Review Article

Factors associated with the quality of life of family carers of people with dementia: A systematic review

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Abstract

Introduction: Family carers of people with dementia are their most important support in practical, personal, and economic terms. Carers are vital to maintaining the quality of life (QOL) of people with dementia. This review aims to identify factors related to the QOL of family carers of people with dementia.

Methods: Searches on terms including "carers," "dementia," "family," and "quality of life" in research databases. Findings were synthesized inductively, grouping factors associated with carer QOL into themes.

Results: A total of 909 abstracts were identified. Following screening, lateral searches, and quality appraisal, 41 studies ($n = 5539$) were included for synthesis. A total of 10 themes were identified: demographics; carer–patient relationship; dementia characteristics; demands of caring; carer health; carer emotional well-being; support received; carer independence; carer self-efficacy; and future.

Discussion: The quality and level of evidence supporting each theme varied. We need further research on what factors predict carer QOL in dementia and how to measure it.

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Keywords: Quality of life; Family carers; Family caregivers; Informal carers; Dementia; Measurement Alzheimer's disease; Systematic review

1. Background

Dementia is one of the most common and serious disorders we face. It is a global issue; 46 million people have dementia, and it costs over $600 billion (£450 billion) per year [1,2]. The numbers with dementia will double and costs at least triple in the next 20 years [1,2]. Dementia causes irreversible decline in cognitive, social, and physical function. Abnormalities in behavior, insight and judgment, anxiety, and depression are all part of the disorder [3].

The National Dementia Strategy for England [3] identifies family carers as "the most valuable resource for people with dementia," with 600,000 family carers providing £8 billion ($11 billion) per annum of unpaid dementia care in the United Kingdom alone. Family carers are a vital determinant of positive outcomes for people with dementia, for example, having a coresident carer exerts a 20-fold protective effect on risk of institutionalization [4]. In this review, the term "family carer" is used to encompass all informal carers (i.e., family and friends/neighbors) of a person with dementia who provide support.

This is the term that our consultation with carers supported most, with "carer" preferred to "caregiver" and "family" preferred to "informal" (even given that this group may include nonfamily members such as neighbors and friends) in distinguishing family carers from "paid" or "formal" carers.

Caring extends beyond hands-on care to include the following: anticipating future support needs, monitoring and supervising, preserving the individual's sense of self, and helping the individual to develop new and valued roles [5]. The challenges of caring are significant. Fifty percent of those with dementia in the community receive 35+ hours of family care per week [6]. Caring in dementia may be complicated by resistance to care, agitation, and/or a lack of insight on the part of the person with dementia into their own needs [6]. Many family carers of people with dementia are older themselves, physically frail with health conditions of their own. Dementia is a progressive, terminal disorder, and caring is not a fixed set of experiences but evolves in a "caregiving career" [7]. The main responsibility for day-to-day care tends to fall to one family member, usually a woman (in order of likelihood: spouse, daughter, daughter-in-law, son, other relative, and nonrelative) [7,8]. Although for many there is personal satisfaction derived from caring, the experience can also be detrimental, physically, psychologically, and financially [3,8]. Family carers of people with dementia have more anxiety, stress, and depression than noncarers, and caring for someone with dementia has more negative impacts than caring for other disorders [9,10] with depression occurring in one third of carers of those with dementia [11]. Without the work of family carers, the formal care system would collapse; supporting family carers is therefore a national and international policy priority.

Given that family carers of people with dementia are such an important resource, it is important to ensure that their own quality of life (QOL) is satisfactory, where we use the World Health Organization definition of QOL as the evaluation by an individual of their position in life, assessed in the context of one's culture, values, goals, expectations, standards, and concerns. Factors influencing QOL include the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and environmental supports. A necessary first step in monitoring and acting to improve QOL is to determine what good QOL looks like in this population. Although there are a number of reviews that have touched on factors that may impact on QOL in carers of people with dementia [12–14], there is no systematic review of this literature. This is a topic that has been identified as needing research attention [15].

2. Aim

The study aim was to complete a systematic review of the quantitative and qualitative literature to identify factors that affect the QOL of family carers of people with dementia.

3. Methods

3.1. Protocol and registration

The methods of this systematic review have been developed in accordance with the recommendations from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols statement [16]. The protocol has been registered in the International Prospective Register of Systematic Reviews–CRD42015029462.

3.2. Literature search

Quantitative, qualitative, and mixed-methods studies, published in English, were searched using accepted systematic review methodology in the electronic databases PubMed, PsycINFO, Web of Science (WoS), and Scopus. The search date was recorded, and all studies identified up to this time were included no matter their date of publication. The gray literature database OpenGrey and the Internet were also searched. Our search strategy was designed to be broad enough and sensitive enough to ensure that we captured all potentially relevant studies (Table 1).

In addition to a highly sensitive electronic search strategy, we used other lateral searches which can be helpful in identifying observational and qualitative studies [17]. These included (1) checking the reference lists from primary studies and systematic reviews ("snowballing") and (2) citation searches using the "Cited by" option on WoS, Google Scholar, and Scopus, and the "Related articles" option in PubMed and WoS ("lateral searching").

