its psychometric properties. It also examines the overall impact and limitations of the overall mixed-methods study and presents conclusions.

The psychometric study was carried out with 182 older people providing care for their family members with dementia at home in the UK. Eighteen of these carers also took part in a retest sample. Evidence of convergent construct validity, internal consistency, retest reliability, face validity, content validity, and practicality was provided, showing that the DQoL-OC is a robust and practical measure of QoL. Bivariate analysis also showed that QoL levels measured with the DQoL-OC was significantly lower in younger-old carers, females, those caring for longer periods of time and more days a week, and those providing care for people with more advanced dementia and uncontrolled dementia symptoms, which helped to ensure the construct validity of the new scale.

This chapter is divided into two parts. The first focuses on discussing the findings of the psychometric study. Strategies the researcher used to tackle some of the methodological issues encountered throughout the quantitative study are detailed. In addition, the psychometric properties of the DQoL-OC are examined in the context of the psychometric properties of other age-specific scales for measuring the QoL of the general older population, those developed for use with family carers of people with dementia, and non-dementia-specific scales. The second part reflects on some of the limitations of the overall study, together with its implications for research and clinical practice and future research related to this field of knowledge, and presents conclusions.

7.2. DISCUSSION OF PSYCHOMETRIC RESULTS

7.2.1. Methodological considerations

As this research was an exploratory investigation of the QoL of older family carers of people with dementia, the methods employed to reach each objective were also exploratory in nature. The use of a sequential and exploratory mixed-methods study design allowed a thorough investigation of the particular aspects associated with the QoL of these individuals, as well as the establishment of various aspects of validity and reliability properties of the new measurement tool (Creswell, 2011). A qualitative investigation prior to scale development provided relevant content for the DQoL-OC, through a detailed investigation of the most relevant aspects of

QoL for these individuals. Besides aiming to ensure the content validity of the new scale, this strategy also sought to follow recent UK care guidelines which advise considering the views and priorities of patients and carers within a dementia context (NICE, 2016). A large set of items was developed from these qualitative findings and later tested using EFA. The latter allowed exploration of the new model being developed, for a better understanding of the relationship between its variables, as well as a reduction in the number of items (Costello and Osborne, 2005, DeVellis, 2012). EFA also helped to identify the maximum amount of variance explained by the retained factor(s) and the selection of variables that best explained the overall QoL of the population under study. Further validity and reliability tests helped to provide evidence of the robustness of the outcomes obtained with the new scale and its appropriateness for use in clinical practice and research (Streiner and Norman, 2003).

Preliminary scale evaluation

Ideally, the expert panel would have had more members, which would have allowed for the use of statistical measurements to reduce the number of items according to their ratings (Rubio et al., 2003). Even though the researcher invited 11 research experts in total, only four were able to take part. A strategy identified by the researcher to tackle this issue was to take a qualitative approach to the scale evaluation. This helped to identify items that could be removed in the next step of the research, meaning that the psychometric study allowed a confirmation of the evaluation process carried out by the experts. Had some items been removed before the psychometric study, these would not have been tested with the target population. Even though this meant that the test questionnaire had a large number of items for the sample size obtained in the psychometric study, the iterative process using repeated EFA procedures several times throughout the process helped to make sure that the best set of items and factors, with better statistical performance with the sample being tested, was retained.

Carrying out a pilot investigation of the DQoL-OC prior to the psychometric study would have allowed for a reduction in the number of items, as well as modification to items that were particularity problematic for face validity, practicality, and relevance, for example (DeVellis, 2012). However, a pilot study was not feasible due to time constraints of this PhD. The researcher was mindful at the start of the psychometric study of the possibility of having to remove some problematic items before continuing with data collection. Because items evaluating content validity, practicality, and relevance of the scale were included in the research booklet, the researcher was able to verify whether any problems had occurred in the first 20 questionnaires received, meaning that she could have modified these if need be. However, none of the items appeared to indicate any particular problem, and so the psychometric study did not need to be interrupted. The entire psychometric study sample thus had the opportunity to offer advice about all the scale items, which helped to improve its quality and future acceptability.

Psychometric study

Even though randomly assigned samples would have been preferable for the psychometric study, this was not feasible given the lack of resources and the time constraints of this PhD research. However, the various methods and settings utilised for recruitment, as well as the flexible approach of the researcher during data collection, helped to include older carers from a variety of backgrounds in the study samples. The researcher visited numerous support groups across the East Midlands area in order to increase access by older carers to the study, which helped to increase participation and also enabled the researcher to have closer contact and experience with the population being investigated. As a result, the demographic characteristics of both qualitative and quantitative study samples were corroborated by previous statistics of older carers in the UK (Carers Trust, 2011, White, 2013, Carers UK, 2015).

Because various methods were used for data collection and a flexible approach was necessary in order to reach the target population, it was not possible to calculate the study response rate. It is important to highlight that older family carers are part of a highly isolated and ‘busy’ population. Having 182 individuals involved in the research and 18 of them taking part in the retest was therefore considered an achievement by voluntary organizations involved with the study, who reported great difficulty in obtaining family carer responses to their own questionnaires. One explanation for this positive response could be that participants were allowed to take the questionnaire home and post it back to the researcher (free of charge) at a time suitable for them. Furthermore, the researcher was careful not to create any additional burden for these people, by asking only a small number of participants to complete the 100-item questionnaire twice for the retest reliability.

It is also important to highlight that prior to the research, informal talks with health professionals and research colleagues about data collecting at GP practices revealed that these services are known for being highly pressured with care demands and having little time for involvement with research. For this reason, other research colleagues have had limited success in involving GP services and therefore did not encourage the researcher to continue with this plan. However, data collection from these services was shown to be quite different from what was expected. Most service managers were interested in getting involved with the study and made all the necessary efforts to help, by sending out invitation letters to potential participants and by advertising the study. Feedback from these services revealed that professionals considered as positive the fact that the study was designed to require minimum time from professionals, which encouraged them to support it.

7.2.2. Psychometric properties of the DQoL-OC

The first two parts in this section highlight the strengths of the newly developed scale and briefly explain the relevance of the study results to improving understanding of older carers' QoL. The following two subsections discuss the psychometric properties of the DQoL-OC in relation to QoL scales developed for use with the general older population and with family carers of people with dementia from any age group. Even though the psychometric properties of the DQoL-OC are not comparable with these tools, as they are designed for different purposes, these comparisons allow some of the strengths and limitations of the newly developed scale to be identified.

7.2.2.1 General aspects of the DQoL-OC

The DQoL-OC was developed to be a valid and reliable scale, acceptable for use in clinical and community settings, and in research. Considerable effort was therefore made to create a short, holistic, acceptable, and easy-to-use tool. Evidence of face validity, relevance, and practicality was obtained by consulting older family carers throughout all the scale development and validation processes. Experts were also consulted to make sure the scale was relevant and fit for the purpose. Overall, the test version of the DQoL-OC was considered relevant, and items were considered easy to complete by experts and carers.

The final version of the scale contains one single factor that explains a great proportion of variance in QoL. This is also the case with other age-specific and multidimensional measures of subjective QoL for older people (e.g. Hyde et al., 2003). While having more than one factor could provide more information about which areas of QoL are mostly affected by caregiving, a single-factor scale generates an overall QoL score that can also be classified in four different categories of QoL levels. The researcher has provided a table of which domain of life each item is evaluating (Table 29 in Chapter 6), which enables clinicians and researchers to identify priority areas according to their sample or individual results. Moreover, considering that none of the 22 items need to be reversed for final calculation of total scores, the DQoL-OC represents a scale that might easy to use in clinical practice and by the other family carers themselves, and its characteristics may reduce chances of errors in calculating older carer’s QoL.

A valid and reliable scale with a smaller number of items could have been created had several items been excluded during EFA. However, the DQoL-OC would thereby have been formed from a more restricted set of items, which would exclude aspects of QoL that were shown to be considered important by older carers during focus groups. Due to the exploratory nature of this current investigation, having a broad scale at this point also offers the opportunity of further development of the DQoL-OC in future research, when a Confirmatory Factor Analysis (CFA) within a randomized and larger sample of older carers may be employed (Brown, 2015). If a smaller number of items had been selected, future exploration of psychometric properties could have been limited. Moreover, even though some concerns about the length of the questionnaire were raised during the NHS Ethics meeting, the older carers mostly rated the test version containing 100 items as being “about right” in length. Considering that the final scale was reduced to 22 items, problems with the length of the questionnaire are not anticipated in future use.

It is also relevant to mention that the WHOQOL-AGE was developed from the WHOQOL-OLD and had its measurement design and practicality evaluated by a large sample of older adults (Caballero et al., 2013). Because the DQoL-OC uses the same rating scores as the WHOQOL-AGE, it is possible to infer that the DQoL-OC is likely to be acceptable by older carers from different cultures and nationalities. Another positive aspect of the DQoL-OC is the fact that it contains two open questions at the end of the tool, not available in most other QoL scales. These two questions were adapted from the HDQoL-C (Aubeeluck and Buchanan, 2007) and were considered a positive aspect of the scale by the panel of experts. These items allow older family carers to express their views on further aspects related to their QoL which have not been covered by the scale, as well as what affects their QoL the most, providing additional and more detailed information to clinicians and researchers about these individuals’ overall QoL.

Because statistically significant correlation scores were found between the DQoL-OC and other previously validated scales that measure the same WHOQOL-AGE QoL model, as well as other caregiving and sociodemographic variables known to be associated with this population’s QoL, it is possible to conclude that the final version of the DQoL-OC successfully measures dimensions of QoL that are particularly relevant for older people who are carers (Guyatt et al., 1993, Streiner and Norman, 2003). In addition, the high Cronbach’s ɑ score obtained suggests high consistency among all items within the 22-item scale, meaning that this item group reliably measures the same construct (Cronbach, 1951). Moreover, the excellent agreement scores identified between the two sets of measurements suggests that the final version of the DQoL-OC provides consistent and reliable outcomes over time (Bonett, 2002). Even though the second sample was considerably small, the high agreement scores identified are clinically important and suggest that the scale shows no substantial change in the construct when measured between the two occasions. This indicates that the DQoL-OC provides better precision of single measurements, which is a required property for better tracking of changes in measurements in research or practice settings (Hopkins, 2000).

7.2.2.2 Relevance of an age-specific QoL model applied to older family carers

Older family carers who took part in the focus groups had a larger number of negative than positive aspects of caregiving associated with their QoL. Even when asked about what helped to improve QoL, participants referred mainly to negative aspects of care. Although the panel of experts strongly recommended including more items related to positive aspects of caregiving within the questionnaire, and focus on negative aspects of life in QoL scales had been previously criticised (Sodergren and Hyland, 2000), results from EFA also demonstrated that negative aspects of caregiving performed much better in predicting the overall QoL of older family carers than positive aspects did. Results from EFA therefore did not suggest the inclusion of any positive-related questions in the final version of the DQoL-OC. Even though this ‘negative approach’ to caregiving could have skewed results to lower levels of QoL, the overall DQoL-OC score was 63 out of 110, meaning that the negatively worded questions did not influence the older carers’ QoL appraisal.

Enquiring about the older carers’ satisfaction in several domains may have helped to balance this potential negative bias from negatively worded questions, as older people often reports high levels of satisfaction with life (Anderson et al., 2013). These findings are corroborated by previous research investigating the QoL of older people, and by the concept that older adults have higher levels of positive psychological outcomes when compared with younger individuals (Bowling, 2005a, Netuveli and Blane, 2008, Anderson et al., 2013). Similar results were identified by Joseph et al. (2012) in a study with general adult family carers, in which age was negatively associated with stress, sense of value, carer satisfaction, and overall QoL.

Older carers who subjectively evaluated their cared-for relatives as being in advanced stages of dementia, those providing more hours per day, and those providing care for more days per week had significantly lower levels of QoL. These findings corroborate those of previous literature that this is probably due to the higher levels of physical burden, financial burden, and limited access to social life at this stage of dementia (Carers Trust, 2011, Carers UK, 2015). Considering that the psychometric study sample was formed mostly of full-time carers, it was expected that the majority of the sample would have lower levels of QoL. In addition, half of this sample also had at least one disease currently affecting them. Nevertheless, bivariate analysis revealed that age was positively associated with QoL levels.

On the other hand, the older carers' subjective perception about their cared-fors' levels of dependence were not associated with carers' QoL levels. This could be a result of an internal response shift resulting from years of caregiving experience and the need to accommodate day-to-day challenges in service of their own well-being (Sprangers and Schwartz, 1999, Rapkin and Schwartz, 2004). Even though a more thorough statistical investigation of these correlations should be carried out, controlling QoL levels with several other variables, these results suggest that age plays a significant role in QoL appraisal.

This study's results demonstrate the importance of applying an age-specific QoL model to older people who are carers. As discussed in Chapter 3, previous studies carried out with older people have used QoL scales developed for use with the general population, which might have underestimated the QoL of older family carers due to their focus on physical health, for example. Results reinforce the study rationale that concepts and concerns related to QoL in later life are different from the general population and that age may play a significant role in the subjective appraisal of QoL.

7.2.2.3 The DQoL-OC in relation to QoL scales developed for use with the general older population

As detailed previously, QoL scales developed for the general older population can be less responsive to changes in QoL, even though these have the benefit of allowing comparison between different populations

(Hyland, 2003). Because responsiveness is critically related to reliability outcomes (Hays and Hadorn, 1992), measurement tools with high reliability scores are therefore more likely to present good responses to changes in QoL. Even though it was not possible to measure this psychometric property within this study, the DQoL-OC showed excellent reliability scores for internal consistency and retest reliability. It is therefore expected that the DQoL-OC will be responsive to changes in QoL in future tests. Comparison between the psychometric properties of the DQoL-OC and other scales developed for use with the general older population indeed suggests that the reliability scores of the DQoL-OC are higher than the other measures of QoL for use with the general population of older people (Table 5, page 67). In addition, the construct validity score of the WHOQOL-AGE with the SWLS is closely related to the value obtained by correlating the DQoL-OC with the same scale, confirming the ability of the DQoL-OC to measure the subjective QoL of older people appropriately.

As discussed in Chapter 2, disease-specific scales often focus on physical health and symptoms, and these constitute the majority of the scales applied to the older population (Hickey et al., 2005). Due to problems with the validity and reliability of these measures, previous research has advised the use of generic HRQoL scales together with the disease-specific ones in order to provide a multidimensional view of QoL (Guyatt et al., 1993). Despite the fact that the DQoL-C is a disease-specific HRQoL scale, it does not focus on physical health or specific dementia symptoms but considers other domains which are valued by the general older population (Table 5, page 67), in line with recommendations on scale development for older people for obtaining valid and reliable outcomes (Hickey et al., 2005). Such characteristics may well indicate that it may not be necessary to use a generic HRQoL scale together with the DQoL-OC when measuring the QoL of older carers of people with dementia, as previously advised (Guyatt et al., 1993), because the DQoL-OC itself already covers a wide range of domains.

7.2.2.4 The DQoL-OC in relation to QoL scales developed for use with family carers of people with dementia

During the literature review carried out as part of this study, the researcher identified only two scales developed and validated for use specifically with dementia family carers and three instruments developed for use with general family carers (Table 6, page 70). This evidence itself already demonstrates that the development of the DQoL-OC is timely. The AC-QoL (Joseph et al., 2012) was the only tool developed and validated in the UK and the only scale presenting more elements of reliability and validity. Nevertheless, even though the authors sought to establish construct validity, the items used for this test were developed by the researchers, rather than using a 'gold standard' measure for comparison.

Mostly, these instruments are separated into subscales whose item scores need to be summed and none has assessed practicality. They also have items with different measurement designs which may confuse the test users [e.g. the PIXEL questionnaire (Thomas et al., 2006) has dichotomous items with one Likert scale evaluating burden between them]. The PIXEL questionnaire is formed of dichotomic items, thus offering fewer options for participants' answers, which may also affect its reliability scores. The CGQOL (Vickrey et al., 2009) is a long questionnaire consisting of 80 items, which may be less acceptable for use in clinical practice.

