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Review article

Ageing and quality of life in family carers of people with dementia being cared for at home: a literature review

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ABSTRACT

Background: Despite the increasing older population providing care for family members with dementia at home, there is no consensus in the literature in terms of how caring impacts on their quality of life (QoL) and the association of the family carer's age with QoL outcomes.

Aims: To explore the available literature investigating the QoL of older family carers (family carers aged ≥ 60) and the association of family carers' age and QoL outcomes in a dementia context.

Methods: A review of the literature to December 2013 was conducted using Embase-OVID, CINAL, Medline-OVID, Psyc INFO-OVID, Grey literature and the references of the included studies. Cross-sectional or prospective longitudinal studies published in English were eligible. The selection and appraisal processes were performed by two reviewers independently and the methodological quality was assessed by STROBE statement.

Results: From the 12 selected studies, 4 were carried

out with older family carers' samples and 8 associated the variable 'age' with QoL outcomes. Eight different instruments were used to assess family carers' QoL, however none were designed specifically for older people or older family carers. The mean age of the carers' samples ranged from 55.2 to 76.0 years old. Older family carers showed low levels of QoL and were often below the age-matched standard population. Carers' age was negatively correlated with QoL outcomes in most of the studies.

Conclusion: Older people are increasingly involved with dementia care and family carer's advanced age was shown to be associated with low levels of QoL. Future research should investigate the QoL of older family carers separately and use QoL instruments containing older family carers' specific needs and perspectives of QoL. In planning care and support, primary health care practitioners should consider family carer's age group and their specific needs.

Keywords: Quality of Life, Older Family Carers, Older Adults, Dementia, Alzheimer's disease

How this fits in with quality in primary care?

What do we know?

Caring for a person with dementia at home is a stressful and burdensome task that may affect younger and older family carers differently. Even though the literature suggests investigating these two age groups separately, few studies have focused on the older family carer's QoL and how carers' age may be associated with their QoL outcomes.

What does this paper add?

This review confirms the increasing number of older people involved in caring for a family member with dementia. It also identified a negative association between carer's age and low levels of QoL in older family carers, with a dearth of longitudinal evidence on this topic. Future research should focus on the impact of caring for older family carers as a unique group and on the impact of long term caregiving, using appropriate QoL instruments. When planning care and support, primary health practitioners should consider family carers' age and the specific needs and perceptions of QoL of this unique group.

Background

As the older population increases worldwide, the prevalence of diseases commonly affecting this age group has increased proportionally.¹ Dementia is one of the most common diseases, causing great indices of disability and being considered one of the most disabling and burdensome health conditions worldwide.²⁻³ It is projected that about 81.1 million people will be affected by dementia by 2040, with a significant proportion living at home and being cared for by family members.^{4,5}

It is estimated that 6 million people provide care and support for family members or friends that are frail, ill or disabled across England and Wales. About 3 million of these carers are aged over 50, and 1.5 million are over 60 years old, and are often co-residing spouses who provide full-time care.⁶ As dementia progresses towards the stage of dependence, several studies have shown how caring can be complex and cause long-term challenges to family carers⁷⁻⁹. Stress, distress and depression are also major consequences derived from caring for a person with dementia, with higher levels of stress being associated with higher rates of mortality among carers when compared with non-carers groups.¹⁰⁻¹³

This should place family carers at the centre of primary care and health and social care strategies, as research and government guidelines have emphasized the need for continued research and resourcing for carers with financial, practical and emotional support. However a paucity of research into family caregiving may be a contributing factor to the lack of focus and clear governmental strategy for this group of carers. This is particularly concerning for older family carers (aged ≥ 60), who often choose to care for their family members at home, for reasons of marital commitment, love, devotion and satisfaction.¹⁴⁻¹⁷

Older family carers often provide full-time care over extended time periods.^{18,19} This may lead to a decline in their own self-care and lead to poor family relationship quality.^{20,21} These carers have shown higher levels of depression, higher risk of cognitive deterioration and higher mortality risk when compared with non-caring older adults' controls.²²⁻²⁴ In addition, researchers have identified differences in younger and older family carers regarding the specificities of the caring context, such as co-residing, and the potential impact of caring on health and other psychosocial factors, socio demographic aspects, depression levels, living arrangements and self-rated health over time.^{22,25-28}

Quality of life of older family carers

Quality of life (QoL) is defined by the World Health Organization (WHO) as the "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".^{29,30} This is a broad and multidimensional concept that incorporates information about physical health, psychological state, level of independence, social relationships, personal beliefs and relationship with the environment in which people live.³⁰⁻³² Health Related Quality of Life (HRQoL) is often used to identify how QoL may be affected over time by a disease, disability or disorder.³³

QoL has become a standard means of assessment for interventions determining choice of treatments and care and, for prioritizing funding in health and social care.³⁴⁻³⁶ QoL dimensions may indicate how life conditions in which the individual lives might affect their self-perception of their life quality, and in the caring context, QoL outcomes and dimensions can reflect how the stress and burden generated by caring affect family carers' self-perception of mental health, physical health and social life. In this sense, a measure of QoL may give a broader understanding of the impact of caring on a carers' life and provide evidence to design appropriate interventions, especially in the primary health care sector.