3.3. Eligible studies, inclusion and exclusion criteria

The aim of this review was to explore, in detail, factors associated with the QOL of family carers of people with dementia. The review included quantitative, qualitative, and mixed-methods articles that explored this relationship. Only original articles were included. Reviews,

Table 1
Search strategy terms

Search terms	
#1 dement*	#7 "quality of life"
#2 alzheimer*	#8 QOL
#3 (#1 OR #2)	#9 QL
#4 carer*	#10 HRQL
#5 caregiver*	#11 HRQOL
#6 (#4 OR #5)	#12 wellbeing
	#13 (#7 OR #8 OR #9 OR #10 OR #11 OR #12)
	#14 informal
	#15 unpaid
	#16 spous*
	#17 family
	#18 (#14 OR #15 OR #16 OR #17)
	#19 (#3 AND #6 AND #13 AND #18)

NOTE. All results were filtered by English language.

commentaries, editorials, conference proceedings, validation, and developmental studies were excluded. We excluded interventional studies from this review, as we predicted that the mechanism in which the intervention might impact carer QOL would complicate the interpretation of findings and limit the clarity of inference possible. The relationship between an intervention and carer QOL would likely be opaque as it was unlikely to be the primary outcome. Included quantitative studies were required to use and report validated measures of generic or disease-specific QOL. Similarly, factors that were compared with carer QOL were required to be measured and reported using validated instruments.

Qualitative studies were limited to those reporting in-depth individual interviews and focus groups that explicitly asked family carers of people with dementia what they considered important to their QOL, or how their QOL had been affected by caring for someone with dementia. All studies included in this review were required to have a sample, or subsample, of family (i.e., family or friend) carers of people with dementia. We did not exclude carers on the basis of the characteristics of the person they cared for (e.g., dementia severity, subtype). We did however exclude studies that covered formal (i.e., paid) carers only, as their motivations and relationship to the person with dementia will be different from those of family carers.

3.4. Study selection

Electronic search results were downloaded into Mendeley^TM bibliographic software where duplicates were deleted. A pragmatic strategy of combining auto- and hand-searching methods of identifying duplicates was used [18]. Two reviewers (N.F. and T.P.) screened titles and abstracts independently against the predefined inclusion and exclusion criteria. Full articles were sought for all potentially relevant studies. All disagreements concerning inclusion were resolved by a group discussion and input by a third researcher (S.D.).

3.5. Quality assessment

We used the Mixed Methods Appraisal Tool (MMAT), which was specifically developed for mixed-methods reviews [19]. This appraisal tool calculates the quality score of a study by dividing the number of positive responses (presence of criteria scored as 1) by the number of "relevant criteria" $\times$ 100. The benefit of this tool is that it makes no value judgment on the relative merits of quantitative versus qualitative methods [19]. Two independent reviewers (N.F. and T.P.) scored eligible studies using this tool. Disagreements in scores were resolved through a group discussion and input from a third researcher (S.D.). At present, there is no consensus or empirically tested method for the exclusion of noninterventional quantitative studies and qualitative studies from reviews on the basis of quality alone; however, to ensure that low-quality studies did not bias the findings,

we excluded any study that failed either the MMAT screening questions or scored 25% or lower on the MMAT.

3.6. Data extraction

Data were extracted independently by two authors (N.F. and T.P.) for all studies that met the inclusion criteria. These data were entered into a predesigned form, which was then piloted. The extracted data included data source, study setting, sample characteristics, objectives, and design. Research assistants subsequently confirmed the accuracy of the extracted data. Outcome measures, the QOL measure used, and results (related to factors affecting carer QOL) were extracted from quantitative outcomes. To gain consistency in results extracted, we used univariate and bivariate results when presented. If relevant information was not presented sufficiently in the identified articles, it was deemed "not reported." We did not approach the authors for clarification. Themes identified by original article authors and findings were extracted from qualitative studies.

3.7. Synthesis

A narrative synthesis method was used to describe the results and followed the general framework set out by Popay et al. [20]. The results section was divided into thematic headings of independent factors that affect, or do not affect, the QOL of family carers of people with dementia. Themes were identified using an inductive approach, driven by the reported outcomes in the results sections of the included articles. Initially, themes from relevant qualitative studies were extracted. Two authors (N.F. and S.D.) then reviewed articles to determine which quantitative outcomes had been compared to carer QOL. These outcomes, regardless of significance, were grouped independently into subthemes and then themes by the two authors. A carer with lived experience of being a family carer of someone with dementia reviewed the themes identified (T.B.).

Two authors (N.F. and T.D.) reviewed the data independently from the included articles and identified factors that were related or unrelated to carer QOL (as determined by a threshold of $P < .05$). Where possible, the relationship between independent factors and the total carer QOL score was entered into a table. QOL subscales (and not the total score) were reported in the article, and these were also included as long as these subscales had face validity; additional notes were made in these circumstances. A summary code was used to describe the amount of evidence supporting an association for each factor in accordance with previously established methods [21,22]. Symbols were used to represent positive ($+$) or negative ($-$) relationships. We calculated the percentage of studies supporting each relationship by dividing the number of studies that found a relationship by the total number of studies that investigated that factor. As in previous reviews [22,23], a "summary of association" decision was used: unrelated (0%–33% of studies

supporting association); unclear (34%–59% of studies supporting an association); or related (60%–100% of studies were associated).

4. Results

4.1. Study selection

The search was conducted on the 12th November 2015; 1919 articles were identified using our search strategy. After automatic and manual deduplication, the titles and abstracts were screened for 909 articles identified. Of the abstracts screened, 104 articles were deemed potentially relevant, and therefore, full texts were obtained. We were only unable to access a single full-text article [24], which could not be identified or obtained through traditional methods (i.e., interlibrary request, online searches). The article itself, and the journal volume, did not appear on the publisher's web site. We were unable to locate the authors' contact details to request the full text directly; however, as the article was published in Supplementary Material, it is unlikely the content would be relevant for this review. After reading the full texts of 104 articles, 46 articles were found to meet the inclusion criteria. An additional eight articles were identified through snowballing and lateral search techniques. See Fig. 1 for the flowchart of the review process and reasons why articles were excluded. Descriptive data were extracted from the 51 studies (54 articles).