Compared with the other two scales which are dementia-specific, the DQoL-OC thus provides much more evidence of appropriateness for measuring the QoL of dementia family carers. It is also the only tool that contains open questions related to QoL, giving family carers the opportunity to disclose further aspects of QoL not covered by the tool and signposting to the clinician the aspect of caregiving that is affecting their QoL the most. The DQoL-OC is the only age- and dementia-specific scale for use with dementia carers and is also the first scale appropriately developed and validated for use with them. If this scale is developed and validated for use in the future with young adult carers, the two scales will represent two powerful measures of QoL for family carers of people with dementia from any age group.

7.3. LIMITATIONS AND IMPACT

7.3.1. Study limitations

This is the first study investigating the psychometric properties of the DQoL-OC, and preliminary evidence of its robustness has been provided. However, it has been mentioned before that the construction of a psychometrically sound test does not terminate at its development but also presents a responsibility to its future users to build up its psychometric profile (American Educational Research Association et al., 2014).

This PhD thesis was focused on identifying the best underlying structure for the DQoL-OC as well as providing a preliminary evaluation of its psychometric characteristics. Even though one of the justifications for the development of an age- and dementia-specific scale is the fact that this is likely to be more responsive to change than general QoL scales, this study did not provide complete evidence of such a property. The study also did not provide evidence of discriminant validity against differing psychological constructs such as burden or depression, for example. Moreover, despite the fact that bivariate analyses have suggested that QoL scores were lower in carers with specific caregiving and sociodemographic characteristics, these variables need to be tested again in a different sample of older carers, as the results from analysis carried out with the same sample used to develop the scale might be biased.

Furthermore, although the characteristics of the samples obtained in the qualitative and quantitative phases of this research are consistent with the older carers' profile in other studies from the literature, these were not randomized. Despite the fact that several services, online forums, and the wider community were involved as recruitment settings, the majority of the participants were those who were receiving help from support organization (e.g. Alzheimer's Society). This means that older carers who are more isolated and thus less supported were mostly not included in the research. This should be taken into consideration when using this study's results. Moreover, the major population of the current study was formed by white British people. Older family carers from other ethnic backgrounds may conceptualize and appraise QoL differently, considering their cultural and sociodemographic differences. Therefore, no conclusion about the suitability of the DQoL-OC for other ethnic groups is possible at this stage. Similarly, although some considerations were made regarding age-specific characteristics of the results obtained in the study, these should also be interpreted with caution. More consistent interpretations could have been drawn if a group of young adult carers had been investigated in parallel and results of QoL appraisal from both age groups had been compared, for example.

7.3.2. Impact

7.3.2.1 Implications for research

Despite its limitations, this study provided a unique, robust, acceptable, and comprehensive age-specific measure of QoL for use with older family carers of people with dementia as a final product of this research. This will help to inspire future research with older family carers, in line with current national and international policies and public reports (HM Government, 2009, Age UK, 2010, HM Government, 2010, Shahly et al., 2013, Carers UK, 2015).

Because the DQoL-OC is a caregiving-, dementia-, and age-specific scale, research utilizing this tool is likely to provide more robust outcome measures about the QoL of these individuals. It is possible to quantify the overall impact of caregiving on the QoL of these people, as well as implement appropriate interventions according to which areas are affected most. At this stage, the DQoL-OC can be validly and reliably used in surveys with older carers, observational studies, epidemiological studies, service evaluations, and clinical audits, for example. In addition, due to its high levels of reliability, this tool can be useful for detecting how much age-specific interventions can enhance the QoL of older carers after a future thorough evaluation of the ability of the DQoL-OC to detect meaningful changes in QoL.

Apart from the main objectives of this research, sociodemographic and caregiving data enabled the establishment of a profile of older carers and the statistical correlation between different variables. This will guide future research with this population. In addition, the literature review in this thesis explored main study outcomes with older family carers and helped to provide a broad overview of current research in this area. It assisted in identifying what type of QoL tools have been used to measure older family carers' QoL and in highlighting the need for an age-specific measure for use with these people. The insights from this review will support future research with older carers of people with dementia.

The qualitative investigation carried out with 19 older family carers of people provided an exploration of the lived experience of older family carers of people with dementia and their subjective QoL. This study identified three main broad areas, as well as 33 specific facets, associated with the negative and the positive impact of caregiving on QoL. These findings may be used in further development of research with this population and direct interventions focused on the aspects which are mostly associated with the QoL of these individuals. Dimensions of life which are particularly affected in older people who are dementia carers were identified in these focus groups, helping to provide evidence for a specific QoL model for older family carers of people with dementia.

These dimensions include, for example, the physical impact of caregiving, concerns about their own health and future, energy for care provision, the role conflicts of being an older carer, identity, the higher impact of financial situation as older people mostly depend on the state to survive, confidence in providing care while being a frail older person, isolation and loneliness derived from a full-time carer role, and sleep deprivation. Each of these components or the entire model can be further explored in association with other variables in future studies for further development and improvement of this model. These findings will add to the existing literature on QoL and help in understanding further how QoL changes as people grow older and what the relevant QoL domains are for older people who are carers.

As discussed in Chapter 2, available caregiving models are currently narrow and do not provide a multidimensional view of the impact of caregiving on the lives of family carers. Besides contributing to QoL research, results from qualitative and quantitative study strands are therefore expected to add to the available literature on family caregiving in dementia. Insights from focus groups and from the retained group of items on the final scale version can inform future theoretical developments in this field, based on the older family carers' priorities.

7.3.2.2 Implications for clinical practice and care

Even though the implications stated in the previous section are related to research, they are also mostly applicable to clinical practice and care. As the DQoL-OC is a dementia- and caregiving-specific scale, it has the benefit of providing information about which area of life and which caregiving aspects are associated with QoL levels, which is meaningful for clinical practice and care (in health services or in the community). Rather than just focusing on reducing burden and stress, having a valid and reliable measure to quantify the QoL levels of older family carers will help clinicians and researchers to identify which people's lives are more affected by the negative aspects of caregiving in order to help them to live better. In addition, because it is easy to use, older family carers can measure their QoL themselves and sum their total QoL score. This may enable application as a tool for 'self-management' of their own QoL, which they can use to discuss with service providers what can be done to improve their life as carers.

As seen in Chapter 3, policies and the academic literature call for more and better health and social interventions with older carers, and therefore this scale may offer a more appropriate measurement tool to evaluate gains in QoL. Even though its responsiveness has not been yet established, the content is appropriate to this population and so far has produced highly valid and reliable outcomes. By measuring older carers' QoL more accurately, adequate funding can be allocated to these individuals to afford appropriate interventions focused on improving those aspects of caregiving that are most likely to affect these individuals' lives.

Perhaps the first major impact of this study's results on clinical practice will be on services that collaborated with the recruitment of participants. Findings will be reported to each of these institutions in the format of partial results (questionnaires distributed via each specific service) and general results. Results will also be available in online forums where the study was publicized and will be fed back to the local community groups. These reports will help service managers to identify major gaps in support for older carers and to implement changes into practice. It is hoped that, by having access to the final results of the study, family carers will be encouraged to participate in future research and professionals may feel encouraged to assist in recruitment of future related studies.

Because the study was developed with significant involvement from voluntary organizations, it is expected that the DQoL-OC and its user guide will be seen as helpful tools for use with the older carers attending these services. Considering that these institutions are responsible for a major part of the support system available for carers in the UK, it is of great importance to involve them in this research and implementation of its results. As support workers were directly involved with recruitment, it is hoped that these people will be much more interested in using the scale in their day-to-day practice. The tool can be used to assess the quality of the support they provide, for example, thus helping to evaluate the benefits of involving these organizations in the care provision within the social sector. Besides the voluntary sector, the DQoL-OC can be used to evaluate the QoL of older family carers attending memory clinics with their relatives with dementia; it can be used by GP practices at the services and in the home environment in order to guide support, or by other community services, such as respite services.

7.3.3. Future research

This is the first study investigating the psychometric properties of the DQoL-OC. Analyses provided evidence of its suitability for use with this particular population, and it has contributed to the current small number of studies investigating these people, in line with current policies and national recommendations (HM Government, 2009, Age UK, 2010, HM Government, 2010, Carers UK, 2015). It is expected that the psychometric properties of this new scale (reliability, construct validity, criterion validity, discriminant validity, etc.) be continuously evaluated and developed in future research.

Immediate future research should be focused on repeating the QoL measurement in a similar population of older family carers of people with dementia in the UK, using the DQoL-OC, in order to establish the validity and reliability of the DQoL-OC further. The psychometric study suggested that QoL scores were significantly associated with age, gender, time per day of care, days per week of care, carers' subjective evaluation of disease stage, stability of symptoms, and levels of dependence of the cared for. Future investigation with this population should thus focus on these particular variables. In exploratory or cross-sectional studies, for example, caregiving variables and other psychological constructs could be correlated with the DQoL-OC outcomes in order to draw associations between QoL variations according to different situations. Results from these exploratory investigations can guide appropriate interventions with these people in order to increase QoL levels (e.g. increase respite, financial support, increase social activity).

The underlying structure of the QoL construct of older family carers of people with dementia identified in the current study needs to be confirmed using robust statistical measures, such as CFA or Item Response Theory. This will allow, for example, the evaluation of method effects, examination of stability or invariance of the factor model over time or informants, and establishment of measurement errors for each scale item (Brown, 2015). Furthermore, CFA will allow measurement invariance evaluation and longitudinal measurement invariance, which establishes whether the measurement tool provides consistent outcomes in subgroups within a heterogeneous population and over time (due to true change) (Brown, 2015). Further investigation of the construct being measured should also be carried out using sophisticated statistical methods, such as multitrait-multimethod matrices. In such advanced tests, the hypothesized model can have its convergent and discriminant validities adjusted for measurement error and error theory.

Sensitivity and responsiveness are also considered essential properties for a measurement tool designed to identify change and effectiveness of interventions (Liang, 2000), and therefore establishing these measurement properties will allow for a valid and reliable evaluation of how much QoL is gained with specific health and social interventions (such as in clinical trials) (Hays and Hadorn, 1992). Establishing these properties will also enable the DQoL-OC to be used in longitudinal study designs, such as cohort studies, to measure the impact of dementia deterioration on older carers' QoL, for example. Given the high levels of reliability of the DQoL-OC so far (internal reliability and outcome consistency over time) and high congruent construct validity with a gold standard measure of QoL for older people, it is expected that this scale will provide high levels of responsiveness to changes in QoL over time. However, these properties need to be tested, for example, by comparing the QoL of two groups of carers (one expected to have lower QoL levels and the other expected to have higher levels) measured using a gold standard measure and with the DQoL-OC.

Further psychometric properties that should be investigated are criterion validity (concurrent and predictive) and divergent validity. Concurrent validity will establish, for example, whether increased morbidity of the cared for or increased levels of burden for the older carer also have lower levels of QoL. Predictive validity, however, will establish whether the QoL is able to predict increased levels of burden, morbidity, or mortality, for example, due to its lower scores in QoL. Divergent validity can be obtained in investigating the QoL of a population of older carers and different psychological construct (e.g. burden or depression) and testing whether these are statistically different. Such properties will expand the usability of the DQoL-OC to different types of research questions and study designs.

The DQoL-OC needs to be validated for use with different populations of older carers in the UK, such as those with different ethnic backgrounds, for example. This will allow future research comparing different groups of older carers and further exploration of the needs of older carers from ethnic minority groups in the UK. This measure can be translated and validated for use with older family carers of people with dementia in other countries. This will allow further exploration of the psychometric properties of this scale and a cross-country evaluation of the QoL of older carers who are living in different sociodemographic conditions, receiving different levels of support, and have different cultural perceptions of QoL.

In addition, because the scale was developed with older individuals providing care at home, it may not be suitable for use with older carers of people with dementia living in nursing homes, as carers in this situation may have different needs related to QoL. The DQoL-OC could thus be validated for use with these carers in the future. In doing so, the QoL levels of carers providing care at home could be compared with those carers of people who live in a care institution, thereby providing evidence of the impact of institutionalization of the person with dementia on the QoL of older carers.

The DQoL-OC can also be adapted into a shorter form in the future, and the results from the full measure and the short version used for different purposes and continuously developed and evaluated. The DQoL-OC can also be developed and validated for use with young adult carers. This second version of the scale will allow comparison between the two age groups and further exploration of how QoL perception and appraisal changes as people grow old, as well as how the impact of caregiving on QoL is differentiated in later/early adult life. Age-specific and caregiving-related QoL models can be further developed from this study. For example, the DQoL-OC can be adapted and validated for use with older carers of people with other chronic and degenerative diseases, such as Parkinson’s disease. If the scale is well validated to other disease contexts, this may allow comparisons between QoL levels of older carers in different disease contexts. Moreover, as one of the benefits of an age- and dementia-specific scale is its potential use in health economics, it is important that research investigates the usability of this scale for the purpose of economic evaluations, for example by evaluating how much a respite intervention can improve QoL and how much this can have an impact in reducing costs for health and social services.

Finally, considering the experiences with recruitment in the current study, future research with older carers should be flexible with regard to types of data collection and methods of recruitment that may allow a better response rate to survey questionnaires and service evaluation. Future research with family carers involving GP services should consider reduced demands on health professionals in order to maximize the involvement from these services. Successful results in involving these services in the current study were due to being mindful of these constraints.

7.4. CONCLUDING REMARKS

This PhD research provided an in-depth and novel exploration of the aspects of QoL that are relevant to older family carers of people with dementia in the UK. A sequential and exploratory mixed-methods research approach was used to develop and evaluate the psychometric properties of the ‘Dementia Quality of Life Scale for Older Family Carers’ (DQoL-OC), a dementia- and age-specific tool for the evaluation of the QoL of older family carers. The qualitative study strand provided a detailed and in-depth analysis of the experience of being an older carer and their QoL. It allowed for the selection of a number of factors associated with older carers’ QoL, which formed the basis for the DQoL-OC. The quantitative study strand provided a thorough evaluation of the psychometric properties of a large set of items. Results demonstrated that the QoL of older family carers of people with dementia can be validly and reliably measured by a single-factor structure containing 22 items, measured on a 1 to 5 Likert scale. The final version of the DQoL-OC addresses a number of important issues relevant to further development in QoL research with older family carers of people with dementia in the UK. It was considered a relevant and practical measure by the older family carers themselves and shown to be valid and reliable for use with these people.

Considering the increasing population affected by dementia and the increasing involvement of older people in caring for these individuals, the DQoL-OC is therefore an excellent starting point for future investigation of QoL within this particular group of individuals. This study is timely and was valuable for improving understanding of the QoL of older family carers of people with dementia in the UK, a currently overlooked population of family carers. This study meets current policies and public reports, which advise that more research should be carried out to understand the older family carers’ needs. The newly developed scale can be used in research, as well as in health and social care services aiming at evaluating and improving the QoL of these individuals.