Caring in old age is considered a chronic stressor due to the persistent physically and emotionally demanding role of caring and the combination of factors such as loss, disability, prolonged distress and stress.¹³ The physical demands of caring and biological vulnerabilities of the older family carers may cause increased risk for physical health problems, leading to a diminished QoL.³⁷⁻³⁸ Although studies from many countries have reported low levels of QoL in family carers of people with dementia of all ages, there is a critical lack of investigation on the unique requirements and QoL of older family carers.^{19,32,49-43}

Grounded on these findings, it is advocated in this review that the QoL of older family carers should be investigated in isolation from younger carers. By investigating older family carers' specific needs and perceptions of QoL, meaningful evidence may be generated for researchers, primary health and social professionals to quantify the experience of caregiving in old age.⁴⁴ Above all, it has the potential to facilitate and drive the implementation and evaluation of social and health interventions with older family carers, as well as ensuring the necessary allocation of resources and services available for this population. In addition, this review may foster further discussions around older family carers' quality of life in a dementia context and about the relationship between carers' ageing and QoL outcomes, providing means for care planning and future research for older family carers of dementia patients.

Aims and Search Questions

This review aimed to synthesize and debate the available literature investigating the QoL of older family carers and the association of family carers' age and their QoL outcomes, seeking to answer the following search questions: **1)** What are the QoL outcomes of older family carers of people with dementia being cared for at home? **2)** What is the association between age and QoL outcomes of family carers in dementia context?

Methods

Design

This literature review utilized a transparent and systematic approach throughout all the steps of search and data appraisal. The search strategy and inclusion criteria used for the identification and assessment of relevant literature, data extraction and methodological rigour evaluation were carried out in line with Hawker, Payne and Higgins and Green.^{45,46} The eligibility criteria of this review were established based on the search questions and aims, as follow:

Eligibility Criteria

Study design: cross-sectional or prospective longitudinal designs.

Publication language: publications in English only.

Publication year: studies published to December 2013.

Type of publication: Any type of publication (conference reports, abstracts, editorials, short reports, dissertation, thesis, etc.) could be selected at the first search.

Participants:

Family carers: There is no agreed definition of 'carers' within the existing literature. Therefore, the term family carer was adopted according to the aims of the review. Family carers were defined as family member who provides care for a person with dementia at home, supervising, encouraging or carrying out the activities that they cannot perform independently anymore.⁴⁷ Studies addressing formal carers or paid carers and studies including family carers of people residing in nursing homes were excluded.

Older family carer: Family carer's aged 60 years or older.
15-16

Outcomes

QoL: Any study measuring carer's QoL was included, regardless of the type of instrument used or QoL construct grounding the research.

Carers' age: A continuous variable normally considered in number of years that could be categorized or not. The included studies must have addressed how this variable was associated with carers' QoL outcomes, by presenting the findings of this relationship.

Search Strategy

The search strategy was constructed in order to embrace all publications related to the QoL of family carers of people with dementia being cared at home and to identify those studies

conducted specifically with older family carers. Relevant key-terms were selected from the Medical Subject Headings (MeSH) and the combinations used are available in Table 1. Due to the wide range of terms applied for carers in the literature, it was attempted to comprise all possible descriptors normally found in the related publications and adjust the key-terms for each database, with the help and supervision of an experienced librarian professional during the search process. The electronic databases Embase-OVID, CINAL, Medline-OVID, PsycINFO-OVID, Grey literature (SIGLE and Google scholar) and the references of the included studies were screened.