4.2. Participant and study characteristics

Of the 51 studies (participant $n = 10,510$), three were qualitative [25–27], one was mixed-methods study [28], and the rest were quantitative in design. Participants were recruited internationally, with the United States (eight studies), Australia (four studies), Brazil (four studies) and the Netherlands (four studies) being the most common countries for recruitment. Only a single study conducted research across multiple countries [29,30]. Overall, 5332 carers were female and were most often spouses or children of the person with dementia. The care recipients in the studies had a diagnosis of Alzheimer disease (23 studies), nonspecific dementia (17 studies), dementia with multiple pathologies (nine studies), young-onset dementia (one study), and frontotemporal dementia (one study). In the quantitative studies, carer QOL was measured using a number of outcomes, the most common being the SF-36 (14 studies), QOL-AD (10 studies), and SF-12 (seven studies). For a full description of the studies, see Appendix A.

4.3. Risk of bias across studies

Many studies did not report in sufficient detail the methodology used, and therefore, it was unclear whether there were sources of bias in the studies. Six studies scored 100%, 15 studies scored 75%, and 20 studies scored 50% on the MMAT. Ten studies scored 25% or less on the MMAT and
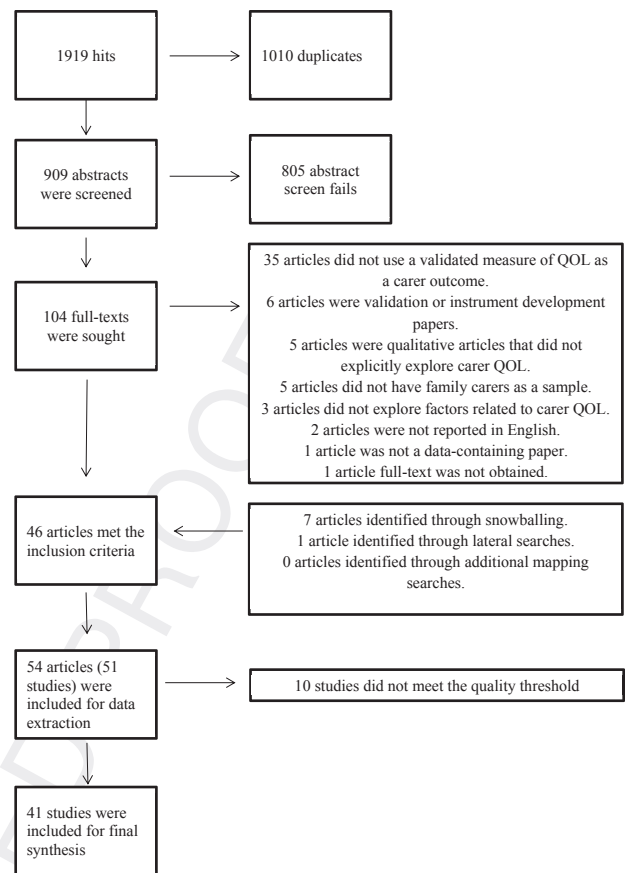

Fig. 1. Flow diagram of the systematic review process. Abbreviation: QOL, quality of life.

thus were excluded from this review. It is important to note that the MMAT score reflects the authors' own reporting of the methods used and may not represent the actual quality of the study. For MMAT scores for each study, see Appendix A.

4.4. Narrative synthesis

The remaining 41 studies (participant $n = 5539$) were included in the narrative synthesis. Of the 41 studies, the studies originated from Europe ($n = 25$), North America ($n = 5$), South America ($n = 5$), Asia ($n = 3$), and Australia ($n = 3$), with no studies from Africa. After extracting themes from qualitative studies and identifying common themes among independent variables from quantitative studies, we developed 10 themes. A table outlining the 10 themes and characterizing the key findings for each is provided in Appendix B. These themes were as follows:

1. Demographics
2. Carer–patient relationship
3. Dementia characteristics
4. Demands of caring
5. Carer health
6. Carer emotional well-being
7. Support received
8. Carer independence

9. Carer self-efficacy
10. Future

4.4.1. Demographics

The nature of the quantitative studies identified meant that demographic information, on both the carer and the person with dementia, was commonly compared to carer QOL. Across all the quantitative studies, there was no strong evidence to suggest that the demographic characteristics of either the carer or the person with dementia impacted on carer QOL. Factors including carer gender and marital status, and the age and education level of the person with dementia, all appeared to be unrelated to carer QOL [31–33]. Data were less clear on associations between carer QOL and carer age, carer education, person with dementia gender, and person with dementia marital status. However, there was emerging evidence that the living situation of the person with dementia and their carer may impact carer QOL, although the evidence is limited. Carers who lived with the person they cared for had poorer QOL compared with those who did not [31]. Perhaps paradoxically, there was also evidence that family carer QOL was poorer where people with dementia lived in a care home or had had a care home placement in the past 12 months [34,35]. The findings are likely to reflect that the living situation of a person with dementia alone does not inform us of the reasons why the person with dementia does not reside with the carer. Indeed, living situation is likely to be a proxy for a number of factors including disease severity, neuropsychiatric symptoms, functional impairment of the person with dementia, and carer factors (e.g., coping style or ill-health).