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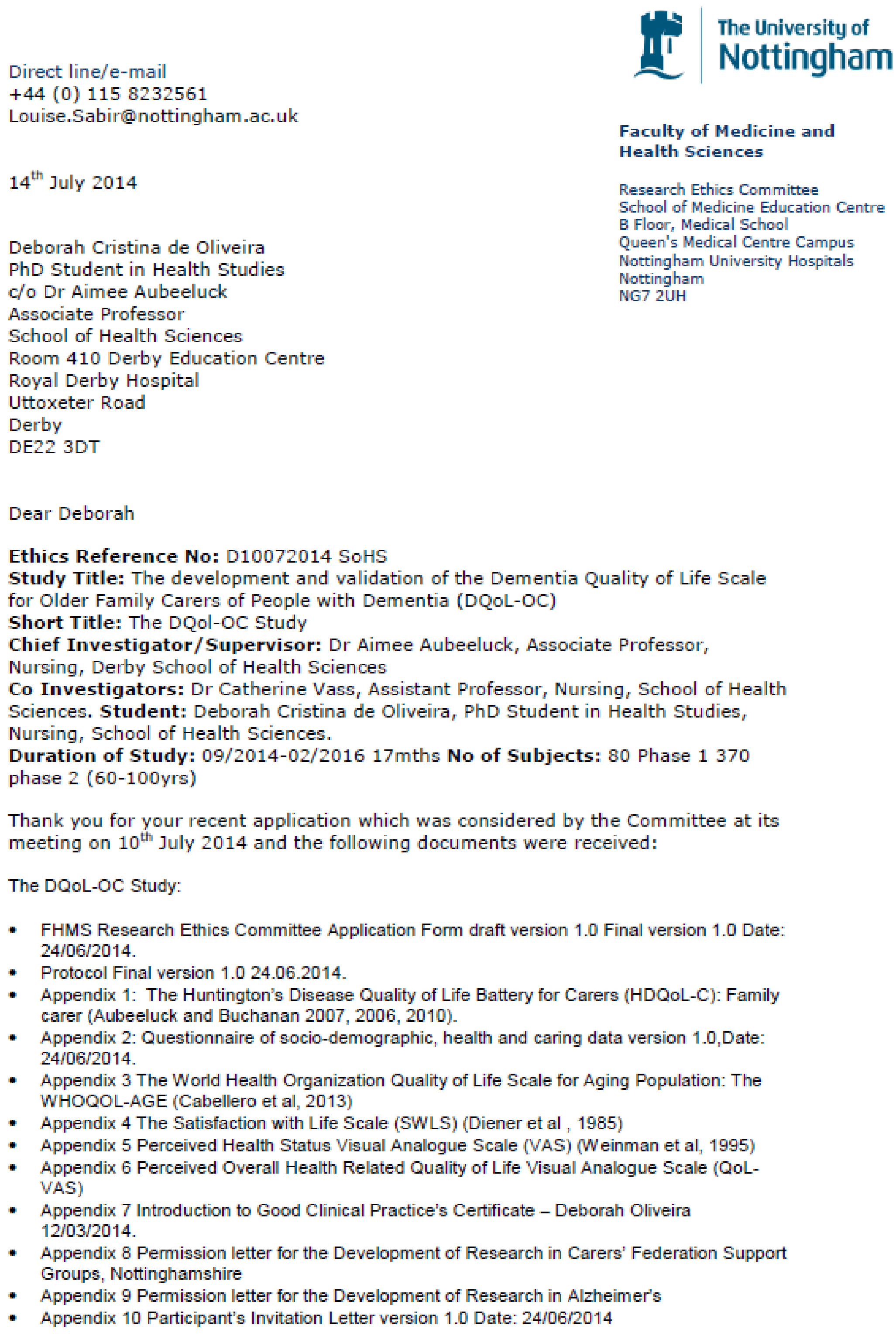
Appendices

APPENDIX 1 – ETHICS AND SERVICES' APPROVALS



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14th July 2014

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Dear Deborah

Ethics Reference No: D10072014 SoHS
Study Title: The development and validation of the Dementia Quality of Life Scale for Older Family Carers of People with Dementia (DQoL-OC)
Short Title: The DQol-OC Study
Chief Investigator/Supervisor: Dr Aimee Aubeeluck, Associate Professor, Nursing, Derby School of Health Sciences
Co Investigators: Dr Catherine Vass, Assistant Professor, Nursing, School of Health Sciences. **Student:** Deborah Cristina de Oliveira, PhD Student in Health Studies, Nursing, School of Health Sciences.
Duration of Study: 09/2014-02/2016 17mths **No of Subjects:** 80 Phase 1 370 phase 2 (60-100yrs)

Thank you for your recent application which was considered by the Committee at its meeting on 10th July 2014 and the following documents were received:

The DQoL-OC Study:

- FHMS Research Ethics Committee Application Form draft version 1.0 Final version 1.0 Date: 24/06/2014.
- Protocol Final version 1.0 24.06.2014.
- Appendix 1: The Huntington's Disease Quality of Life Battery for Carers (HDQoL-C): Family carer (Aubeeluck and Buchanan 2007, 2006, 2010).
- Appendix 2: Questionnaire of socio-demographic, health and caring data version 1.0,Date: 24/06/2014.
- Appendix 3 The World Health Organization Quality of Life Scale for Aging Population: The WHOQOL-AGE (Cabellero et al, 2013)
- Appendix 4 The Satisfaction with Life Scale (SWLS) (Diener et al , 1985)
- Appendix 5 Perceived Health Status Visual Analogue Scale (VAS) (Weinman et al, 1995)
- Appendix 6 Perceived Overall Health Related Quality of Life Visual Analogue Scale (QoL-VAS)
- Appendix 7 Introduction to Good Clinical Practice's Certificate – Deborah Oliveira 12/03/2014.
- Appendix 8 Permission letter for the Development of Research in Carers' Federation Support Groups, Nottinghamshire
- Appendix 9 Permission letter for the Development of Research in Alzheimer's
- Appendix 10 Participant's Invitation Letter version 1.0 Date: 24/06/2014

- Appendix 11 Focus Group Schedule, version 1.0 Date 24/06/2014
- Participant Information Sheet Draft v1.0 Final version 1.0 20.06.2014
- Consent Form Final version 1.0 19.06.2014

These have been reviewed and are satisfactory and the study is approved.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

1. You must follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a form).

2. You must notify the Chair of any serious or unexpected event.

3. This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

4. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

Dr Clodagh Dugdale
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

NHS
Health Research Authority

Social Care REC
Ground Floor
Skipton House
80 London Road
London
SE1 6LH

Telephone: 0207 972 2568

06 August 2015

Dr. Aimee Aubeeluck
Room 410 Derby Education Centre
Royal Derby Hospital, Uttoxeter Road
Derby
DE22 3DT

Dear Dr. Aubeeluck

Study title:	**Development of the Dementia Quality of Life Scale for Older Family Carers of People with Dementia (DQoL-OC) and Evaluation of its Psychometric Properties**
REC reference:	**15/IEC08/0041**
Protocol number:	**15045**
IRAS project ID:	**182378**

Thank you for your letter of 30 July 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC during the week commencing 03 August 2015. A list of the Sub-Committee members is attached.

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 favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Barbara Cuddon, nrescommittee.social-care@nhs.net . Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

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

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

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System 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.

Guidance on Research Governance approval for social care organisations is available from the Research Governance Framework: Resource Pack for Social Care, 2nd Edition, April 2010 and can be found at:
http://www.hra.nhs.uk/resources/before-you-apply/non-nhs-recs/national-social-care-research-ethics-committee/

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

Registration of Clinical Trials

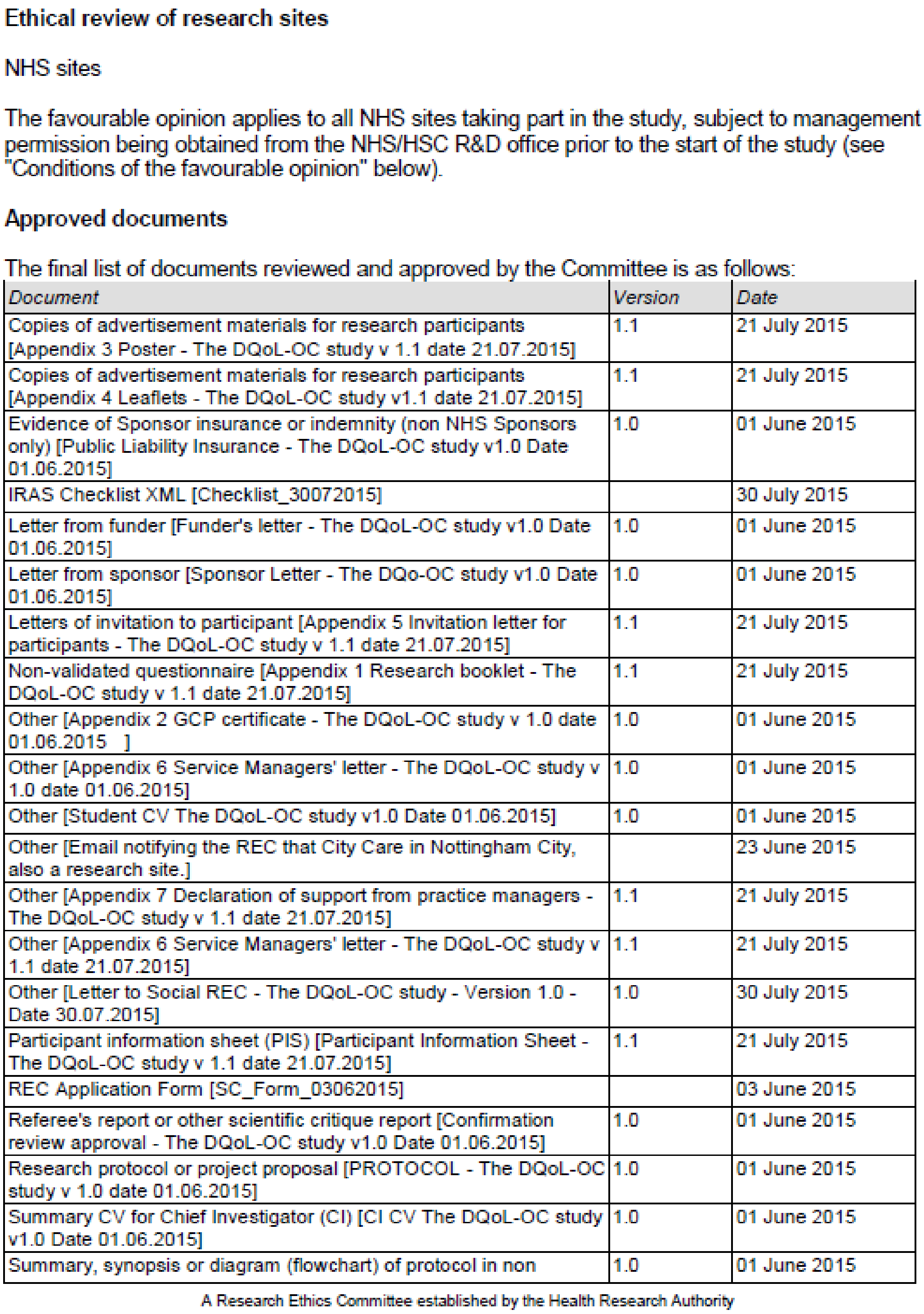
All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

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 NRES. 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 [Appendix 3 Poster - The DQoL-OC study v 1.1 date 21.07.2015]	1.1	21 July 2015
Copies of advertisement materials for research participants [Appendix 4 Leaflets - The DQoL-OC study v1.1 date 21.07.2015]	1.1	21 July 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Public Liability Insurance - The DQoL-OC study v1.0 Date 01.06.2015]	1.0	01 June 2015
IRAS Checklist XML [Checklist_30072015]		30 July 2015
Letter from funder [Funder's letter - The DQoL-OC study v1.0 Date 01.06.2015]	1.0	01 June 2015
Letter from sponsor [Sponsor Letter - The DQo-OC study v1.0 Date 01.06.2015]	1.0	01 June 2015
Letters of invitation to participant [Appendix 5 Invitation letter for participants - The DQoL-OC study v 1.1 date 21.07.2015]	1.1	21 July 2015
Non-validated questionnaire [Appendix 1 Research booklet - The DQoL-OC study v 1.1 date 21.07.2015]	1.1	21 July 2015
Other [Appendix 2 GCP certificate - The DQoL-OC study v 1.0 date 01.06.2015]	1.0	01 June 2015
Other [Appendix 6 Service Managers' letter - The DQoL-OC study v 1.0 date 01.06.2015]	1.0	01 June 2015
Other [Student CV The DQoL-OC study v1.0 Date 01.06.2015]	1.0	01 June 2015
Other [Email notifying the REC that City Care in Nottingham City, also a research site.]		23 June 2015
Other [Appendix 7 Declaration of support from practice managers - The DQoL-OC study v 1.1 date 21.07.2015]	1.1	21 July 2015
Other [Appendix 6 Service Managers' letter - The DQoL-OC study v 1.1 date 21.07.2015]	1.1	21 July 2015
Other [Letter to Social REC - The DQoL-OC study - Version 1.0 - Date 30.07.2015]	1.0	30 July 2015
Participant information sheet (PIS) [Participant Information Sheet - The DQoL-OC study v 1.1 date 21.07.2015]	1.1	21 July 2015
REC Application Form [SC_Form_03062015]		03 June 2015
Referee's report or other scientific critique report [Confirmation review approval - The DQoL-OC study v1.0 Date 01.06.2015]	1.0	01 June 2015
Research protocol or project proposal [PROTOCOL - The DQoL-OC study v 1.0 date 01.06.2015]	1.0	01 June 2015
Summary CV for Chief Investigator (CI) [CI CV The DQoL-OC study v1.0 Date 01.06.2015]	1.0	01 June 2015
Summary, synopsis or diagram (flowchart) of protocol in non	1.0	01 June 2015

technical language [Study Synopsis - The DQoL-OC study v1.0 Date 01.06.2015]		
Validated questionnaire [Appendix 1 Research booklet - The DQoL-OC study v 1.0 date 01.06.2015]	1.0	01 June 2015

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/

15/IEC08/0041 **Please quote this number on all correspondence**

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

Social Care REC

Attendance at Sub-Committee of the REC meeting held during the week commencing 03 August 2015

Committee Members:

Name	*Profession*	*Present*
Dr Martin Stevens - Chair	Senior Research Fellow	Yes
Dr Kathylene F Siska	Social Worker/Academic	Yes

Also in attendance:

Name	*Position (or reason for attending)*
Ms Barbara Cuddon	REC Manager

Yours sincerely

Dr Martin Stevens
Chair

Email: nrescommittee.social-care@nhs.net

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments* "After ethical review – guidance for researchers"
Copy to:	*Mrs Angela Shone* *Dr Maria Koufali, Nottingham University Hospitals NHS Trust*

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Nottinghamshire Healthcare NHS
NHS Foundation Trust

Research and Development
Nottinghamshire Healthcare NHS Foundation Trust
Duncan Macmillan House
Porchester Road
Mapperley
Nottingham
NG3 6AA
E-mail: shirley.mitchell@nottshc.nhs.uk

Our Ref: Oliveira/NCCCG/120815

Date of letter: 12 August 2015

Miss Deborah Oliveira
Room B33: Post graduate student office
SoHS, South Block
QMC
Derby Road
Nottingham

Dear Deborah

Study title: Development of the Dementia Quality of Life Scale for older family carers of people with Dementia (DQoL-OC) and Evaluation of its psychometric properties
IRAS/REC ID: 15/IEC08/0041
Sponsor: University of Nottingham
CCG and/or GP Practice: GP practices within **Nottingham City CCG**

Thank you for submitting your application for the above study. Your application has been reviewed by Nottinghamshire Healthcare NHS Foundation Trust Research Support Service. We provide a research governance function for GP practices in Nottingham City and Nottinghamshire County. We provide assurance that research studies meet nationally agreed research governance criteria to assist GP practices in deciding whether to take part in a research study.

I am pleased to confirm that this application has satisfied the governance criteria for Participant Identification Centres[1]

This assurance is issued on the basis that the study is conducted in accordance with the following version of the protocol and supporting documents submitted with your application (see below).