Screening and Assessment of Relevance

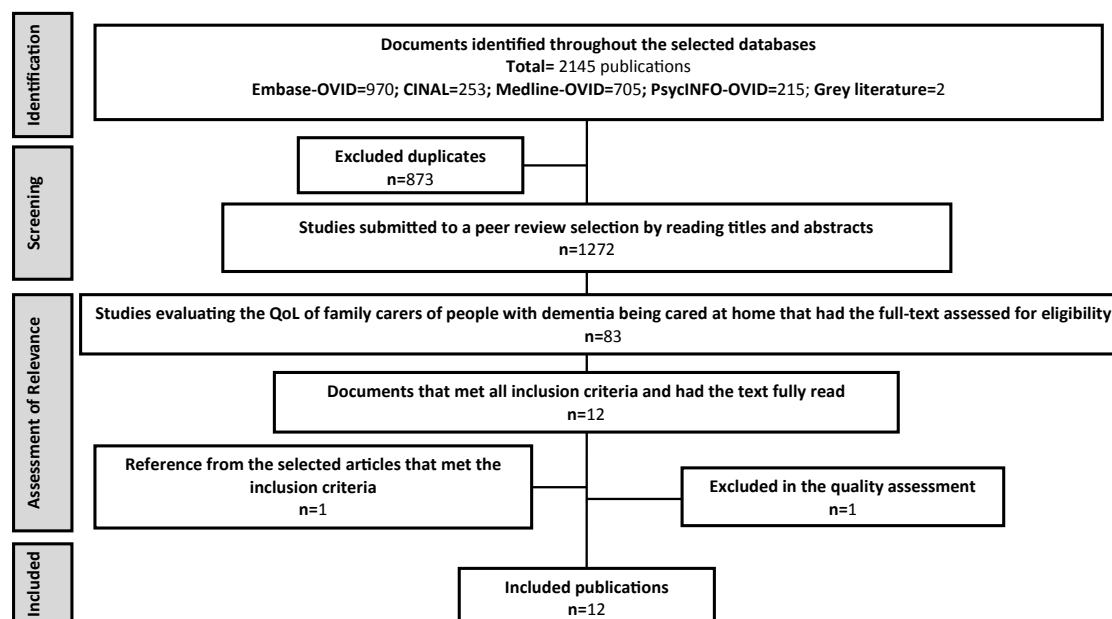
The studies identified in the search were systematically screened following the PRISMA statement, as presented in Flow chart 1.⁴⁸ The results were uploaded to EndNote®7th version (Thomson Reuters Scientific Inc., Carlsbad, California, United States) in order to enable the identification of duplicate files and the organization of the identified documents. The screening process and assessment of relevance were performed by two revisers independently and after each step they met and compared the results. Any disagreement regarding the inclusion or exclusion of any publication involved a third researcher to reach a decision.

A total of 2145 papers were collated from the initial search. After excluding duplicates, 1272 documents had their titles and abstracts scanned in order to identify all the studies investigating the QoL of family carers of people with dementia being cared for at home. Some publications had their full content assessed at this phase due to the dearth of information available in the abstracts. The excluded studies were mainly focused on other family carers' outcomes (stress, distress, anxiety and burden, for example), on the care recipient outcomes (quality of life, care and treatment, for example), or were studies carried out in nursing homes, hospital, hospices, long-term care units, home care service, or investigated formal carers or nurses.

Eighty-three studies were selected from the screening process and had their full-text assessed aiming to select those meeting the inclusion criteria. If short publications, such as conference

Table 1 : Search strategy.

| AND | | | |
|-----|---------------------------------------------------------------|------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| OR | Quality of Life/ Quality adj5 Life QoL.mp. HRQoL.mp. | exp Dementia Dementia.mp. exp Alzheimer Disease Alzheimer\$ disease | Caregiv\$ |
| | | | Caregivers/ |
| | | | Carer\$ |
| | | | Family caregiver\$ |
| | | | Family caregiving |
| | | | Family carer\$ |
| | | | Informal caregiver\$ |
| | | | Informal caregiving |
| | | | Informal carer\$ |
| | | | Older caregiver\$ |
| | | | Older carer\$ |
| | | | Elder\$ carer\$ |
| | | | Elder\$ caregiver\$ |
| | | | Aging/ Aging.mp. Ageing.mp. Longevity/ Longevity.mp. Aged/ Aged.mp. Aged, 80 and over Aged, 80 and over.mp. Older\$ Older people Older adult\$ Elder\$ Geriatrics Geriatrics.mp. Gerontology |



Flow chart 1 - The main results derived from the selection process.

abstracts and short reports, met the inclusion criteria the authors were contacted in order to request the full detail of these studies. Finally, 12 studies were selected in this process and had their references screened. One reference met the inclusion criteria and was also submitted to the appraisal process.

Thirteen studies were selected for assessment of their methodological quality by using the STROBE statement.⁴⁹ This tool has been used to assess the content of cross-sectional and longitudinal studies and provides guidance on how to report observational research. For each criterion, symbols were adopted in order to qualify the studies: (+) if the items were described, (-) if the information was not provided and (NA) if it was not applicable in that case. In situations where the criterion was partially described, but there was enough information about that specific topic, it was considered positive (+). The results from this assessment are outlined in Table 2.