4.4.2. Carer–patient relationship

The importance of the relationship between the carer and the person with dementia emerged from the quantitative literature. The literature surrounding this theme is sparse, with the predominant factor explored in studies being whether the type of relationship between the carer and the person with dementia (e.g., spouse [not defined by marriage but incorporating those married or not and whatever the gender relationship], child) influences carer QOL. Two studies found that being a spousal carer was associated with worse carer QOL, compared to offspring who cared [31,36]. This may be cofounded by coresidence or not of the person with dementia and the family carer. A single study found carer emotional closeness impacted on carer QOL, as measured by the mental health component of the SF-12 [37]. Only one study examined sexual satisfaction in spousal carers, and it was found to be unrelated to carer QOL [38].

Within the qualitative literature, one study identified that perceived change in relationship was seen to be an important determinant of carer QOL [25], with the change in the ability to communicate with the person with dementia described as upsetting. However, this was not identified as a key theme in the other qualitative studies [26,27].

4.4.3. Dementia characteristics

A common theme identified in much of the qualitative literature was that the health of the person with dementia is seen as a vital determinant of carer QOL [26,27]. Quantitative literature in part supports this, with unmet medical needs being related to carer QOL [39]. This is however a single index of health and is not synonymous with disease progression. The majority of the literature finds no association between carer QOL and severity of cognitive impairment [31,33,38,40–44] or global severity [43–46]. Interestingly, the duration of the disorder and age of onset were generally related to carer QOL [33,35], with younger onset and longer duration of disease being related to better carer QOL.

Functional impairment of the person with dementia, which is a predictor of carer burden [46], was frequently reported as being negatively associated with carer QOL [31,36,38,41,42,48,49]. However, a number of studies found no such association [32,33,40,50], making it unclear whether there is a relationship between these factors.

In the literature reviewed, we found indications that it may be the symptoms of the disease, in particular comorbidities, which are associated with carer QOL. A single study identified that carers of people with Lewy body dementia had a poorer QOL than those with AD [51]. This could be due to the presence of hallucinations which are common in the disease. This is supported by the relationship between behavioral and psychological symptoms in dementia, with studies generally finding a negative association [31,42,48,51], although this is not consistent [33,38,41,42,50].

Several studies have identified that carer QOL is interlinked with the QOL of the person with dementia [31,33,38,49]. This is a fundamental finding because QOL is a broad and holistic measure of the life experiences of the individual. However, caution should be taken in the interpretation of these findings, particularly if they use proxy reports of the QOL of the person with dementia. Carers may project their assessment of their own QOL and health state into their assessment of the person with dementia [53]. In one study, the authors found that there was no relationship between carer QOL and patient-reported measures of QOL of the person with dementia, but there was a relationship with carer-reported QOL of the person with dementia [41].

The final factor identified under this theme was the person with dementia's awareness of the disease, with a negative association being reported between impairment of insight and carer QOL in all studies that measured this outcome [38,49]. This finding is also supported in a qualitative study, which found that carers want to be recognized for their caring role [25].

4.4.4. Carer health

A number of factors identified were related to carer physical and mental health, termed here "carer health status." Carer depression was the most common factor associated with low carer QOL. Apart from a single study [48], carer

depression was consistently found to be negatively associated with carer QOL [31–33,41,43,44,51,54,55]. Carer anxiety was only explored in two studies, but it too was found to be negatively associated with carer QOL [33,56]. Impairment in carer mental health, physical health, health in general, and sleep quality were all negatively associated with carer QOL [44,50,56–59]. No association was reported between carer QOL and daytime sleepiness in the single study that measured this outcome [59]. The observed relationship between carer QOL and health indices may be a function of many of the studies this review using generic health-related QOL measures (e.g., SF-36).

4.4.5. Carer emotional well-being

This theme was composed of emotional reactions toward the caring role and was rarely explored in literature. Carer QOL was negatively associated with carer burnout and carer stress [43,56]. The ability to find meaning in caring and a sense of coherence were found to be positively related to carer QOL [44,60]. More broadly, it was unclear whether carer satisfaction with life was associated with carer QOL, with one study reporting a positive association [55], and another reporting no such association [54]. However, from the qualitative studies, it was reported that most carers felt some satisfaction and reward from caregiving, which was perceived to improve their QOL [27].

4.4.6. Demands of caring

The theme of demands of caring was composed of subjective carer burden measures (e.g., Zarit Carer Burden Inventory) and objective physical and time commitment outcomes. In all studies that compared carer QOL to subjective carer burden, there was a negative association reported [32,33,36,38,50,54,55,60–63].

Conversely, it does not appear that objective measures of carer demand are related consistently to carer QOL. Only two studies identified that objective measures of carer demands, time spent caring [31], and length of time caring [60], respectively, were negatively associated with carer QOL.

4.4.7. Support received

Within the qualitative literature, carers often felt that they did not receive adequate support in general or that the level of support from professionals did not meet their expectations [25,26]. As a result, carers felt that receipt of additional support would improve their QOL [26]. In the quantitative literature, there is little evidence that the amount of support received positively affects carer QOL [36,52], with the majority of studies reporting no association between the two [31,32,50]. However, receiving support may reflect a restriction in available household resources, with finances dictating the quality and choice of both formal support and health care received. Some carers believed that their QOL would benefit from additional financial support [27]. The majority of evidence shows increased carer income to be related to improved QOL [32,60,63].