Document	Version	Date
Study Protocol	1.0	01.06.2015
Participant Information Sheet	1.1	21.07.2015
Research booklet	1.1	21.07.2015
Poster	1.1	21.07.2015
Leaflet	1.1	21.07.2015
Invitation letter for participants	1.1	21.07.2015

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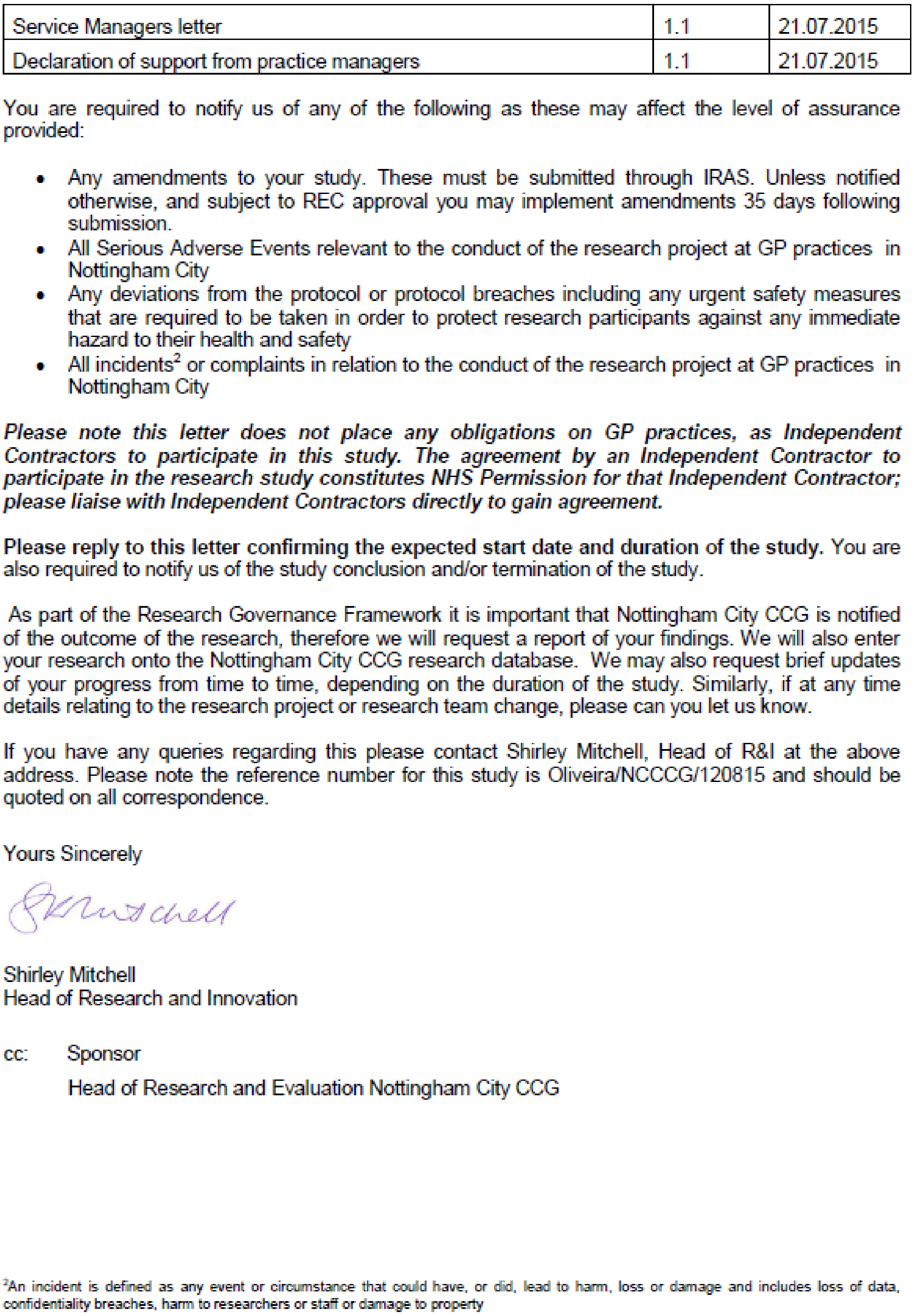
[1] Where potential participants will be identified through NHS organisations other than research sites themselves; these organisations are termed 'Participant Identification Centres' (PIC) IRAS Question Specific Guidance – Part C version 2.2 dated April 2009



Service Managers letter	1.1	21.07.2015
Declaration of support from practice managers	1.1	21.07.2015

You are required to notify us of any of the following as these may affect the level of assurance provided:

- Any amendments to your study. These must be submitted through IRAS. Unless notified otherwise, and subject to REC approval you may implement amendments 35 days following submission.
- All Serious Adverse Events relevant to the conduct of the research project at GP practices in Nottingham City
- Any deviations from the protocol or protocol breaches including any urgent safety measures that are required to be taken in order to protect research participants against any immediate hazard to their health and safety
- All incidents[2] or complaints in relation to the conduct of the research project at GP practices in Nottingham City

Please note this letter does not place any obligations on GP practices, as Independent Contractors to participate in this study. The agreement by an Independent Contractor to participate in the research study constitutes NHS Permission for that Independent Contractor; please liaise with Independent Contractors directly to gain agreement.

Please reply to this letter confirming the expected start date and duration of the study. You are also required to notify us of the study conclusion and/or termination of the study.

As part of the Research Governance Framework it is important that Nottingham City CCG is notified of the outcome of the research, therefore we will request a report of your findings. We will also enter your research onto the Nottingham City CCG research database. We may also request brief updates of your progress from time to time, depending on the duration of the study. Similarly, if at any time details relating to the research project or research team change, please can you let us know.

If you have any queries regarding this please contact Shirley Mitchell, Head of R&I at the above address. Please note the reference number for this study is Oliveira/NCCCG/120815 and should be quoted on all correspondence.

Yours Sincerely

Shirley Mitchell
Head of Research and Innovation

cc: Sponsor
Head of Research and Evaluation Nottingham City CCG

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[2] An incident is defined as any event or circumstance that could have, or did, lead to harm, loss or damage and includes loss of data, confidentiality breaches, harm to researchers or staff or damage to property

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Nottinghamshire Healthcare NHS
NHS Foundation Trust

Research and Development
Nottinghamshire Healthcare NHS Foundation Trust
Duncan Macmillan House
Porchester Road
Mapperley
Nottingham
NG3 6AA
E-mail: shirley.mitchell@nottshc.nhs.uk

Our Ref: Oliveira/NCoCCG/120815

Date of letter: 12 August 2015

Miss Deborah Oliveira
Room B33: Post graduate student office
SoHS, South Block
QMC
Derby Road
Nottingham

Dear Deborah

Study title: Development of the Dementia Quality of Life Scale for older family carers of people with Dementia (DQoL-OC) and Evaluation of its psychometric properties
IRAS/REC ID: 15/IEC08/0041
Sponsor: University of Nottingham
CCG and/or GP Practice: GP practices within **Nottinghamshire County CCGs**

Thank you for submitting your application for the above study. Your application has been reviewed by Nottinghamshire Healthcare NHS Foundation Trust Research Support Service. We provide a research governance function for GP practices in Nottingham City and Nottinghamshire County. We provide assurance that research studies meet nationally agreed research governance criteria to assist GP practices in deciding whether to take part in a research study.

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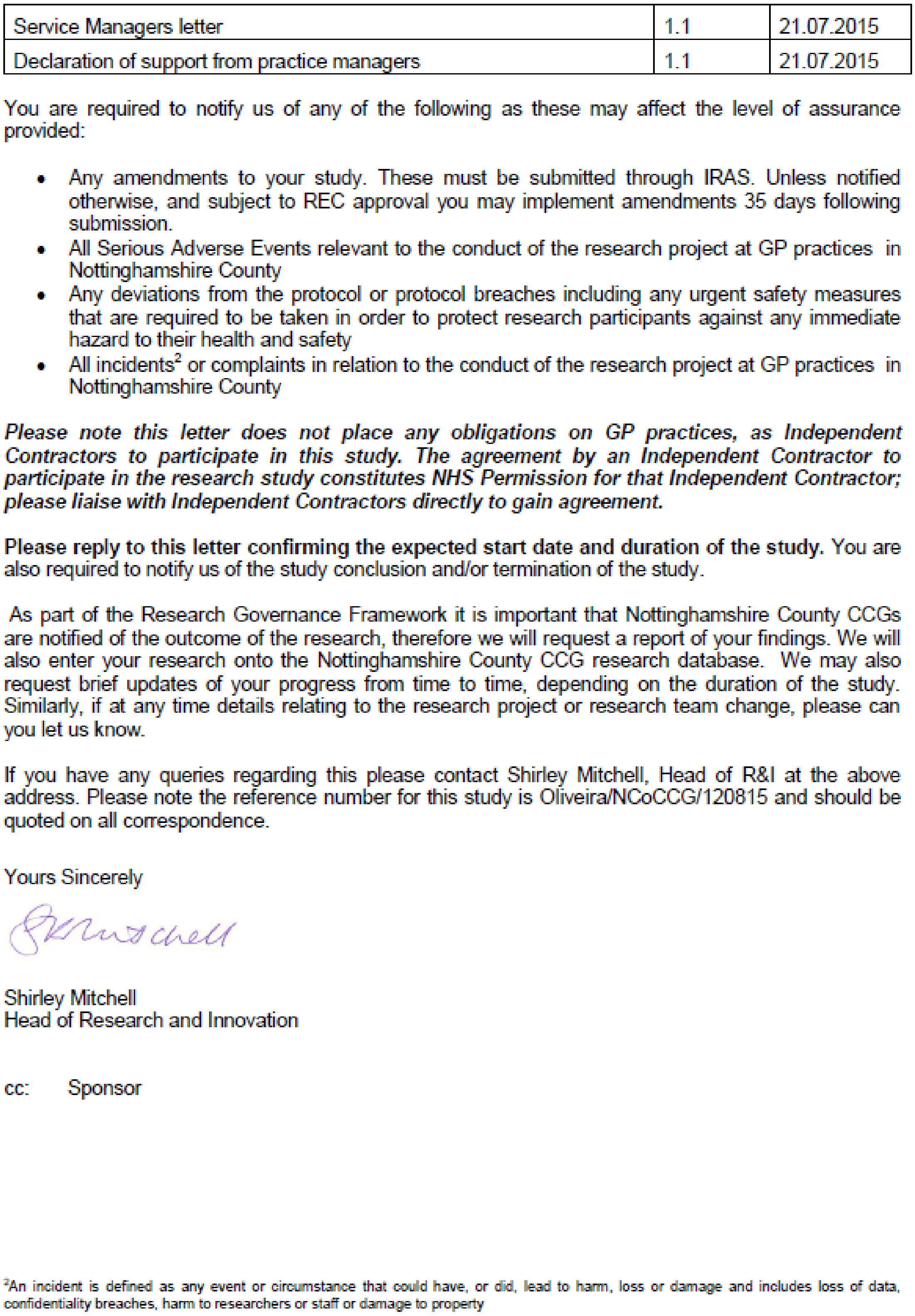

Service Managers letter	1.1	21.07.2015
Declaration of support from practice managers	1.1	21.07.2015

You are required to notify us of any of the following as these may affect the level of assurance provided:

- Any amendments to your study. These must be submitted through IRAS. Unless notified otherwise, and subject to REC approval you may implement amendments 35 days following submission.
- All Serious Adverse Events relevant to the conduct of the research project at GP practices in Nottinghamshire County
- Any deviations from the protocol or protocol breaches including any urgent safety measures that are required to be taken in order to protect research participants against any immediate hazard to their health and safety
- All incidents[2] or complaints in relation to the conduct of the research project at GP practices in Nottinghamshire County

Please note this letter does not place any obligations on GP practices, as Independent Contractors to participate in this study. The agreement by an Independent Contractor to participate in the research study constitutes NHS Permission for that Independent Contractor; please liaise with Independent Contractors directly to gain agreement.

Please reply to this letter confirming the expected start date and duration of the study. You are also required to notify us of the study conclusion and/or termination of the study.

As part of the Research Governance Framework it is important that Nottinghamshire County CCGs are notified of the outcome of the research, therefore we will request a report of your findings. We will also enter your research onto the Nottinghamshire County CCG research database. We may also request brief updates of your progress from time to time, depending on the duration of the study. Similarly, if at any time details relating to the research project or research team change, please can you let us know.

If you have any queries regarding this please contact Shirley Mitchell, Head of R&I at the above address. Please note the reference number for this study is Oliveira/NCoCCG/120815 and should be quoted on all correspondence.

Yours Sincerely

SMitchell

Shirley Mitchell
Head of Research and Innovation

cc: Sponsor

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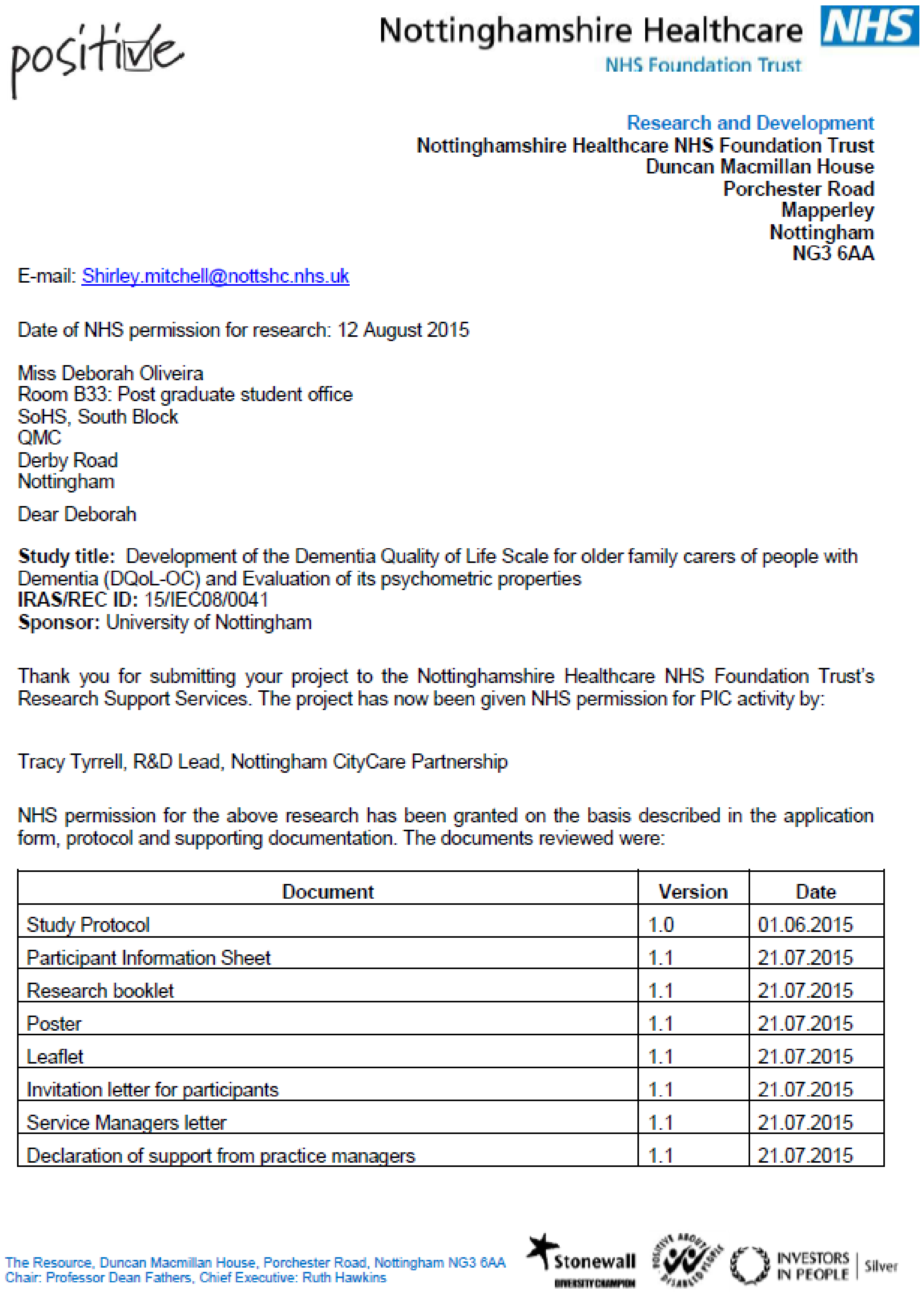
[2] An incident is defined as any event or circumstance that could have, or did, lead to harm, loss or damage and includes loss of data, confidentiality breaches, harm to researchers or staff or damage to property