As there is no consensus on the cut-off point in this evaluation for inclusion in a review⁽⁵⁰⁾, all studies that met the inclusion criteria were included, with exception of one published in a short report in which important information about the sampling and data collection were not presented. Finally, a total of 12 articles were included in this review.

Results

General aspects of the included studies

From the 12 included studies, only 3 were conducted with older family carers' samples and 2 were part of the same prospective cohort (Table 3). One study carried out with spousal carers did not describe the age range, but compared the results with values of older adults who were non-carers², and was thus considered as an older family carers' sample in this review.⁵¹ The majority of the studies were carried out in Australia (n=5) and Norway (n=2) and others were carried out in other European countries, United States and Canada.

They were 11 cross-sectional studies and one with prospective longitudinal design, with generally small sample

sizes (range: 49 to 237 carers; mean: 123.16 participants). Some studies were part of on-going research, such as base line report of clinical trials, in which the evaluation of the QoL of family carers was not the main study purpose. Two investigations focused on the care recipients' QoL and two studies correlated the QoL of family carers of people with different conditions.

The 12 studies utilized 8 different instruments to assess family carers' QoL. Six were for the assessment of HRQoL and 2 for overall QoL (Table 4). Only one instrument was specifically developed for family carers and none were developed specifically for older people or older family carers. Three studies utilized a scale developed and validated for use with people with AD, rather than for family carers.

Age and quality of life of family carers

Women and spouses were the predominant population and those co-residing with the care recipient were found significantly older. The mean age of family carers ranged from 55.2 to 73.4 years old. Among the 4 studies conducted with older family carers, the mean age ranged from 69.5 to 76.0. One study considered 'older family carers' as those aged 60 or above and the others considered 'older family carers' as 65 years old or above.

Older family carers were found to have low levels of general QoL, often below the standard comparison population, and research dividing HRQoL into components showed older family carers with lower levels of mental component summary (MCS). The single longitudinal study selected was carried out with older family carers and showed better physical component summary (PCS) levels associated with better capacity to perform domestic chores, better capacity to perform household maintenance and better capacity to provide service to others. After two years, those carers who continued providing care maintained lower PCS and domestic chores' performance and continued with extremely low level of social activity. Older family carers that stopped caring activity had less sense of health decline, improved MCS and had a relevant increase in activity than those who continued caring.⁵²

| | | | | | | | | | | | | | |
|------------|------------------|---|---|---|---|---|---|---|---|---|---|---|---|
| Discussion | Key results | + | + | + | + | + | + | + | + | + | + | + | + |
| | Limitations | - | + | + | + | + | + | + | + | + | - | + | + |
| | Interpretation | + | + | + | + | + | + | + | + | + | + | + | + |
| | Generalizability | + | + | + | + | + | + | + | + | + | + | + | + |
| Other | Funding | + | - | + | - | - | + | + | - | + | + | - | - |

* Symbols indicate: + Yes; - No; NA: not applicable

Table 3 - Summary of the content of interest from the included studies (n=12).

| Reference and country | Design and aims | QoL tool ¹ | Participants and setting | Carers' age, gender and relationship with the patient | Important findings related to carers' QoL |
|-----------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|--------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Valimaki, Vehvilainen-Julkunen ⁽¹⁰⁾ Finland | Cross-sectional. 1) To evaluate the relationship between sense of coherence and QoL in spousal caregivers of patients with AD. | 15D | N = 170 AD carers (spouses) | Age: 71.7(7.2) Gender: Women: 107(62.9%); Men: 63 (37.1) Relationship: spouses only | QoL not related with age. Low QoL: using more drugs, severe depressive symptoms and distress. High QoL: strongly related to high levels of sense of coherence. |
| Rosness, Mjørud ⁽⁵⁰⁾ Norway | Cross-sectional. 1) To examine specifically the QoL and depression among cohabitant (married or unmarried) carers of early onset dementia patients. | QoL-AD | N = 49 AD carers. | Age: 60.3(6.1) Gender: - AD carer: Women: 25(65.7); Men: 13(34.2) - Non-AD carer: Women: 9(81.8); Men: 2(18.2) Relationship: not provided | Older age: increased levels of QoL. |
| Serrano-Aguilar, Lopez-Bastida ⁽⁴³⁾ Spain | Cross-sectional. 1) To assess the impact on QoL and perceived burden of informal caregivers of patients with Alzheimer's disease. | Euro-QoL-5D | N = 237 AD carers. | Age: 55.2(14.5) - Men significantly older than women Gender: Women: 75.5%; Men: 24.5% Relationship: caregivers of male patients were spouses in 71% of cases. Caregivers of female patients were daughters or sons in 66.7% of cases. | Low QoL and general health than standard population. Lower QoL: older age, limitations for ADL, pain, discomfort, anxiety or depression, high patients' dependency, high burden, more committed time to care. Higher QoL: better education, son or daughter relationship. |
| Bruvik, Ulstein ⁽³²⁾ Norway | Cross-sectional. 1) To measure the QoL in people with dementia by self-reporting and by proxy report and to identify factors affecting the QoL in people with dementia as assessed themselves and a proxy. 2) To examine the QoL of the family carers to explore how the factors associated with their QoL compared those of the people with dementia. | QoL-AD | N = 230 AD carers. | Age: 63.5(12) - Female carers significantly younger than male carers Gender: Women: 177(77.0); Men: 53(23.0) Relationship: spouses (53.0) | Lower QoL: older age (linear regression) Significant association between proxy-rated QoL and carer QoL. |