4.4.8. Carer independence

Carer independence was defined as activities and time not spent on caring duties. The relationship between carer independence and carer QOL has been explored [31,32,48,65] by measuring the activities carers participate in other than caring. Irrespective of the activity measured (e.g., leisure activities, employment, household activities, or service to others), the majority of the quantitative literature reports a positive association between carer independence and carer QOL. Qualitative research also supports the notion that carer independence is important to carer QOL. In one qualitative study, it was identified that carers felt their QOL would improve if they could have more time for themselves, away from the person that they are caring for [26]. Other studies reported that carer independence was important in allowing carers to pursue their own interests, potentially activities which they had discontinued due to caring [25,27].

4.4.9. Carer self-efficacy

Self-efficacy is the individual's belief that they are able to influence successfully domains that affect their lives [64]. For carers in dementia, self-efficacy may be dominated by an individual's confidence in coping effectively with different caring tasks. Few studies have used measures devised specifically to measure self-efficacy, however, those that have found a positive association with carer QOL [52,63]. One study found that coping skills were positively associated with carer QOL [63].

4.4.10. Future

Dementia being a neurodegenerative disorder means that the role of the carer is ever changing. Qualitative research has identified that worrying about the future, particularly in relation to disease progression, is perceived as worsening carer QOL [26,27]. No quantitative study has explored whether worrying about the future impacts on carer QOL; however, it is possible that carer anxiety may also capture elements of this theme.

5. Discussion

This systematic review seeks to provide a comprehensive evaluation of factors that are associated with the QOL of family carers of people with dementia, drawing on both the quantitative and qualitative literature. Recognition of the modifiable factors that may improve or harm the QOL of family carers of people with dementia can guide the formulation and delivery of policy, treatment, care, and support to maintain good QOL in the carers who play such a vital role in dementia care.

Of the 10 themes inductively identified, better carer health (physical and mental) was most consistently associated with better carer QOL. This is an important finding because this is a potentially modifiable factor and serves to underline the potential value of attending effectively to carer

heath. Greater carer independence was also positively related to better carer QOL [31,32,48,65] with the positive finding that carers perceived time pursuing their own interests as beneficial [25,27]. Systems and services should work to maximize carer health and support their independence while still caring. The themes "carer emotional well-being," "future," and "carer self-efficacy" all present potential avenues for carer support and quality improvement for carers that would be likely to be also beneficial for people with dementia. Further empirical research is needed to investigate these findings and to test the impact of interventions designed to enhance carer QOL measuring outcomes for the person with dementia as well as the family carer.

This review also identified several themes that are less likely to impact carer QOL, with most demographic factors being unrelated to carer QOL. The only exception was the living situation of carers and the person with dementia, which may underpin a number of other themes such as support received and demands of caregiving. Although the level of cognitive impairment or functional impairment of the person with dementia does not appear to impact carer QOL, the health status of the person with dementia and behavioral and psychological symptoms appear to be detrimental. This supports their importance as targets for intervention. Functional impairment is likely to be mediated by coping strategies as well as additional support received, and therefore, the subsequent impact on carer QOL may be increased or decreased. The dissociation between objective and subjective burden is indicative that carer appraisal of the situation and perceived stress are likely to be the important determinant of carer QOL. The relationship between income and carer QOL needs further exploration as its effects are likely to be moderated by the availability and funding of statutory services as well as the source of the income (e.g., carers allowance, pension) and how the income is used for carer support.

Measures of QOL can be generic (i.e., designed to be used across all disorders and health states) or disease/condition specific (i.e., relating to a single disorder or health state). It is apparent from the review that generic measures of QOL (e.g., SF-36, EQ-5D) are most commonly used to assess QOL in carers of people with dementia. This is in line with a previous systematic review that investigated the types of instruments used to measure carer QOL of people with dementia, which found that all studies used generic measures of QOL [66]. This is problematic as generic measures of QOL may fail to capture disease-specific elements crucial to QOL in that condition and may not be sensitive enough to detect changes in outcome following intervention [67,68].

We identified a number of studies that appear to have used a disease-specific measure of QOL, most commonly the QOL-AD, as a measure of the QOL of the carer of the person with dementia. This is surprising, and the

rationale for this is not clear. This tool was not developed in any way to assess the QOL in carers of people with dementia; instead, it is a measure of the QOL of the person with dementia [68]. This is not the same thing, and it does not appear to have been validated as a condition-specific measure of carer QOL in dementia. Given this, any data from its use to measure the QOL of carers are likely to subject to substantial measurement error. However, the use of this instrument in this way is likely to signify dissatisfaction with the generic QOL instruments available and indicate a demand for a condition-specific measure of carer QOL in dementia. This is a clear gap in the literature. We only identified two validated measures of carer QOL in dementia, the CGQOL [70] and the ACQLI [71]. However, these measures are not widely used; they were not used in any of the studies identified in this systematic review. A formal evaluation of the development process of these measures is needed to ascertain whether they are suitable for future use.

This review focused on capturing studies that investigated factors associated with carer QOL internationally, albeit published in English. Family carers play a vital role in dementia care and support across all countries. Of the 41 studies identified, the majority originated from European countries ($n = 25$), with few studies being reported in North America, South America, Asia, and Australia ($n < 6$ each). No studies investigated factors that affect carer QOL in Africa. Only a single study included participants across multiple countries [29,30], and then, all countries were European; that study was ultimately excluded because of low study quality. We need cross-national studies of the determinants and improvement of family carer QOL in dementia. There are fascinating differences in supports and systems of care, within and between countries. We may have much to learn from the supports and systems across lower and middle income countries as well as the more developed economies [72].