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Nottinghamshire Healthcare NHS
NHS Foundation Trust

Research and Development
Nottinghamshire Healthcare NHS Foundation Trust
Duncan Macmillan House
Porchester Road
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Nottingham
NG3 6AA

E-mail: Shirley.mitchell@nottshc.nhs.uk

Date of NHS permission for research: 12 August 2015

Miss Deborah Oliveira
Room B33: Post graduate student office
SoHS, South Block
QMC
Derby Road
Nottingham

Dear Deborah

Study title: Development of the Dementia Quality of Life Scale for older family carers of people with Dementia (DQoL-OC) and Evaluation of its psychometric properties
IRAS/REC ID: 15/IEC08/0041
Sponsor: University of Nottingham

Thank you for submitting your project to the Nottinghamshire Healthcare NHS Foundation Trust's Research Support Services. The project has now been given NHS permission for PIC activity by:

Tracy Tyrrell, R&D Lead, Nottingham CityCare Partnership

NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version	Date
Study Protocol	1.0	01.06.2015
Participant Information Sheet	1.1	21.07.2015
Research booklet	1.1	21.07.2015
Poster	1.1	21.07.2015
Leaflet	1.1	21.07.2015
Invitation letter for participants	1.1	21.07.2015
Service Managers letter	1.1	21.07.2015
Declaration of support from practice managers	1.1	21.07.2015

The Resource, Duncan Macmillan House, Porchester Road, Nottingham NG3 6AA
Chair: Professor Dean Fathers, Chief Executive: Ruth Hawkins

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP [ONLY if applicable], and NHS Trust policies and procedures available http://www.nottinghamshirehealthcare.nhs.uk/contact-us/freedom-of-information/policies-and-procedures/
The research sponsor or the Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D office should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D Office should be notified within the same time frame of notifying the REC and any other regulatory bodies. All amendments (including changes to the local research team) need to be submitted in accordance with guidance in IRAS.

Please note that the NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research.

Yours Sincerely

SMitchell

Shirley Mitchell
Head of Research and Innovation

CC:

Sponsor

NCCP R&D Lead

APPENDIX 2 – PRELIMINARY VERSION OF THE DQOL-OC

The Dementia Quality of Life Scale for Older Family Carers (DQoL-OC)

Déborah Cristina de Oliveira, Catherine Vass and Aimee Aubeeluck

Correspondence to:
Déborah Cristina de Oliveira
Room B33
Faculty of Medicine and Health Sciences, School of Nursing
The University of Nottingham, Queen's Medical Centre, South Block
Derby Road, NG7 2UH, Nottingham, United Kingdom
Tel: 0115 92 49924

E-mail: deborah.oliveira@nottingham.ac.uk

Thank you for taking the time to fill in this questionnaire. The questionnaire has four sections. The first section will ask for some factual information. The next three will ask about different aspects of your role as a carer, how satisfied you are, and how you feel about various aspects of your life.

Please answer all the questions. If you are unsure about which response to give to a question, **please choose the ONE** that seems most appropriate (this is often your initial response).

Section 1

This section asks for information about yourself and the care you provide. Please answer all the questions, and do not spend too much time on any one item.

1 a) What is your date of birth? _______/______/________	**1 b)** What is your gender? ☐ Male ☐ Female ☐ I prefer not to say
1 c) What is the highest qualification you hold? ☐ No qualifications ☐ GCSE ☐ A level ☐ Diploma ☐ University degree ☐ Postgraduate degree	**1 d)** What is your marital status? ☐ Single ☐ Married ☐ Partnership ☐ Separated ☐ Divorced ☐ Widowed
1 e) Do you currently work somewhere besides being a carer? ☐ Yes ☐ No ☐ Retired ☐ Never had a job ☐ Stopped working to be a carer	**1 f)** Have you ever cared for other people? ☐ No ☐ Yes
1 g) Do you care for more than one person? ☐ No ☐ Yes	**1 h)** What is your ethnic group? ☐ White ☐ Afro-Caribbean ☐ Asian ☐ Arab ☐ Other ethnic group ☐ I prefer not to say
1 i) Has your doctor ever told you that you have any disease or disorder? ☐ No ☐ Yes ☐ If YES, what is (are) the disease(s)?____________________ ________________________________ ________________________________ ________________________________ ________________________________	**1 j)** Do you have any of these problems? ☐ Difficulties hearing ☐ Difficulties seeing ☐ Difficulties walking ☐ Pain ☐ Fatigue ☐ Insomnia ☐ Other(s):_____________
1 k) Do you live with the family member	**1 l)** What is your relationship with

you care for? ☐ Yes ☐ No	the family member you care for? ☐ Spouse ☐ Son or daughter ☐ Sibling ☐ Other
1 m) Approximately, how long have you been caring for your family member? ☐ Less than 1 year ☐ 1 to 3 years ☐ 4 to 6 years ☐ 7 to 10 years ☐ 10+ years	**1 n)** How long has your family member been diagnosed with dementia? ☐ Less than 1 year ☐ 1 to 3 years ☐ 4 to 6 years ☐ 7 to 10 years ☐ 10+ years
1 o) What type of dementia was your family member diagnosed with? ☐ Alzheimer's disease ☐ Frontotemporal dementia ☐ Vascular dementia ☐ Lewy body dementia ☐ Other type ☐ Still not defined the type ☐ I don't remember	**1 p)** On average, how many HOURS PER DAY do you care for your family member? ☐ Less than 6 hours ☐ 6 to 12 hours ☐ 24 hours
1 q) On average, how many DAYS PER WEEK do you care for your family member? ☐ 1 ☐ 2 to 3 ☐ 4 to 5 ☐ 6 to 7	Does your family member have any other health problems that require care? (e.g. diabetes and need for insulin application) ☐ No ☐ Yes ☐ If yes, what is (are) the health problem(s): ___________________________________ ___________________________________ ___________________________________

Section 2

We want to know now how you feel about your role as a carer, your health, and your quality of life. Please circle the number that most accurately represents your situation.

Please keep in mind your standards, hopes, pleasures, and concerns. We ask that you think about your life **in the last four weeks.** For example, thinking about the last four weeks, a question might ask:

How often do you have access to appropriate information about dementia and caring?	Never 1	Rarely 2	Occasionally 3	Frequently 4	Very frequently 5

In this question, you should circle the number that best fits how often you had access to appropriate information about dementia and caring over the last four weeks. So you would circle the number that corresponds to the option "Rarely" if you rarely had access to appropriate information about dementia and caring in the last four weeks, as follows:

How often do you have access to appropriate information about dementia and caring?	Never 1	Rarely [✓ 2]	Occasionally 3	Frequently 4	Very frequently 5

In this case, "Never" (number 1) means the lowest possible frequency of receiving appropriate information about dementia and caregiving, and "Very frequently" (number 5) the highest frequency possible.

Please read each question, assess your feelings, and circle the number on the questionnaire for each question that gives the best answer for you.

This first set of questions asks for information about different aspects associated with your role as a carer of a family member with dementia. Please circle the number that best describes your situation in the last four weeks.

		Never	**Rarely**	**Occasionally**	**Frequently**	**Very frequently**
1.	How often does your family member receive appropriate support from health and social services?	1	2	3	4	5
2.	How often are emergency requests for health and social support attended to?	1	2	3	4	5
3.	How often do you have access to appropriate care facilities?	1	2	3	4	5
4.	How often do you have access to professionals that have enough knowledge of dementia and understand its implications?	1	2	3	4	5
5.	How often do you receive appropriate health support for YOUR OWN NEEDS?	1	2	3	4	5
6.	How often do you have access to information about dementia and caring?	1	2	3	4	5
7.	How often do you receive support from other family members or friends?	1	2	3	4	5
8.	How often does dementia and caregiving negatively affect your relationships with family and friends?	1	2	3	4	5
9.	How often is your financial situation affected by the demands of caring?	1	2	3	4	5
10.	How often do you experience a conflict of interest between what you want and what your family member wants?	1	2	3	4	5
11.	How often do you feel					

	burdened by the daily hassles of caregiving?	1	2	3	4	5
12.	How often are you restricted by the need to maintain a regimented daily routine?	1	2	3	4	5
13.	How much have you had to change YOUR OWN LIFE AND INTERESTS to fit around your family member's needs?	1	2	3	4	5
14.	How much has YOUR FAMILY ROUTINE AND INTERESTS been adapted to suit your family member's needs?	1	2	3	4	5
15.	How often is caring physically hard for you?	1	2	3	4	5
16.	How often do you have respite from caring for your family member?	1	2	3	4	5
17.	How often does your family member cooperate with you?	1	2	3	4	5
		Totally dependent	**Mostly dependent**	**Partially (in)dependent**	**Mostly independent**	**Totally independent**
18.	How much does your family member depend on you for his/her daily activities?	1	2	3	4	5
		Totally instable	**Mostly instable**	**Partially (in)stable**	**Mostly stable**	**Totally stable**
19.	How do you evaluate your family member at this moment, in terms of disease progression and symptoms?	1	2	3	4	5

Section 3

This next set of questions asks how you *feel* about different aspects of your life. Please choose the option that best describes how you have *felt* about each area of your life in the last four weeks.

		Very frequently	**Frequently**	**Occasionally**	**Rarely**	**Never**
20.	I feel worried about my health	1	2	3	4	5
21.	I feel that I haven't got the health and the strength that I used to have in the past	1	2	3	4	5
22.	I feel that there is simply too much to do	1	2	3	4	5
23.	I feel that there are simply too many decisions to make	1	2	3	4	5
24.	I feel housebound	1	2	3	4	5
25.	I feel upset with my family member	1	2	3	4	5
26.	I feel unsure about how to deal with my family member	1	2	3	4	5
27.	I feel that my family member needs more than I can give in terms of care	1	2	3	4	5
28.	I feel that accepting care services is a trade-off for me	1	2	3	4	5
29.	I feel that it is difficult for me to ask for help with caregiving	1	2	3	4	5
30.	I worry about my financial situation	1	2	3	4	5
31.	I feel that I can trust health and social services to care for my family member	1	2	3	4	5
32.	I feel worried about the future	1	2	3	4	5
33.	I feel comforted by my religion or beliefs	1	2	3	4	5
34.	I feel that my own needs are not important to others	1	2	3	4	5
35.	I feel that I can't cope	1	2	3	4	5
36.	I feel lost	1	2	3	4	5
37.	I feel worried if I am away from my family member	1	2	3	4	5
38.	I feel that nothing helps me feel better	1	2	3	4	5

39.	I feel as if my family member had changed from who he/she used to be and this affects me negatively	1	2	3	4	5
40.	I feel worried about my family member's HEALTH	1	2	3	4	5
41.	I feel worried about my family member's HAPPINESS	1	2	3	4	5
42.	I feel worried about my family member's QUALITY OF LIFE	1	2	3	4	5
43.	I feel worried about my family member's SAFETY	1	2	3	4	5
44.	I don't expect anything of my life anymore	1	2	3	4	5
45.	I feel I deserve some gratitude for everything that I do for my family member	1	2	3	4	5
46.	I feel sad or depressed	1	2	3	4	5
47.	I feel there has been a change of roles in my relationship with my family member	1	2	3	4	5
48.	I feel as if I have lost the boundaries between my caring role and my own life	1	2	3	4	5
49.	I feel that dementia has had a negative impact on my life	1	2	3	4	5
50.	I feel as if I always have to put my family member first	1	2	3	4	5
51.	I feel that I have failed as a carer	1	2	3	4	5
52.	I feel that I have failed as a family member	1	2	3	4	5
53.	I feel acceptance of the situation that I am in	1	2	3	4	5
54.	I feel acceptance towards the changes in my family member	1	2	3	4	5
55.	I feel that my family member controls me and my decisions	1	2	3	4	5
56.	I feel that I have lost control over the everyday events and decisions in my life	1	2	3	4	5
57.	I feel that I am not safe	1	2	3	4	5
58.	I feel exhausted	1	2	3	4	5
59.	I feel that dementia has brought something positive to my life	1	2	3	4	5
60.	I try to think positively	1	2	3	4	5
61.	I feel as if I have no choice about being a	1	2	3	4	5

	carer					
62.	I feel that I am the only person that my family member can rely on	1	2	3	4	5
63.	I feel as if I have had a 'duty of care' placed on me	1	2	3	4	5
64.	I feel that my family member expects me to do all the caring for him/her	1	2	3	4	5
65.	I feel frustrated that I am not fulfilling my own needs and aspirations	1	2	3	4	5
66.	I feel that I have given up things that I enjoy because my family member needs me	1	2	3	4	5

Section 4

The next set of questions asks how *satisfied* you are with different aspects of your life. Please choose the option that best describes how satisfied you are with each aspect of your life. “Very satisfied” (number 5) means the higher satisfaction possible and “Very dissatisfied” (number 1) means the lowest satisfaction possible.

		Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
67.	How satisfied are you with the comfort you receive from your religion/beliefs?	1	2	3	4	5
68.	How satisfied are you with your close relationships with your FAMILY?	1	2	3	4	5
69.	How satisfied are you with your close relationships with your FRIENDS?	1	2	3	4	5
70.	How satisfied are you with the help you receive from other family members and friends?	1	2	3	4	5
71.	How satisfied are you with how much time you can spend with other family members and friends?	1	2	3	4	5
72.	How satisfied are you with your confidence?	1	2	3	4	5
73.	How satisfied are you with how well you can cope?	1	2	3	4	5
74.	How satisfied are you with what you have achieved in life?	1	2	3	4	5
75.	How satisfied are you with your own happiness?	1	2	3	4	5
76.	How satisfied are you that you do the things you want to?	1	2	3	4	5
77.	How satisfied are you with your relationship with the family member you care for?	1	2	3	4	5
78.	How satisfied are you with your own life?	1	2	3	4	5
79.	How satisfied are you with the support received from health and social services for your family member?	1	2	3	4	5

80.	How satisfied are you with the care you provide to your family member?	1	2	3	4	5
81.	How satisfied are you with yourself?	1	2	3	4	5
82.	How satisfied are you with the quality of your sleep?	1	2	3	4	5
83.	How satisfied are you with being a carer?	1	2	3	4	5
84.	How satisfied are you with your health?	1	2	3	4	5
85.	How satisfied are you with the support you receive from health services for your own needs?	1	2	3	4	5
86.	How satisfied are you with how much you can look after yourself?	1	2	3	4	5
87.	How satisfied are you with how safe you feel?	1	2	3	4	5
88.	How satisfied are you with the control you have over your own life?	1	2	3	4	5
89.	How satisfied are you with your overall quality of life?	1	2	3	4	5

Please tell us:

1) **What do you think would most help to improve your quality of life as a carer?**

2) **Is there anything else that is related to your caring role or your quality of life that you feel hasn't been covered in this questionnaire.**

Thank you for your time.

APPENDIX 3 – TEST VERSION OF THE DQOL-OC

Development of the 'Dementia Quality of Life Scale for Older Family Carers' (DQoL-OC) and Evaluation of its Psychometric Properties

DATE: ___/___/______

START TIME: _____h _____min

The Dementia Quality of Life Scale for Older Family Carers (DQoL-OC)

Thank you for taking the time to fill in this questionnaire. The questionnaire has four sections. The first section will ask for some factual information. The next three will ask about different aspects of your role as a carer, how satisfied you are, and how you feel about various aspects of your life.