| | | | | | |
|-------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------|-----------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Bosboom, Alfonso ⁽³¹⁾ Australia | Cross-sectional. 1) To determine the agreement in QoL ratings between community-dwelling patients with mild to moderate dementia and family carers. 2) To determine the factors associated with self-reported and two types of carer-reported QoL ratings: carer-carer perspective and carer-patient perspective. | QoL-AD | N = 80 AD carers. | Age: 66.6(14.5) Gender: Women: 46(57.5); Men: 34(42.5) Relationship: spouses (61.4) | Carer-carer QoL: inversely associated with carers' age, burden, patient's number of medications, anxiety and living together lower than carer-patient ratings. Carer-patient QoL: affected by carers' age. |
| Bruce, Paley ⁽⁵¹⁾ Australia | Cross-sectional. 1) To determine whether physical health problems contribute to stress in dementia caregivers. | SF-12 | N = 91 Dementia carers. | Age: Bimodal distribution: median 62 years old (38-85) - Live-in caregivers significantly older than non-live-in caregivers Gender: Women: 6 (71.4); Men: 26(28.6) Relationship: spouses (45.0); daughter (39.6) | MCS: lower than the standard population; no relation to carers' age; lower in those with high levels of stress, mental health problems or taking medications. PCS: lower when older age, worse physical health, stress, those with physical health problems, taking medications. |
| Riedijk, De Vugt ⁽⁵²⁾ Netherlands | Cross-sectional. 1) To assess the burden and QoL as well as coping of caregivers of patients with FTD and AD and compare these groups. | SF-36 | FTD: N = 29 AD: N = 90 | Age: FTD: 57.1(10.7); AD: 63.5(12.4) Gender: FTD: Male: 16(55); Female: 13(45). AD: Male: 35(39); Female: 51(61). Relationship: AD: spouses (52.0); FTD: spouses (93.0) | Higher MCS: older caregivers of people with FTD for longer duration. Lower MCS: younger caregivers of AD people with shorter time dementia PCS: no difference between FTD and AD caregivers. |
| Zawadzki, Mondon ⁽⁵³⁾ France | Cross-sectional. 1) To assess attitudes towards AD in caregivers of people with AD and their correlation with the level of perceived emotional distress and burden. | PIXEL | N = 51 AD carers. | Age: Women: 64.3(10.2); Men: 74.5(14.7) - Women significantly younger than men. Gender: Men: 17(33.3); Women: 34(66.7) Relationship: men caregivers: spouses (76.5); women: daughter (47.1) | Caregivers' advanced age: association with QoL scores, burden and general health. |
| Clark and Bond ^{(54)**} Australia | Cross-sectional. 1) To determine the value of the Adelaide Activities Profile for the systematic examination of caregiver activities. 2) To explore caregiver activity patterns. 3) To investigate the association between caregiver activity and psychological wellbeing and health. 4) To explore the possibility of a trade-off between the levels of activity of the caregiver and those of the person with dementia; 5) To examine the extent to which caregiver activity levels are associated with the use of respite services. | SF-36 | N = 163 Older spouses' carers (≥ 65) | Age: 71.7(7.6) Gender: Men: 69(42.3) Women: 94(57.7) Relationship: all spouses | PCS: above the population norm. MCS: below the population norm. Caregivers' age inversely related to the capacity to perform social activities, capacity to perform domestic chores and to perform household maintenance. PCS: higher levels associated with better capacity to perform domestic chores, better capacity to perform household maintenance and better capacity to provide service to others. |