There are limitations and strengths to this review. First, in this review, we only searched for noninterventional studies, as we predicted that the mechanism in which the intervention might impact carer QOL would complicate the interpretation of findings. The relationship between an intervention and carer QOL would be likely to be opaque as it was often not the primary outcome. Second, as many of the studies identified do not have carer QOL as a primary outcome, findings could be incidental. The number of statistically significant associations with carer QOL may have been inflated as correlation matrices were common, without correction for multiple comparisons, so increasing the risk of type I error. Third, there was heterogeneity between groups, with characteristics of the carer varying between studies. Most carers were either spouses or children, and therefore, the conclusions made here may not be generalizable to other carer relationships. Heterogeneity and missing information were also common in the characteristics of the person with

dementia. Fourth, in an attempt to summarize the findings, we adopted a "vote counting" method. Although there is a place for such a method as a synthesis tool [20], one shortcoming of this approach is that it assumes equal weighting to studies that may not be equal (e.g., different sample size). Fifth, given the heterogeneity of the studies reviewed, we did not calculate standardized effect sizes enabling associations to be compared directly between studies. This would be methodologically complex but is an area for further research. Finally and importantly, there is a lack of data on how ethnic and cultural factors might influence carer QOL and its measurement. This is a function of this seldom having been investigated in the literature available, either within or between countries. There is a clear need for more and better research in this fundamental area.

6. Conclusions

This review identifies that the QOL of carers of people with dementia is a complex construct and is affected by multiple factors. Additional research is needed to explore these factors and carer type in more detail, in well-designed studies that have carer QOL as a primary outcome. The data generated would allow policy makers, service providers, and clinicians to promote and maintain good QOL in family carers to the benefit of the carers, those they care for, and society as whole. These themes can be tested empirically in future research, and this might well lead to the combination, change, or deletion of themes as well as the generation of new ones. There is a clear need for more cross-cultural research. The lack of an established and psychometrically sound condition–specific measure of QOL for carers of people with dementia is a clear gap in the evidence base. The findings presented here could provide the groundwork for development of such a measure.

Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.jalz.2016.12.010.

RESEARCH IN CONTEXT

1. Systematic review: We completed a systematic review of the literature using electronic databases (e.g., PubMed, PsycINFO) to identify factors that promote or diminish the QOL of family carers of people with dementia. Previous reviews were used to identify gaps in the literature.

2. Interpretation: Thematic analyses of the data identified 10 themes that determine family carer QOL in dementia. Carer independence and health were commonly found to be related to carer QOL. Demographic factors were generally unrelated to carer QOL.

3. Future directions: Certain themes need further exploration. We identified the need for the development of a psychometrically sound measure of QOL specifically for carers of people with dementia, to provide an outcome that is responsive to change. Further cross-cultural research is needed to explore the factors that affect the QOL of family carers of people with dementia outside the United States and Europe.

References

[1] Alzheimer's Disease International. The Global Economic Impact of Dementia. London, England: Alzheimer's Disease International (ADI); 2010.

[2] Alzheimer's Disease International. World Alzheimer's Report 2009. London, England: Alzheimer's Disease International; 2009.

[3] Department of Health. Living Well with Dementia: A National Dementia Strategy. London: TSO; 2009.

[4] Banerjee S, Murray J, Foley B, Atkins L, Schneider J, Mann A. Predictors of institutionalisation in people with dementia. J Neurol Neurosurg Psychiatry 2003;74:1315–1316.

[5] Nolan M, Keady J, Grant G. Developing a typology of family care: implications for nurses and other service providers. J Adv Nurs 1995; 21:256–265.

[6] Murray J, Schneider J, Banerjee S, Mann A. EUROCARE: a cross-national study of co-resident spouse carers for people with Alzheimer's disease: II—a qualitative analysis of the experience of caregiving. Int J Geriatr Psychiatry 1999;14:662–667.

[7] Aneshensel CS, Pearlin LI, Mullan JT, Zarit SH, Whitlatch CJ. Profiles in Caregiving: The Unexpected Career. Academic Press; 1995.   Q7

[8] O'Rourke N, Tuokko H. The psychological and physical costs of caregiving: The Canadian Study of Health and Aging. J Appl Gerontol 2000;19:389–404.

[9] Cooper C, Balamurali T, Livingston G. A systematic review of the prevalence and covariates of anxiety in caregivers of people with dementia. Int Psychogeriatr 2007;19:175–195.

[10] Moise P, Schwarzinger M, Um M-Y. Dementia Care in 9 OECD Countries. Paris: OECD Publishing; 2004.

[11] Schoenmakers B, Buntinx F, Delepeleire J. Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. Maturitas 2010;66:191–200.

[12] Crellin NE, Orrell M, McDermott O, Charlesworth G. Self-efficacy and health-related quality of life in family carers of people with dementia: a systematic review. Aging Ment Health 2014;18:954–969.

[13] de 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. Qual Prim Care 2015;23:18–30.

[14] Zacharopoulou G, Zacharopoulou V, Lazakidou A. Quality of life for caregivers of elderly patients with dementia and measurement tools: a review. Int J Health Res Innov 2015;3:49–64.

[15] Manthrope J, Bowling A. Quality of life measures for carers for people with dementia: measurement issues, gaps in research and promising paths. Res Policy Plan 2016;31:163–178.