Completing all the questions is desirable, but you do not need to answer any question that causes you distress or if you just do not wish to give an answer.

If you are unsure about which response to give to a question, **please choose the one** that seems the most honest and appropriate answer to you at the moment.

There is no right or wrong answer.

Section 1

This section asks for information about yourself and the care you provide. Please answer all the questions, and do not spend too much time on any one item.

a)	What is your date of birth?	.... / .... / .... day month year
b)	What is your gender?	☐ Female ☐ Male ☐ I prefer not to say
c)	What is the highest qualification you hold?	☐ No qualifications ☐ Vocational ☐ GCSE ☐ A level ☐ Diploma ☐ University degree ☐ Postgraduate degree ☐ Other: ___________________
d)	What is your relationship status?	☐ Single ☐ Married ☐ Partnership ☐ Separated ☐ Divorced ☐ Widowed
e)	Do you currently work somewhere besides being a carer?	☐ Yes ☐ No ☐ Stopped working to be a carer ☐ Never had a job ☐ Retired
f)	Are you currently and regularly providing care for MORE THAN ONE PERSON in a non-formal caring capacity? (including children or grandchildren)	☐ No ☐ Yes ☐ ☐ If yes, WHO ELSE do you provide care for? ___________________________________ ___________________________________
g)	What is your ethnic group?	☐ White ☐ Afro-Caribbean ☐ Asian ☐ Arab ☐ Other ethnic group:__________ ☐ I prefer not to say
h)	Has your doctor told you that you have any disease or disorder currently affecting you?	☐ Yes ☐ No IF YES, what is (are) the disease(s)? ___________________________________
i)	Do you regularly	☐ Difficulties hearing

	experience any of these problems? (Please tick ALL APPLICABLE)	☐ Difficulties seeing ☐ Difficulties walking ☐ Pain ☐ Fatigue ☐ Insomnia ☐ Other (s): _________________
j)	Do you live with the family member you care for?	☐ Yes ☐ No
k)	What is your relationship with the family member you care for?	☐ Spouse ☐ Son or daughter ☐ Sibling ☐ Other:_____________________
l)	Approximately how long have you been caring for your family member?	☐ Less than 1 year ☐ 1 to 3 years ☐ 4 to 6 years ☐ 7 to 10 years ☐ 10+ years
m)	How long is it since you first suspected the family member you care for has dementia?	☐ Less than 1 year ☐ 1 to 3 years ☐ 4 to 6 years ☐ 7 to 10 years ☐ 10+ years
n)	What type of dementia was your family member diagnosed with? (Please tick ALL APPLICABLE)	☐ Alzheimer’s disease ☐ Frontotemporal dementia ☐ Vascular dementia ☐ Lewy body dementia ☐ Other type:_____________ ☐ Still not defined the type ☐ I don’t remember
o)	On average, how many HOURS PER DAY do you care for your family member? (‘care’ means anything that you need to do for your family member because he/she is not able to do this on their own anymore)	☐ ☐ Less than 3 hours ☐ 3 to 6 hours ☐ 6 to 12 hours ☐ 12 to 24 hours
p)	On average, how many DAYS PER WEEK do you care for your family member?	☐ 1 ☐ 2 to 3 ☐ 4 to 5 ☐ 6 to 7

Section 2

Instructions

We want to know how you feel about your role as a carer, your health and your quality of life at this moment in time. Please keep in mind your values, hopes, pleasures, and concerns, and circle the number that most accurately represents your situation.

Example

Thinking about your role as a carer, a question might ask:

How often do you have access to appropriate information about dementia and caring?	Never 1	Rarely 2	Occasionally 3	Frequently 4	Very frequently 5

In this question, you should circle the number that BEST FITS how often you had access to appropriate information about dementia and caring. So you would circle the number that corresponds to the option "Rarely" if you rarely had access to appropriate information about dementia and caring, as follows:

How often do you have access to appropriate information about dementia and caring?	Never 1	Rarely [✓ 2]	Occasionally 3	Frequently 4	Very frequently 5

In this case, "Never" (number 1) means the lowest possible frequency of receiving appropriate information about dementia and caring, and "Very frequently" (number 5) the highest frequency possible.

Please read each question, assess your feelings, and circle the number on the questionnaire for each question that gives the best answer for you at this moment in time.

This first set of questions asks for information about different aspects associated with your role as a carer of a family member with dementia. Please circle the number that best describes your role as a carer.

		Not at all	**A little**	**Moderately**	**Mostly**	**As much as needed**
1.	Overall, how much appropriate support is the person that you care for given by Health and/or Social Services?	1	2	3	4	5
2.	How many of your requests have immediate responses from health and social services?	1	2	3	4	5
3.	How much access do you have to appropriate dementia care facilities?	1	2	3	4	5
4.	How much access do you have to health professionals that have enough knowledge of dementia and understand its implications?	1	2	3	4	5
5.	How much information do you receive about dementia and caring?	1	2	3	4	5
6.	How much support are you given by family or friends?	1	2	3	4	5
7.	How much appropriate health support do you receive for your own needs?	1	2	3	4	5
8.	How much respite from caring for your family member do you have?	1	2	3	4	5
		Never	**Rarely**	**Occasionally**	**Frequently**	**Always**
9.	How often does the caring negatively affect your relationships with family or/and friends?	1	2	3	4	5
10.	How often is your financial situation affected by the demands of caring?	1	2	3	4	5
11.	How often do you experience a conflict of interest between what you want and what the person you care for	1	2	3	4	5

	wants?					
12.	How often does the person that you care for cooperate with their everyday caring needs?	1	2	3	4	5
13.	How often are you restricted by the need to maintain a regimented daily routine?	1	2	3	4	5
14.	How often have you had to change your own life and interests to fit around the needs of the person you care for?	1	2	3	4	5
15.	How often is caring physically hard on you?	1	2	3	4	5
16.	How often do you feel burdened by the care demands?	1	2	3	4	5
		Totally dependent	**Mostly dependent**	**Partially (in) dependent**	**Mostly independent**	**Totally independent**
17.	How much does the person you care for depend on you for his/her daily activities?	1	2	3	4	5
		Totally uncontrolled	**Mostly uncontrolled**	**Partially (un)controlled**	**Mostly controlled**	**Totally controlled**
18.	How would you describe your family member's dementia symptoms at this moment? (e.g. regarding memory loss, difficulty in communicating, inability to reason, disorientation)	1	2	3	4	5
		Initial stage	**Moderate stage**	**Advanced stage**		
19.	How would you describe the stage of your family member's dementia at the moment?	1	2	3		

Section 3

This next set of questions asks how you feel about different aspects of your life. Please choose the option that best describes how you have felt about each area of your life as a carer.

		Very frequently	**Frequently**	**Occasionally**	**Rarely**	**Never**
1.	I feel worried about my health	1	2	3	4	5
2.	I feel that I haven't got the same energy that I used to have in the past	1	2	3	4	5
3.	I feel that dementia has had a negative impact on my life	1	2	3	4	5
4.	I feel that there is simply too much to do	1	2	3	4	5
5.	I feel exhausted	1	2	3	4	5
6.	I feel as if the person I care for has changed from who she or he used to be and this affects me negatively	1	2	3	4	5
7.	I feel that the relationship with the person that I care for has deteriorated since the dementia started	1	2	3	4	5
8.	I feel unsure about how to deal with the person I care for	1	2	3	4	5
9.	I feel as if I have 'swapped roles' in the relationship with the person that I care for	1	2	3	4	5
10.	I feel that the person I care for upsets me	1	2	3	4	5
11.	I feel worried about my financial situation	1	2	3	4	5
12.	I feel worried about the future	1	2	3	4	5
13.	I feel that I cannot help myself	1	2	3	4	5
14.	I feel that it is difficult for me to ASK FOR or ACCEPT extra help with caring from anyone else	1	2	3	4	5
15.	I feel that nothing helps me to feel better	1	2	3	4	5
16.	I feel as if I have failed as a family carer	1	2	3	4	5
17.	I feel that the person that I care for needs more than I can give in terms of care	1	2	3	4	5

18.	I feel worried about the HEALTH of the person I care for	1	2	3	4	5
19.	I feel worried about the HAPPINESS of the person I care for	1	2	3	4	5
20.	I feel worried about the QUALITY OF LIFE of the person I care for	1	2	3	4	5
21.	I feel worried about the SAFETY of the person I care for	1	2	3	4	5
22.	I feel worried if I am away from the person I care for	1	2	3	4	5
23.	I feel as if I have a ‘duty of care placed on me	1	2	3	4	5
24.	I feel I have no choice about being a carer	1	2	3	4	5
25.	I feel that the person that I care for controls me and my decisions	1	2	3	4	5
26.	I feel like I always have to put the person that I care for first	1	2	3	4	5
27.	I feel that I have lost control over the everyday events and decisions in my life	1	2	3	4	5
28.	I feel that I am the only person that the person that I care for can rely on	1	2	3	4	5
29.	I feel that the person that I care for expects me to do all the caring for him/her	1	2	3	4	5
30.	I feel that I am not safe in my caring role	1	2	3	4	5
31.	I feel housebound	1	2	3	4	5
32.	I feel that I have given up things that I enjoy because the person that I care for needs me	1	2	3	4	5
33.	I feel frustrated that I am not fulfilling my own needs and aspirations	1	2	3	4	5
34.	I don’t expect anything of my life anymore	1	2	3	4	5
35.	I feel as if the boundaries between my own life and my caring role have become blurred	1	2	3	4	5
36.	I feel that caring has affected my relationship with friends	1	2	3	4	5
37.	I feel that caring has affected my relationship with family	1	2	3	4	5
38.	I feel that other people do not understand the situation I am now in	1	2	3	4	5
39.	I feel that I deserve some gratitude for everything that I do as a carer	1	2	3	4	5

40.	I feel that my own needs are not important to others	1	2	3	4	5
41.	I feel sad or depressed	1	2	3	4	5
42.	I feel isolated	1	2	3	4	5
43.	I feel lonely	1	2	3	4	5
44.	I feel that I can trust health and social services to care for my family member	1	2	3	4	5
45.	I feel that my religion or spiritual beliefs bring me comfort	1	2	3	4	5
46.	I feel able to cope	1	2	3	4	5
47.	I feel acceptance towards the changes in my family member	1	2	3	4	5
48.	I feel acceptance of the situation that I and the person that I care for are in	1	2	3	4	5
49.	I feel that dementia has brought something positive to my life	1	2	3	4	5
50.	I feel rewarded for being able to care for my family member	1	2	3	4	5
51.	I appreciate being a carer	1	2	3	4	5
52.	I try to think positively about my caring situation	1	2	3	4	5
53.	I feel supported	1	2	3	4	5
54.	I feel frustrated	1	2	3	4	5
55.	I feel guilty	1	2	3	4	5
56.	I feel stressed	1	2	3	4	5

Section 4

The next set of questions asks how satisfied you are with different aspects of your life as a carer. Please choose the option that best describes your situation. "Very satisfied" (number 5) means the highest satisfaction possible and "very dissatisfied" (number 1) means the lowest satisfaction possible.

		Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
57.	How satisfied are you with the comfort you receive from your religion or beliefs?	1	2	3	4	5
58.	How satisfied are you with your close relationships with your FAMILY?	1	2	3	4	5
59.	How satisfied are you with your close relationships with your FRIENDS?	1	2	3	4	5
60.	How satisfied are you with the help you receive from other family members and friends?	1	2	3	4	5
61.	How satisfied are you with how much time you can spend with other family members and friends?	1	2	3	4	5
62.	How satisfied are you with how much confidence you feel with your caring role?	1	2	3	4	5
63.	How satisfied are you with how well you can cope with your caring situation?	1	2	3	4	5
64.	How satisfied are you with what you have achieved in life?	1	2	3	4	5
65.	How satisfied are you with your own happiness?	1	2	3	4	5
66.	How satisfied are you that you can do the things you want to?	1	2	3	4	5
67.	How satisfied are you with your relationship with the person that you care for?	1	2	3	4	5
68.	How satisfied are you with your own life?	1	2	3	4	5
69.	How satisfied are you with the SUPPORT that the person you care for receives from health and/or social services?	1	2	3	4	5
70.	How satisfied are you with the TREATMENT that your family member receives from health services?	1	2	3	4	5

71.	How satisfied are you with the care you provide to your family member?	1	2	3	4	5
72.	Overall, how satisfied are you with how much you can be yourself?	1	2	3	4	5
73.	How satisfied are you with how well you can sleep?	1	2	3	4	5
74.	How satisfied are you with your role as a carer?	1	2	3	4	5
75.	How satisfied are you with your own health?	1	2	3	4	5
76.	How satisfied are you with the support you receive from health services for YOUR OWN NEEDS?	1	2	3	4	5
77.	How satisfied are you with how much you can care for yourself?	1	2	3	4	5
78.	How satisfied are you with how safe you feel in your caring role?	1	2	3	4	5
79.	How satisfied are you with how much control you have over your own life?	1	2	3	4	5
80.	How satisfied are you with feeling part of your local community or groups?	1	2	3	4	5
81.	How satisfied are you with your overall quality of life?	1	2	3	4	5

Please tell us:

1. **What do you think would most help to improve your quality of life as a carer?**

2. **Is there anything else that is related to your caring role or your quality of life that you feel hasn't been covered in this questionnaire?**

Thank you for your time.