| | | | | | |
|---------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------|----------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Bond, Clark ^{(55)**} Australia | Longitudinal. 1) To determine the extent to which changes overtime in QoL differed between continuing caregivers, those who had yielded to formal care, and those who had been widowed. 2) To examine whether change in QoL variables was associated with time since yielding to formal care and time since death. | SF-36 | N = 150 Older spouse's carers (≥ 65). | Caregivers: continued providing care (n=60) Age: 69.5(7.6) Yielders: admitted the spouses in a permanent residential care (n=53) Age: 73.4(7.5) Widows: patient died (n=37) Age: 71.1(6.5) Gender: Women: 87(58); Men: 63(42) Relationship: all spouses | Non-participants significantly older. Caregivers younger than yielders, lower scores for physical health and domestic chores than widows and continued with low level of social activity. Yielders and Widows: less sense of health decline than caregivers, increases in activity. Mental health improved for widows and yielders. Longer time since the spouse was institutionalized: MCS. PCS: improved mental health, depression, domestic chores and social activities. |
| Scholzel-Dorenbos, Draskovic ^{(57)**} Netherlands | Cross-sectional 1) To explore in a sample of mild-to-moderate Alzheimer's disease patients predictors of QoL, by rating QoL and burden. | SEIQoL | N = 87 Older spouses' carers | Age: 73.5(7.2) Gender: Women: 41(47.0) Men: 46(53.0) Relationship: spouses only | Lower QoL: Caregiver's age, burden and patient cognition, when compared with non-caregivers' older population. |
| Draper, Poulos ^{(56)**} Australia | Cross-sectional 1) To compare elderly co-resident caregivers of stroke and dementia sufferers to determine whether caring for those with predominantly mental disability (dementia) is more stressful to caregivers than caring for those with predominantly physical disability (stroke). | Quality of Life Questionnaire (QLQ) | Stroke carers: N = 48 Dementia carers: N = 51 Older carers (≥ 60), co-residents with the care recipient. | Age: stroke carers: 72(6.2); dementia carers: 76(6.6) Gender: stroke - men: 24(50) - women: 24(50); dementia - men: 27(53) - women: 24(47) Relationship: stroke - spouses (90.0); dementia - (90.0) | No differences in QoL between the two groups. Association between QoL of dementia carers and levels of stress, general health and chronic general health. |

AD: Alzheimer's disease; FTD: frontotemporal dementia; QoL: quality of life; HRQoL: health related quality of life; MCS: Mental Component Summary; PCS: Physical Component Summary; * More information about the instruments are available in Table5.; ** Older adults sample

The majority of the studies showed a negative correlation between carer's age and QoL outcomes (Table 5). Lower physical component summary (PCS) of HRQoL was associated with carers' advanced age. Other variables often associated with lower QoL were female gender, care recipient behaviour, co-residence, long time caring and lower education. The majority aimed to associate negative aspects of caring with the QoL outcomes, such as burden, depression, anxiety and stress. A few studies considered positive aspects in caring, such as coping, sense of coherence and hope. All the negative aspects impacted on carers' QoL, with exception of 'perceived incompetence', and all the positive aspects assessed were correlated with higher levels QoL, even when negative aspects had an impact.

Discussion

This review has identified a dearth of research investigating older family carers' and an association between carers'

advanced age and QoL outcomes in cross-sectional and prospective longitudinal studies. The increasing participation of older adults in a dementia care context was confirmed, with a high mean age of carers in the mix age samples and studies with older family carers indicating a relatively big proportion of oldest old family carers. This demonstrates an urgent need for further research focused on the impact of caring and the specific needs of the older family carers. Some of the available literature was not focused on the family carers, but on the care recipient's QoL, and had generally small sample sizes. Additionally, studies investigating older family carers are considered in different age standards (60 or 65 years old), demonstrating once again the problem of definitions in family caregiving research. Finally, the instruments of QoL utilized were not developed specifically for older adults or older family carers, and this limitation was not acknowledged in the studies.

Table 4 - Instruments of quality of life utilized in the studies selected in the literature review.