[16] Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. Ann Intern Med 2009;151:264–269.

[17] Greenhalgh T, Peacock R. Effectiveness and efficiency of search methods in systematic reviews of complex evidence: audit of primary sources. BMJ 2005;331:1064–1065.

[18] Qi X, Yang M, Ren W, Jia J, Wang J, Han G, et al. Find duplicates among the PubMed, EMBASE, and Cochrane library databases in systematic review. PLoS One 2013;8.

[19] Pluye P, Gagnon MP, Griffiths F, Johnson-Lafleur J. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in mixed studies reviews. Int J Nurs Stud 2009;46:529–546.

[20] Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, et al. Guidance on the conduct of narrative synthesis in systematic reviews. A Product from the ESRC Methods Programme Version 1, 2006.

[21] Sallis JF, Cervero RB, Ascher W, Henderson KA, Kraft MK, Kerr J. An ecological approach to creating active living communities. Annu Rev Public Health 2006;27:297–322.

[22] Stubbs B, Eggermont L, Soundy A, Probst M, Vandenbulcke M, Vancampfort D. What are the factors associated with physical activity (PA) participation in community dwelling adults with dementia? A systematic review of PA correlates. Arch Gerontol Geriatr 2014;59:195–203.

[23] Vancampfort D, Vanderlinden J, Stubbs B, Soundy A, Pieters G, Hert MD, et al. Physical activity correlates in persons with binge eating disorder: a systematic review. Eur Eat Disord Rev 2014;22:1–8.

[24] Costa B, Sanvitto A, Turazzini M, Silvestri M. Alzheimer disease and caregivers' stress. Neurol Sci 2000;21:S165.

[25] Jones C, Edwards RT, Hounsome B. Qualitative exploration of the suitability of capability based instruments to measure quality of life in family carers of people with dementia. ISRN Family Med 2014; 2014:919613.

[26] Vellone E, Piras G, Talucci C, Cohen MZ. Quality of life for caregivers of people with Alzheimer's disease. J Adv Nurs 2008;61:222–231.

[27] Vellone E, Piras G, Venturini G, Alvaro R, Cohen MZ. Quality of life for caregivers of people with Alzheimer's disease living in Sardinia, Italy. J Transcult Nurs 2012;23:46–55.

[28] Duggleby WD, Swindle J, Peacock S, Ghosh S. A mixed methods study of hope, transitions, and quality of life in family caregivers of persons with Alzheimer's disease. BMC Geriatr 2011;11:88.

[29] Alvira MC, Risco E, Cabrera E, Farre M, Rahm Hallberg I, Bleijlevens MH, et al. The association between positive-negative reactions of informal caregivers of people with dementia and health outcomes in eight European countries: a cross-sectional study. J Adv Nurs 2015;71:1417–1434.

[30] Bleijlevens MH, Stolt M, Stephan A, Zabalegui A, Saks K, Sutcliffe C, et al. Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia: evidence from the European RightTimePlaceCare prospective cohort study. J Adv Nurs 2015;71:1378–1391.

[31] Bruvik FK, Ulstein ID, Ranhoff AH, Engedal K. The quality of life of people with dementia and their family carers. Dement Geriatr Cogn Disord 2012;34:7–14.

[32] Papastavrou E, Andreou P, Middleton N, Papacostas S, Georgiou IK. Factors associated with quality of life among family members of patients with dementia in Cyprus. Int Psychogeriatr 2014;26:443–452.

[33] Santos RL, Sousa MF, Simões-Neto JP, Nogueira ML, Belfort TT, Torres B, et al. Caregivers' quality of life in mild and moderate dementia. Arq Neuropsiquiatr 2014;72:931–937.

[34] Argimon JM, Limon E, Vila J, Cabezas C. Health-related quality-of-life of care-givers as a predictor of nursing-home placement of patients with dementia. Alzheimer Dis Assoc Disord 2005;19:41–44.

[35] Riedijk SR, De Vugt ME, Duivenvoorden HJ, Niermeijer MF, Van Swieten JC, Verhey FR, et al. Caregiver burden, health-related quality of life and coping in dementia caregivers: a comparison of frontotemporal dementia and Alzheimer's disease. Dement Geriatr Cogn Disord 2006;22:405–412.

[36] Serrano-Aguilar PG, Lopez-Bastida J, Yanes-Lopez V. Impact on health-related quality of life and perceived burden of informal caregivers of individuals with Alzheimer's disease. Neuroepidemiology 2006;27:136–142.

[37] Fauth E, Hess K, Piercy K, Norton M, Corcoran C, Rabins P, et al. Caregivers' relationship closeness with the person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. Aging Ment Health 2012; 16:699–711.

[38] Nogueira MM, Neto JP, Sousa MF, Santos RL, Rosa RD, Belfort T, et al. Spouse-caregivers' quality of life in Alzheimer's disease. Int Psychogeriatr 2015;27:837–845.

[39] Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. J Am Geriatr Soc 2013;61:2087–2095.

[40] Andrieu S, Rive B, Guilhaume C, Kurz X, Scuvée-Moreau J, Grand A, et al. New assessment of dependency in demented patients: impact on the quality of life in informal caregivers. Psychiatry Clin Neurosci 2007;61:234–242.

[41] Novelli MM, Caramelli P. The influence of neuropsychiatry and functional changes on quality of life in Alzheimer's disease. Dement Neuropsychol 2010;4:47–53.