APPENDIX 4 – TABLE OF INITIAL CORRECTED ITEM–TOTAL CORRELATIONS

Table of initial corrected item–total correlations

Items	Corrected Item–total correlation	Cronbach's α if Item Deleted
1. How much appropriate support is your family member given by health and social services?	.232	.974
2. How much of your emergency requests have immediate responses from health and social services?	.322	.974
3. How much access do you have to appropriate dementia care facilities?	.330	.974
4. How much access do you have to health professionals that have enough knowledge of dementia and understand its implications?	.272	.974
5. How much information do you receive about dementia and caring?	.268	.974
6. How much support are you given by other family members or friends?	.367	.974
7. How much appropriate health support do you receive for your own needs?	.336	.974
8. How much respite from caring for your family member do you have?	.279	.974
9. How often does the caring negatively affect your relationships with family or/and friends?	.609	.974
10. How often is your financial situation affected by the demands of caring?	.560	.974
11. How often do you experience a conflict of interest between what you want and what your family member wants?	.510	.974
12. How often does your family member cooperate with the everyday caring needs?	.365	.974
13. How often are you restricted by the need to maintain a regimented daily routine?	.427	.974
14. How often have you had to change your own life and interests to fit around your family member's needs?	.487	.974
15. How often is caring physically hard on you?	.563	.974
16. How often do you feel burdened by the care demands?	.693	.974

(items 17, 18 and 19 were excluded from the analysis, as detailed in Chapter 6)

Items	Corrected Item–total correlation	Cronbach's α if Item Deleted
20. I feel worried about my health	.569	.974
21. I feel that I haven't got the same vigour that I used to have in the past	.440	.974
22. I feel that dementia has had a negative impact on my life	.636	.974
23. I feel that there is simply too much to do	.621	.974
24. I feel exhausted	.622	.974
25. I feel as if my family member has changed from who she/he used to be and this affects me negatively	.645	.974
26. I feel that the relationship with my family member has deteriorated since the dementia	.601	.974
27. I feel unsure about how to deal with my family member	.645	.974
28. I feel as if I had swapped roles in the relationship with my family member	.402	.974
29. I feel upset with my family member	.547	.974
30. I feel worried about my financial situation	.570	.974
31. I feel worried about the future	.635	.974
32. I feel that I cannot help myself	.689	.974
33. I feel that it is difficult for me to ask for or to accept extra help with the caring	.518	.974

34. I feel that nothing helps me to feel better	.707	.974
35. I feel as if I have failed as a family carer	.637	.974
36. I feel that my family member needs more than I can give in terms of care	.653	.974
37. I feel worried about the HEALTH of my cared for	.397	.974
38. I feel worried about the HAPPINESS of my cared for	.452	.974
39. I feel worried about the QUALITY OF LIFE of my cared for	.449	.974
40. I feel worried about the SAFETY of my cared for	.468	.974
41. I feel worried if I am away from my family member	.461	.974
42. I feel as if I have a 'duty of care' placed on me	.528	.974
43. I feel I have no choice in being a carer	.607	.974
44. I feel that my family member controls me and my decisions	.678	.974
45. I feel like I always have to put my family member first	.496	.974
46. I feel that I have lost control over the everyday events and decisions in my life	.755	.974
47. I feel that I am the only person that my family member can rely on	.542	.974
48. I feel as if my family member expects me to do all the caring for him/her	.579	.974
49. I feel that I am not safe in my caring role	.519	.974
50. I feel housebound	.617	.974
51. I feel that I have given up things that I enjoy because my family member needs me	.718	.974
52. I feel frustrated that I am not fulfilling my own needs and aspirations	.697	.974
53. I don't expect anything of my life anymore	.713	.974
54. I feel as if the boundaries between my own life and my caring role have become blurred	.682	.974
55. I feel that caring has affected my relationship with friends	.700	.974
56. I feel that caring has affected my relationship with family	.651	.974
57. I feel that other people do not understand the situation that I am now in	.662	.974
58. I feel that I deserve some gratitude for everything that I do for my family member	.583	.974
59. I feel that my own needs are not important to others	.664	.974
60. I feel sad or depressed	.638	.974
61. I feel isolated	.730	.974
62. I feel lonely	.673	.974
63. I feel that I can trust health and social services to care for my family member	.121	.974
64. I feel comforted by my religion or beliefs	.140	.975
65. I feel able to cope	.475	.974
66. I feel acceptance towards the changes in my family member	.410	.974
67. I feel acceptance towards the situation that me and my family member are in	.382	.974
68. I feel that dementia has brought something positive to my life	.266	.974
69. I feel rewarded for being able to care for my family member	.372	.974
70. I appreciate being a carer	.455	.974
71. I try to think positively about my caring situation	.426	.974
72. I feel supported	.567	.974
73. I feel frustrated	.586	.974
74. I feel guilty	.545	.974
75. I feel stressed	.593	.974

76. How satisfied are you with the comfort you receive from your religion or beliefs?	.339	.974
77. How satisfied are you with your close relationships with your FAMILY?	.420	.974
78. How satisfied are you with your close relationships with your FRIENDS?	.454	.974
79. How satisfied are you with the help you receive from other family members and friends?	.494	.974
80. How satisfied are you with how much time you can spend with other family members and friends?	.586	.974
81. How satisfied are you with how much confidence you feel with your caring role?	.499	.974
82. How satisfied are you with how well you can cope with your caring situation?	.553	.974
83. How satisfied are you with what you have achieved in life?	.509	.974
84. How satisfied are you with your own happiness?	.659	.974
85. How satisfied are you that you can do the things you want to?	.714	.974
86. How satisfied are you with the relationship with the family member you care for?	.539	.974
87. How satisfied are you with your own life?	.707	.974
88. How satisfied are you with the support that your family member receives from health and social services?	.418	.974
89. How satisfied are you with feeling part of your local community or groups?	.404	.974
90. How satisfied are you with the care you provide to your family member?	.304	.974
91. How satisfied are you with the TREATMENT that your family member receives from health services?	.673	.974
92. How satisfied are you with how well you can sleep?	.494	.974
93. How satisfied are you with your role as a carer?	.599	.974
94. How satisfied are you with your own health?	.461	.974
95. How satisfied are you with the support you receive from health services for your own needs?	.457	.974
96. How satisfied are you with how much you can look after yourself?	.520	.974
97. How satisfied are you with how safe you feel in your caring role?	.502	.974
98. How satisfied are you with how much control you have over your life?	.700	.974
99. Overall, how satisfied are you with how much you can be yourself?	.570	.974
100. How satisfied are you with your overall quality of life?	.765	.974

APPENDIX 5 – TABLE OF ITEM COMMUNALITIES FOR A SEVEN-FACTOR SOLUTION

Table of item communalities for a seven-factor solution

Items	Initial	Extraction
1. How much appropriate support is your family member given by health and social services?	.776	.554
2. How much of your emergency requests have immediate responses from health and social services?	.792	.479
3. How much access do you have to appropriate dementia care facilities?	.797	.585
4. How much access do you have to health professionals that have enough knowledge of dementia and understand its implications?	.791	.627
5. How much information do you receive about dementia and caring?	.801	.531
6. How much support are you given by other family members or friends?	.818	.603
7. How much appropriate health support do you receive for your own needs?	.704	.404
8. How much respite from caring for your family member do you have?	.693	.239
9. How often does the caring negatively affect your relationships with family or/and friends?	.806	.460
10. How often is your financial situation affected by the demands of caring?	.816	.449
11. How often do you experience a conflict of interest between what you want and what your family member wants?	.689	.331
12. How often does your family member cooperate with the everyday caring needs?	.594	.158
13. How often are you restricted by the need to maintain a regimented daily routine?	.691	.340
14. How often have you had to change your own life and interests to fit around your family member's needs?	.839	.452
15. How often is caring physically hard on you?	.794	.517
16. How often do you feel burdened by the care demands?	.817	.643
(items 17, 18 and 19 were excluded from the analysis, as detailed in Chapter 6)		
20. I feel worried about my health	.794	.566
21. I feel that I haven't got the same vigour that I used to have in the past	.778	.477
22. I feel that dementia has had a negative impact on my life	.832	.531
23. I feel that there is simply too much to do	.763	.483
24. I feel exhausted	.835	.639
25. I feel as if my family member has changed from who she/he used to be and this affects me negatively	.813	.579
26. I feel that the relationship with my family member has deteriorated since the dementia	.790	.489
27. I feel unsure about how to deal with my family member	.813	.568
28. I feel as if I had swapped roles in the relationship with my family member	.712	.283
29. I feel upset with my family member	.778	.514
30. I feel worried about my financial situation	.762	.416
31. I feel worried about the future	.809	.495
32. I feel that I cannot help myself	.876	.579
33. I feel that it is difficult for me to ask for or to accept extra help with the caring	.737	.289
34. I feel that nothing helps me to feel better	.864	.615
35. I feel as if I have failed as a family carer	.826	.521
36. I feel that my family member needs more than I can give in terms of care	.817	.587
37. I feel worried about my family member's HEALTH	.770	.352
38. I feel worried about my family member's HAPPINESS	.855	.429
39. I feel worried about my family member's QUALITY OF	.821	.404

LIFE		
40. I feel worried about my family member's SAFETY	.716	.411
41. I feel worried if I am away from my family member	.775	.366
42. I feel as if I have a 'duty of care' placed on me	.784	.437
43. I feel I have no choice in being a carer	.830	.462
44. I feel that my family member controls me and my decisions	.786	.545
45. I feel like I always have to put my family member first	.795	.482
46. I feel that I have lost control over the everyday events and decisions in my life	.887	.677
47. I feel that I am the only person that my family member can rely on	.824	.555
48. I feel as if my family member expects me to do all the caring for him/her	.767	.453
49. I feel that I am not safe in my caring role	.800	.450
50. I feel housebound	.832	.475
51. I feel that I have given up things that I enjoy because my family member needs me	.860	.642
52. I feel frustrated that I am not fulfilling my own needs and aspirations	.880	.596
53. I don't expect anything of my life anymore	.867	.621
54. I feel as if the boundaries between my own life and my caring role have become blurred	.850	.578
55. I feel that caring has affected my relationship with friends	.869	.644
56. I feel that caring has affected my relationship with family	.870	.582
57. I feel that other people do not understand the situation that I am now in	.819	.519
58. I feel that I deserve some gratitude for everything that I do for my family member	.805	.397
59. I feel that my own needs are not important to others	.779	.520
60. I feel sad or depressed	.809	.474
61. I feel isolated	.900	.640
62. I feel lonely	.865	.531
63. I feel that I can trust health and social services to care for my family member	.645	.213
64.I feel comforted by my religion or beliefs	.787	.297
65. I feel able to cope	.729	.448
66. I feel acceptance towards the changes in my family member	.874	.321
67. I feel acceptance towards the situation that me and my family member are in	.882	.270
68. I feel that dementia has brought something positive to my life	.733	.315
69. I feel rewarded for being able to care for my family member	.841	.523
70. I appreciate being a carer	.869	.600
71. I try to think positively about my caring situation	.739	.405
72. I feel supported	.854	.551
73. I feel frustrated	.857	.495
74. I feel guilty	.840	.403
75. I feel stressed	.848	.485
76. How satisfied are you with the comfort you receive from your religion or beliefs?	.781	.227
77. How satisfied are you with your close relationships with your FAMILY?	.759	.493
78. How satisfied are you with your close relationships with your FRIENDS?	.736	.434
79. How satisfied are you with the help you receive from other family members and friends?	.845	.658
80. How satisfied are you with how much time you can spend with other family members and friends?	.805	.600
81. How satisfied are you with how much confidence you	.825	.590

feel with your caring role?		
82. How satisfied are you with how well you can cope with your caring situation?	.811	.623
83. How satisfied are you with what you have achieved in life?	.764	.465
84. How satisfied are you with your own happiness?	.874	.614
85. How satisfied are you that you can do the things you want to?	.873	.724
86. How satisfied are you with the relationship with the family member you care for?	.819	.560
87. How satisfied are you with your own life?	.897	.718
88. How satisfied are you with the support that your family member receives from health and social services?	.816	.493
89. How satisfied are you with feeling part of your local community or groups?	.727	.346
90. How satisfied are you with the care you provide to your family member?	.719	.318
91. How satisfied are you with the TREATMENT that your family member receives from health services?	.828	.599
92. How satisfied are you with how well you can sleep?	.684	.301
93. How satisfied are you with your role as a carer?	.838	.617
94. How satisfied are you with your own health?	.765	.432
95. How satisfied are you with the support you receive from health services for your own needs?	.728	.387
96. How satisfied are you with how much you can look after yourself?	.765	.399
97. How satisfied are you with how safe you feel in your caring role?	.782	.464
98. How satisfied are you with how much control you have over your life?	.883	.748
99. Overall, how satisfied are you with how much you can be yourself?	.811	.449
100. How satisfied are you with your overall quality of life?	.887	.711

APPENDIX 6 – TABLE OF REPRODUCED CORRELATION MATRIX AND RESIDUALS

Table of reproduced correlation matrix and residuals (22 items)

	Items	46	16	51	61	54	25	15	31	20	10	9	82	14	11	86	100	24	43	92	60	74	81
RC	46	.624[b]	.609	.602	.598	.581	.545	.492	.512	.489[b]	.467	.479	.453	.442	.442	.435	.561	.530[b]	.488	.398	.500	.421	.394
	16		.595[b]	.588	.584	.567	.533	.481	.500	.477	.456[b]	.468	.442	.432	.431	.425	.548	.517	.476[b]	.389	.488	.411	.385
	51			.581[b]	.578	.561	.527	.475	.495	.472	.451	.463[b]	.437	.427	.427	.420	.542	.511	.471	.384[b]	.482	.407	.380
	61				.574[b]	.557	.523	.472	.491	.469	.447	.460	.434[b]	.424	.424	.417	.538	.508	.468	.382	.479[b]	.404	.378
	54					.541[b]	.508	.458	.477	.455	.435	.446	.422	.412[b]	.411	.405	.523	.493	.454	.371	.465	.392[b]	.367
	25						.477[b]	.430	.448	.427	.408	.419	.396	.387	.386[b]	.380	.491	.463	.426	.348	.437	.368	.344[b]
	15							.388[b]	.404	.386	.368	.378	.357	.349	.349	.343[b]	.443	.418	.385	.314	.394	.332	.311
	31								.421[b]	.401	.383	.394	.372	.363	.363	.357	.461[b]	.435	.401	.327	.410	.346	.323
	20									.383	.366	.375	.355	.346	.346	.341	.440	.415	.382	.312	.391	.330	.308
	10										.349	.359	.339	.331	.330	.325	.420	.396	.365	.298	.374	.315	.295
	09											.368	.348	.340	.339	.334	.431	.407	.375	.306	.384	.324	.303
	82												.329	.321	.321	.316	.408	.385	.354	.289	.363	.306	.286
	14													.313	.313	.308	.398	.375	.346	.282	.354	.299	.279
	11														.313	.308	.398	.375	.345	.282	.354	.298	.279
	86															.303	.392	.370	.340	.278	.349	.294	.275
	100																.505	.477	.439	.358	.450	.379	.354
	24																	.450	.414	.338	.424	.358	.334
	43																		.381	.311	.391	.329	.308
	92																			.254	.319	.269	.251
	60																				.400	.337	.315

Table of reproduced correlation matrix and residuals (22 items)

	74																					.284	.266
	81																						.249
RE	46		-.031	.032	.037	.068	-.020	-.044	.057	-.041	.040	.040	-.047	.085	-.012	-.032	-.027	-.049	-.001	-.001	-.026	-.018	-.028
	16			-.036	-.012	-.034	.036	.115	-.053	.088	-.064	-.043	-.028	-.008	-.005	-.013	-.017	.118	.031	-.041	.051	-.041	-.025
	51				.030	.136	.014	.003	-.028	-.034	.020	-.048	-.098	.151	.011	-.041	.021	-.054	.051	.014	-.075	-.016	-.100
	61					.035	-.008	.013	-.047	.044	-.079	-.053	-.100	.006	-.007	-.040	.006	-.017	-.032	.017	.176	.040	-.046
	54						-.023	-.062	-.025	-.036	-.030	-.029	-.069	.080	.038	.016	-.009	-.039	.035	-.009	-.050	.004	-.039
	25							-.050	.003	-.066	-.051	-.025	-.030	.031	-.060	.063	.025	.004	.079	.007	.056	.021	-.011
	15								.002	.181	.151	.001	-.018	.100	-.053	-.108	-.020	.158	-.087	-.085	-.047	-.084	-.133
	31									.037	.028	.004	.046	-.052	-.069	-.063	-.024	.079	.055	.042	.005	.020	-.005
	20										.027	-.116	.095	-.088	-.060	-.104	-.004	.160	-.028	.034	-.020	-.060	-.052
	10											.231	-.001	.149	.023	-.141	.021	4.821E-005	-.057	-.024	-.094	-.104	-.043
	09												-.050	.121	.175	.068	-.016	-.030	-.067	-.006	-.091	.040	-.027
	82													-.179	-.021	.137	.087	-.064	.015	.004	.041	.026	.404
	14														.111	-.108	-.055	-.049	-.063	.017	-.206	-.031	-.095
	11															.125	-.119	-.047	-.014	.063	-.063	.035	.030
	86																.019	-.100	.070	.016	-.011	.087	.264
	100																	-.041	.056	-.005	.090	-.029	.045
	24																		-.036	.066	.041	-.015	-.113
	43																			-.057	-.017	-.020	.046
	92																				-.013	-.026	-.013
	60																					.174	.039
	74																						.010
	81																						

b. Reproduced communalities

c. Residuals are computed between observed and reproduced correlations. There are 90 (38.0%) non-redundant residuals with absolute values > 0.05.

RC: reproduced correlation

RE: residuals

APPENDIX 7 – THE FINAL VERSION OF THE ‘DEMENTIA QUALITY OF LIFE SCALE FOR OLDER FAMILY CARERS’ (DQOL-OC)

Dementia Quality of Life Scale for Older Family Carers (DQoL-OC)

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Thank you for taking the time to fill in this questionnaire. The questionnaire has four sections. The first section will ask for some factual information. The next three will ask about different aspects of your role as a carer, how satisfied you are, and how you feel about various aspects of your life.