| Instrument | Quality of life | Characteristics | Dimensions | Studies |
|----------------------------|-----------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------|
| 15D ⁽⁵⁹⁾ | HRQoL | Generic, multidimensional. Profile and single index score. 10 cm visual analogue score was used in association to assess overall QoL. 15 questions (1-5). | Mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort and symptoms, depression, distress, vitality and sexual activity. | Valimaki, Vehvilainen-Julkunen ⁽¹⁰⁾ |
| QoL-AD ⁽⁶⁰⁻⁶¹⁾ | HRQoL | AD specific, multidimensional, originally designed to assess people with dementia. Rates the dementia sufferer's QoL from both patient and carer perspectives. 13 items (1-4). | Finances, physical condition, mood, and an overall assessment of QoL. | Bosboom, Alfonso ⁽³¹⁾ , Bruvik, Ulstein ⁽³²⁾ , Rosness, Mjørud ⁽⁵⁰⁾ |
| EuroQoL-5D ⁽⁶²⁾ | HRQoL | Generic, multidimensional. Profile and single index score. Self-administered, 5 questions (1-5). | Mobility, self-care, usual activities, pain/discomfort, anxiety/depression, with three levels for each dimension. | Serrano-Aguilar, Lopez-Bastida ⁽⁴³⁾ |
| SF-12 ⁽⁶³⁾ | HRQoL | Generic, multidimensional. Subset form of SF-36. 12 items (0-100). | Provides PCS and MCS. 8 dimensions divided in: MCS - vitality, social functioning, role limitations resulting from emotional problems, psychological distress; and PCS - physical functioning, role limitations due to physical health problems, bodily pain and general health). | Bruce, Paley ⁽⁵¹⁾ |
| SF-36 ^{(33, 64)*} | HRQoL | Generic, multidimensional. 36 items (0-100). | Provides PCS and MCS. 8 dimensions divided in: MCS - vitality, social functioning, role limitations resulting from emotional problems, psychological distress; and PCS - physical functioning, role limitations due to physical health problems, bodily pain and general health). | Riedijk, De Vugt ⁽⁵²⁾ , Clark and Bond ⁽⁵⁴⁾ , Bond, Clark ⁽⁵⁵⁾ |
| SEIQoL ^{(65-66)*} | HRQoL | Generic, multidimensional. Level of functioning in 5 self-nominated aspects of life (qualitative information) and the relative weight or importance attached to these areas. | Aspects of life considered by the individual to be crucial to the QoL; Current functioning/satisfaction with each aspect is rated by the individual; 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, Draskovic ⁽⁵⁷⁾ |
| QLQ ^{(56, 67)*} | QoL | Dementia specific, assess participation in social and recreational pursuits in the 'last few weeks'. Adapted from the results of a RCT. Dichotomous, 10 items. | The items assess the carer's participation in social and recreational pursuits in the last few weeks. | Draper, Poulos ⁽⁵⁶⁾ |
| PIXEL ^{(68)**} | QoL | Dementia specific, multidimensional. 20 items ('yes', 'no', 'does not know') (0-100). | The ability to cope with problems generated by the care recipient, relationship to the environment, awareness of the situation and perception of distress. | Zawadzki, Mondon ⁽⁵³⁾ |

*Applied to older carers samples; ** Instrument specifically developed for carers; MCS: Mental Component Summary; PCS: Physical Component Summary; AD: Alzheimer's disease; RCT: Randomized controlled trial.

All investigations were carried out in developed countries, even though the current literature has emphasized the need to study the impact of dementia in developing countries.⁵³⁻⁵⁴ It is known that a considerable and neglected burden associated with physical, psychological, social, time, and financial issues is imposed on carers from low and middle income countries and levels of strain have being found at least as high as in developed

countries.⁵³⁻⁵⁵ It might be the case that these studies have been indexed in other electronic databases or in other languages. However, it may also indicate that older family carers do not have their QoL assessed in these countries and not enough attention has been given to the association of carers' age with QoL outcomes.

Table 5 - Results from the correlation between age and QoL of family carers in the selected studies (n=12).

| | Valimaki, Vehviläinen-Julkunen ⁽¹⁰⁾ | Rosness, Mjørud ⁽⁵⁰⁾ | Serrano-Aguilar, Lopez-Bastida ⁽⁴³⁾ | Bruvik, Ulstein ⁽³²⁾ | Bosboom, Alfonso ⁽³¹⁾ | Bruce, Paley ⁽⁵¹⁾ | Riedijk, De Vugt ⁽⁵²⁾ | Zawadzki, Mondon ⁽⁵³⁾ | Scholzel-Dorenbos, Draskovic ^{(57)*} | Bond, Clark ^{(55)*} | Draper, Poulos ^{(56)*} | Clark and Bond ^{(54)*} |
|-------------|------------------------------------------------|---------------------------------|------------------------------------------------|---------------------------------|----------------------------------|------------------------------|----------------------------------|----------------------------------|-----------------------------------------------|------------------------------|---------------------------------|---------------------------------|
| Correlation | nc | + | - | - | - | - | - | - | - | / | / | / |

* Older family carers sample; /: not evaluated; nc: no correlation; +: positive correlation; -: negative correlation.

The cross-sectional studies carried out with older family carers showed generally low levels of QoL in these participants. Even though the literature regarding older family carers in a dementia context was scarce for comparison, the available literature provides evidence that older, female and spousal carers (the most frequent characteristics of the family carers in the selected studies), are highly affected by their caregiving role in aspects of their lives that are very likely to be related to QoL outcomes. For example, chronic illness, depression, disability, physical morbidity, psychiatric symptoms, lower life satisfaction and strain.⁵⁶⁻⁶² Older family carers' age, female gender, care recipient behaviour changes, as well as co-residence and higher number of hours spent caring and are also considered to be risk factors for burden in the literature.^{9, 18, 61, 63-64}

Recent studies suggest an increase of carers' burden as the severity of the care recipient's symptoms increase and dementia progresses.^{8,65} Despite the lack of longitudinal studies investigating older family carers' QoL or correlating carers' ageing with their perception of QoL over time in this review, it is known that QoL is likely to be affected by high levels of burden.^{66,67} The single prospective longitudinal study identified in this review highlights this relationship, showing an improvement in physical capacity, mental health, and depressive symptoms when older family carers stopped their caring role.

The cross-sectional studies included in this review demonstrated a frequent negative association between family carers' age and QoL outcomes. Carers' age and QoL did not have association in one study and old age was positively associated with QoL in another study. One explanation for these differences may be the use of a QoL scale developed primarily for use with AD sufferers, rather than for the carers, which may question the reliability of these measures.

Another explanation may be the fact that family carers have psychological strategies such as self-efficacy, personality or coping strategies that allow them to cope with the stressors and perceive the caring situation from a positive perspective, changing a negative situation into a beneficial and meaningful experience, which might be also be mediated by carers' age.⁶⁸⁻⁷⁰ However, the same hypothesis could be applied to the other studies, in which lower levels of QoL would have been associated with lower capacity to cope or lower levels of self-efficacy, for example, which would have affected how those family carers perceived their life quality. Nevertheless, from these studies, it is not clear as to what extent psychological attributes would be protective of the high levels of burden derived from caring, especially in advanced ages. Further research is required to

clarify the aspects that mediate the family carers' perception of their own QoL. Investigating factors that both mediate and diminish levels of QoL in older family carers' may lead to a better understanding of the impact of these issues in long-term caregiving.

Finally, the findings from this review highlight a need for researchers and support services to modify how older family carers are considered within the literature and the need for further and continuous investigation into the specificities of this unique group. Differences of age, gender, living arrangements, time spent caring and relationship with the care recipient, for example, are considered as essential variables to be investigated and correlated with QoL outcomes in family carers' research.

Furthermore, this investigation highlights the requirement for a QoL scale that includes the specific needs and perceptions of QoL of older family carers in order to provide valid and reliable measures of QoL in this population. Considering the unavailability of such a tool in the literature, this research team is currently developing this unique scale.⁷¹ A preliminary qualitative investigation has identified that older family carers have specific needs, particular views and perceptions of QoL that must be considered, such as worrying about their own death and the increasing physical demands of caring. This new scale, the Dementia Quality of Life Scale for Older Family Carers (DQoL-OC) is being validated for use in research and clinical practice and is hoped to provide more reliable and valid information about older family carers for researchers and health practitioners. One of the limitations of this literature review is that only the main health databases and publications in English were considered, not covering unpublished or on-going longitudinal studies or other languages. The study was also limited by the characteristics of the included research, as they had a wide variability with regards to research design, older family carers' age groups (60 or 65 years old for older family carers), sample size, QoL instruments, scoring and reliability, which limited the possibility of conducting a meta-analysis, that would certainly provide more robust quantitative conclusions.

Conclusion

This paper offers an overview on the available literature related to the quality of life of the older family carers of people with dementia being cared for at home and gives evidence of an association between carers' advanced age and levels of perceived QoL. The review indicated an increasing number of older people involved with dementia care alongside negative associations between carers' advanced age and QoL outcomes.

It also highlighted the need to improve the quality of research investigating the QoL of older family carers, by carrying out studies with bigger samples, better methodological quality and use of QoL instruments containing older family carers' specific QoL needs, which may allow for future comparisons between the samples. Furthermore, considering that a great proportion of family carers of older people with dementia are older people themselves, it becomes necessary to focus research on the specific needs and perceptions of QoL of this specific age group, as younger and older family carers may not form a homogenous group.

Considering the chronic and progressive nature of dementia with increasing burden on family members, having reliable QoL measures and setting up appropriate interventions aimed at enhancing its levels become a primary goal in primary health care. Thereby this review hopes to encourage discussion on the importance of considering older family carers' specific needs and calls primary health care practitioners to reflect upon the need to consider family carers' age when planning care and support. Health professionals can benefit from the findings of this review by identifying variables potentially related to the improvement or worsening of QoL in older family carers and by understanding the importance of choosing appropriate scales when assessing family carers of people with dementia.

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