Please answer all the questions. If you are unsure about which response to give to a question, **please choose the ONE** that seems most appropriate (this is often your initial response).

Section 1

This section asks for information **about yourself and the care you provide**. Please answer all the questions, and do not spend too much time on any one item.

a)	What is your date of birth?	………../……….. /……….. day month year
b)	What is your gender?	☐ Female ☐ Male ☐ I prefer not to say
c)	What is your ethnic group?	☐ White ☐ Afro-Caribbean ☐ Asian ☐ Arab ☐ Other ethnic group:__________ ☐ I prefer not to say
d)	What is the highest qualification you hold?	☐ No qualifications ☐ Vocational ☐ GCSE ☐ A level ☐ Diploma ☐ University degree ☐ Postgraduate degree ☐ Other:
e)	Are you currently and regularly providing care for MORE THAN ONE PERSON in a non-formal caring capacity? (including children or grandchildren)	☐ No ☐ Yes
f)	Do you live with the family member you care for?	☐ No ☐ Yes
g)	What is your relationship with the family member you care for?	☐ Spouse ☐ Son or daughter ☐ Sibling ☐ Other:
h)	Approximately how long have you being caring for your family member?	☐ Less than 1 year ☐ 1 to 3 years ☐ 4 to 6 years ☐ 7 to 10 years ☐ More than 10 years
i)	On average, how many HOURS PER DAY do you care for your family member? ('care' means anything that you need to do for your family member because he/she is not able to do this on their own anymore)	☐ Less than 3 hours ☐ 3 to 6 hours ☐ 6 to 12 hours ☐ More than 12 hours
j)	On average, how many DAYS PER WEEK do you care for your family member?	☐ 1 day ☐ 2 to 3 days ☐ 4 to 5 days ☐ 6 to 7 days

k)	How would you describe your family member’s dementia symptoms at this moment? (e.g. regarding memory loss, difficulty in communicating, inability to reason, disorientation)	☐ Totally uncontrolled ☐ Mostly uncontrolled ☐ Partially (un)controlled ☐ Mostly controlled ☐ Totally controlled
l)	How would you describe the stage of your family member’s dementia at the moment?	☐ Initial stage ☐ Moderate stage ☐ Advanced stage

Section 2

Instructions

We want to know how you feel about your role as a carer, your health, and your quality of life at this moment in time. Please keep in mind your values, hopes, pleasures, and concerns, and circle the number that most accurately represents your situation.

Example

Thinking about your role as a carer, a question might ask:

	Always	**Frequently**	**Occasionally**	**Rarely**	**Never**
How often does the caring negatively affect your relationships with family or/and friends?	1	2	3	4	5

In this question, you should circle the number that BEST FITS how often the caring negatively affects your relationships with family or/and friends. So you would circle the number that corresponds to the option “Occasionally” if caregiving occasionally affects negatively your relationships with family or/and friends, as follows:

	Always	**Frequently**	**Occasionally**	**Rarely**	**Never**
How often does the caring negatively affect your relationships with family or/and friends?	1	2	[✓ 3]	4	5

Please read each question, assess your feelings, and circle the number on the questionnaire for each question that gives the best answer for you at this moment in time.

The Dementia Quality of Life Scale for Older Family Carers (DQoL-OC)

This first set of questions asks for information about different aspects associated with your role as a carer of a family member with dementia. Please circle the number that best describes your role as a carer.

	Questions	**Always**	**Frequently**	**Occasionally**	**Rarely**	**Never**
1	How often does the caring negatively affect your relationships with family or/and friends?	1	2	3	4	5
2	How often is your financial situation affected by the demands of caring?	1	2	3	4	5
3	How often do you experience a conflict of interest between what you want and what your family member wants?	1	2	3	4	5
4	How often have you had to change your own life and interests to fit around your family member's needs?	1	2	3	4	5
5	How often is caring physically hard on you?	1	2	3	4	5
6	How often do you feel burdened by the care demands?	1	2	3	4	5

This next set of questions asks how you feel about different aspects of your life. Please choose the option that best describes how you have felt about each area of your life as a carer.

	Questions	**Very frequently**	**Frequently**	**Occasionally**	**Rarely**	**Never**
7	I feel worried about my health	1	2	3	4	5
8	I feel exhausted	1	2	3	4	5
9	I feel as if my family member has changed from who she/he used to be and this affects me negatively	1	2	3	4	5
10	I feel worried about the future	1	2	3	4	5
11	I feel I have no choice in being a carer	1	2	3	4	5
12	I feel that I have lost control over the everyday events and decisions in my life	1	2	3	4	5
13	I feel that I have given up things that I enjoy because my family member needs me	1	2	3	4	5
14	I feel as if the boundaries between my own life and my caring role have become blurred	1	2	3	4	5
15	I feel sad or depressed	1	2	3	4	5
16	I feel isolated	1	2	3	4	5
17	I feel guilty	1	2	3	4	5

The next set of questions asks **how satisfied you are with different aspects of your life as a carer**. Please **choose the option that best describes your situation.** "Very satisfied" (number 5) means the highest satisfaction possible and "Very dissatisfied" (number 1) means the lowest satisfaction possible.

		Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
18	How satisfied are you with how much confidence you feel with your caring role?	1	2	3	4	5
19	How satisfied are you with how well you can cope with your caring situation?	1	2	3	4	5
20	How satisfied are you with the relationship with the family member you care for?	1	2	3	4	5
21	How satisfied are you with how well you can sleep?	1	2	3	4	5
22	How satisfied are you with your overall quality of life?	1	2	3	4	5

And finally, please tell us:

1. What do you think would most help to improve your quality of life as a carer?

2. Is there anything else that is related to your quality of life that you feel hasn't been covered in this questionnaire.

Thank you for your time.

APPENDIX 8 – INSTRUCTIONS FOR ADMINISTRATORS

Dementia Quality of Life Scale for Older Family Carers (DQoL-OC)

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1. Objectives of the DQoL-OC

The Dementia Quality of Life Scale for Older Family Carers (DQoL-OC) was primarily developed to measure the quality of life (QoL) of older people (aged ≥60 years old) providing care for their family members with dementia (e.g. Alzheimer's disease, vascular dementia) being cared for at home in the United Kingdom, in order to implement and assess interventions.

The DQoL-OC:

(a) **Is multidimensional.** The DQoL-OC items reflect various aspects of life that are particularly relevant to older family carers of people with dementia, such as an individual's psychological and physical health; energy and vitality; independence, control, and freedom; leisure, social, and solo activities; identity and relationships; satisfaction with life and caregiving; and financial situation.

(b) **Measures QoL from a subjective perspective.** The DQoL-OC measures the individual's perception about the quality of his/her life. It evaluates relevant QoL domains via cognitive and affective psychological mechanisms, and therefore it provides evidence about feelings and satisfaction with life.

(c) **Has been validated for use with OLDER family carers of people with dementia being cared for at home.** Because subjective QoL appraisal and the relevance of several life domains change in later life, the QoL of older people needs to be measured using age-specific scales. At present, the DQoL-OC has only been validated for use with older family carers of people with dementia (aged ≥ 60) being cared for at home in the UK.

(d) **Is psychometrically sound.** The DQoL-OC was developed from focus groups with older family carers of people with dementia being cared for at home in the UK. A panel of experts evaluated its face validity and relevance for use with older family carers of people with dementia. It has been tested in a psychometric study with older family carers, demonstrating excellent internal consistency, evidence of test-retest reliability, and convergent construct validity. Participants in the psychometric study also evaluated its practicality, content, and face validity. Because the scale has been developed and tested in the UK, it is advisable for the researcher to check the psychometric properties if the scale is used outside the UK and/or with a population with a different background.

2. Administration

The DQoL-OC was developed to be self-administered, and it contains two sections:

Section 1: 12 demographic/objective items.

Section 2: 22 subjective items related to QoL.

Section 1 requests demographic and objective information from the older carer, and each question should be treated independently. This information can be used in research to investigate the factors that may predict QoL in caregiving, for example. It may also be used by the practitioner or researcher to build up an overall picture of a carer. As this section does not in itself constitute a scale, the tool administrator is able to either omit questions or include additional questions that may be of interest.

Section 2 comprises the QoL scale itself, containing 22 items about different aspects of dementia-specific and subjective QoL. Because the scale contains an overall factor, it provides a single QoL score about the individual being assessed. Final QoL scores can also be divided into poor (22 to 44), poor to moderate (45 to 66), good (67 to 88), or very good (89 to 110) QoL. The DQoL-OC should take about five to 10 minutes to complete.

3. Calculation of results

Whether the tool is used in clinical practice or in research, the DQoL-OC users should calculate an overall QoL score from the sum of the points obtained from each item of the scale. However, as each item reflects a different domain of life, practitioners and researchers may well identify which areas of QoL may be suffering for the purpose of individual monitoring in line with interventions (Table 1).

Table 1. DQoL-OC items and their respective QoL domains

Items	General QoL domains									
	Relationships	Financial situation	Psychological health	Independence, control over life, freedom	Leisure, social and solo activities	Physical health	General health	Energy and vitality	Satisfaction with life and caregiving	Identity	Life in general
1	x										
2		x									
3				x							
4				x							
5					x						
6						x					
7							x				
8								x			
9			x								
10			x								
11				x							
12				x							
13				x							
14										x	
15			x								
16					x						
17			x								
18									x		
19			x								
20	x										
21								x			
22											x

Section 1: These are demographic and objective variables. They do not form part of the QoL score. They do not need to be totalled in any way but can be used to build up an overall picture of the individual being assessed.

Section 2: Each of the 22 item-scores can simply be added up to give a total score, without the need to reverse the scores of any items. If an individual has completed all the items in this section, total scores can range from 22 to 110. The higher the final scores, the higher the QoL level. This final score can also be divided by five, generating four QoL level groups: poor (22 to 44), poor to moderate (45 to 66), good (67 to 88), or very good (89 to 110).

4. Entering data into a statistical package

If you are using a statistical package such as SPSS®, enter the items using the following procedure:

Section 1: Demographic and objective information

This information can be used to investigate the factors that may predict or are associated with the QoL of older family carers of people with dementia.

Alternatively, this information can be used to gain an overall picture of a carer.

Note: Each item in this component should be treated independently, as these items do not constitute a scale.

Procedure for coding the answers to each item of Section 1:

Item	**Enter:**
1a) What is your date of birth?	The number of years
1b) What is your gender?	1 for "Male" 2 for "Female" 3 for "I prefer not to say"
1c) What is the highest qualification you hold?	1 for "No qualifications" 2 for "Vocational" 3 for "GCSE" 4 for "A level" 5 for "Diploma" 6 for "University degree" 7 for "Postgraduate degree" 8 for "Other"
1d) Are you currently and regularly providing care for MORE THAN ONE PERSON in a non-formal caring capacity? (including children or grandchildren)	1 for "No" 2 for "Yes"
1e) Do you live with the family member you care for?	1 for "No" 2 for "Yes"
1f) What is your relationship with the family member you care for?	1 for "Spouse" 2 for "Son or daughter" 3 for "Sibling" 4 for "Other"
1g) Approximately how long have you being caring for your family member?	1 for "Less than 1 year" 2 for "1 to 3 years" 3 for "4 to 6 years" 4 for "7 to 10 years" 5 for "More than 10 years"
1h) On average, how many HOURS PER DAY do you care for your family member? ('care' means anything that you need to do for your family member because he/she is not able to do this on their own any more)	1 for "Less than 3 hours" 2 for "3 to 6 hours" 3 for "6 to 12 hours" 4 for "More than 12 hours"
1i) On average, how many DAYS PER WEEK do you care for your family member?	1 for "1 day" 2 for "2 to 3 days" 3 for "4 to 5 days" 4 for "6 to 7 days"
1j) How would you describe your family member's dementia symptoms at this moment? (e.g. regarding memory loss, difficulty in communicating, inability to reason, disorientation)	1 for "Totally uncontrolled" 2 for "Mostly uncontrolled" 3 for "Partially (un)controlled" 4 for "Mostly controlled" 5 for "Totally controlled"
1k) How would you describe the stage of your family member's dementia at the moment?	1 for "Initial stage" 2 for "Moderate stage" 3 for "Advanced stage"

If you are using the questionnaire with a different population, please code as necessary.

Section 2: Quality of life evaluation

These items should be summed up to provide a total QoL score. Alternatively, the scale user may look at which item(s) is mostly suffering for the purpose of monitoring in line with appropriate intervention.

Procedure for coding the answers in each item of Section 2:

It is suggested that the data are entered into the computer for each item independently according to the option chosen by the participant (1=1; 2=2; 3=3; 4=4; 5=5). You can then create an additional variable that will automatically sum up all the 22 items for each participant, providing individual total QoL scores. You can then create a new variable, in which you code "1" for poor QoL (22 to 44 points), "2" for poor to moderate QoL (45 to 66 points), "3" for good QoL (67 to 88 points), and "4" for very good QoL (89 to 110 points).
Note: Use the score of 99 to allow computer identification of missing values. If this scheme is used, care needs to be taken that these '99' values are recognized as excluded values and not included as data.

5. Psychometric properties of the DQoL-OC

5.1. Construction of the DQoL-OC

The DQoL-OC was developed from the input of older family carers themselves. Experts in the field of dementia, family caregiving, QoL, and scale development were also consulted prior to field testing.

Validity

Face validity, content validity, and practicality:
Content validity refers to the extent to which a measure represents all facets of the construct being measured, whereas face validity is the extent to which a test is subjectively viewed as covering the construct. Practicality concerns the usability of the new scale (e.g. length, difficulty). There is no statistical way of measuring face and content validities, but there are strategies that one can use to ensure these properties. For the DQoL-OC, focus groups were carried out with older family carers of people with dementia, and the scale items were created based on what these people judged as being important to their QoL. Items developed based on these findings had their content and face validity ensured by a panel of experts and were also reviewed by all individuals taking part in the psychometric

study. These procedures helped to make sure that the scale is relevant for measuring the QoL of the target population while being easy to complete.

Convergent construct validity:

Convergent construct validity establishes the validity of a new tool by correlating scores from it with scores from a previously validated test measuring the same construct. The total scores of Section 2 of the DQoL-OC were correlated with the WHOQOL-AGE (Caballero et al., 2013), a well-validated QoL scale developed by the World Health Organization for use with older adults. Results revealed strong positive correlation between the two scales (Pearson's correlation coefficient of $r=0.736$; $p<0.001$), which confirms that the DQoL-OC measures QoL of older people.

Reliability

Reliability of the DQoL-OC was measured by calculating the internal consistency across all items and by carrying out a test retest. Internal consistency was assessed using Cronbach's α coefficient, which measures the overall correlation between items as well as the level of correlation between items within a scale. Reliability scores range from 0 to 1; Cronbach's α scores ≥ 0.7 are considered acceptable, and Cronbach's α scores ≥ 0.9 are considered excellent (Cronbach, 1951). The DQoL-OC scale had a Cronbach's α total score of 0.936 and ≥ 0.930 for item–total correlation in all 22 items.

Test-retest reliability assesses whether an instrument produces highly similar results on repeated administrations when respondents have not changed, thus providing evidence of stability of QoL measurement across a short period of time. For testing the DQoL-OC, retest questionnaires were completed within a period of two weeks following the psychometric study, and both set of measurements were then correlated using Intraclass Correlation coefficient (ICC). Results demonstrated strong and significant correlation among the two set of measurements scores (lower bound $r=0.835$; $p<0.0001$).

Note: Please contact the researchers if you intend to use the scale for any purpose. You should also contact us for any further details of item analysis if required. We are continuing to develop and standardize the DQoL-OC for use in the UK and globally.

References

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