[42] Schiffczyk C, Romero B, Jonas C, Lahmeyer C, Müller F, Riepe MW. Efficacy of short-term inpatient rehabilitation for dementia patients and caregivers: prospective cohort study. Dement Geriatr Cogn Disord 2013;35:300–312.

[43] Takai M, Takahashi M, Iwamitsu Y, Oishi S, Miyaoka H. Subjective experiences of family caregivers of patients with dementia as predictive factors of quality of life. Psychogeriatrics 2011;11:98–104.

[44] Välimäki TH, Vehviläinen-Julkunen KM, Pietilä AM, Pirttilä TA. Caregiver depression is associated with a low sense of coherence and health-related quality of life. Aging Ment Health 2009; 13:799–807.

[45] Lopez-Bastida J, Serrano-Aguilar P, Perestelo-Perez L, Oliva-Moreno J. Social-economic costs and quality of life of Alzheimer disease in the Canary Islands, Spain. Neurology 2006;67:2186–2191.

[46] Välimäki TH, Martikainen JA, Hongisto K, Väätäinen S, Sintonen H, Koivisto AM. Impact of Alzheimer's disease on the family caregiver's long-term quality of life: results from an ALSOVA follow-up study. Qual Life Res 2016;25:687–697.

[47] Razani J, Kakos B, Orieta-Barbalace C, Wong JT, Casas R, Lu P, et al. Predicting caregiver burden from daily functional abilities of patients with mild dementia. J Am Geriatr Soc 2007;55:1415–1420. **Q8**

[48] Clark MS, Bond MJ. The effect on lifestyle activities of caring for a person with dementia. Psychol Health Med 2000;5:13–27.

[49] Conde-Sala JL, Reñé-Ramírez R, Turró-Garriga O, Gascón-Bayarri J, Juncadella-Puig M, Moreno-Cordón L, et al. Factors associated with the variability in caregiver assessments of the capacities of patients with Alzheimer disease. J Geriatr Psychiatry Neurol 2013;26:86–94.

[50] Coen RF, O'Boyle CA, Swanwick GR, Coakley D. Measuring the impact on relatives of caring for people with Alzheimer's disease: quality of life, burden and well-being. Psychol Health 1999;14:253–261.

[51] Thomas P, Lalloué F, Preux PM, Hazif-Thomas C, Pariel S, Inscale R, et al. Dementia patients caregivers quality of life: the PIXEL study. Int J Geriatr Psychiatry 2006;21:50–56.

[52] Zhang S, Edwards H, Yates P, Li C, Guo Q. Self-efficacy partially mediates between social support and health-related quality of life in family caregivers for dementia patients in Shanghai. Dement Geriatr Cogn Disord 2014;37:34–44.

[53] Arons AM, Krabbe PF, Schölzel-Dorenbos CJ, van der Wilt GJ, Rikkert MG. Quality of life in dementia: a study on proxy bias. BMC Med Res Methodol 2013;13:110.

[54] Moreno JA, Nicholls E, Ojeda N, De los Reyes-Aragón CJ, Rivera D, Arango-Lasprilla JC. Caregiving in dementia and its impact on psychological functioning and health-related quality of life: Findings from a Colombian sample. J Cross cult Gerontol 2015;30:393–408.

[55] Perrin PB, Morgan M, Aretouli E, Sutter M, Snipes DJ, Hoyos GR, et al. Connecting health-related quality of life and mental health in dementia caregivers from Colombia, South America. J Alzheimers Dis 2014;39:499–509.

[56] Bruce DG, Paley GA, Nichols P, Roberts D, Underwood PJ, Schaper F. Physical disability contributes to caregiver stress in dementia caregivers. J Gerontol A Biol Sci Med Sci 2005;60:345–349.

[57] Bell CM, Araki SS, Neumann PJ. The association between caregiver burden and caregiver health-related quality of life in Alzheimer disease. Alzheimer Dis Assoc Disord 2001;15:129–136.

[58] Cupidi C, Realmuto S, Lo Coco G, Cinturino A, Talamanca S, Arnao V, et al. Sleep quality in caregivers of patients with Alzheimer's disease and Parkinson's disease and its relationship to quality of life. Int Psychogeriatr 2012;24:1827–1835.

[59] Lee D. Health-related quality of life in dementia caregiving: relationships with sleep quality and daytime sleepiness. Prim Care Community Psychiatry 2008;13:119–125.

[60] McLennon SM, Habermann B, Rice M. Finding meaning as a mediator of burden on the health of caregivers of spouses with dementia. Aging Ment Health 2011;15:522–530.

[61] Coen RF, O'Boyle CA, Coakley D, Lawlor BA. Individual quality of life factors distinguishing low-burden and high-burden caregivers of dementia patients. Dement Geriatr Cogn Disord 2002; 13:164–170.

[62] Schölzel-Dorenbos CJ, Draskovic I, Vernooij-Dassen MJ, Olde Rikkert MG. Quality of life and burden of spouses of Alzheimer disease patients. Alzheimer Dis Assoc Disord 2009;23:171–177.

[63] Tay KC, Seow CC, Xiao C, Lee HM, Chiu HF, Chan SW. Structured interviews examining the burden, coping, self-efficacy, and quality of life among family caregivers of persons with dementia in Singapore. Dementia (London) 2016;15:204–220.

[64] Bandura A. Self-Efficacy. Corsini Encycl. Psychol. John Wiley & Sons, Inc.; 2010.

[65] Zawadzki L, Mondon K, Peru N, Hommet C, Constans T, Caillard P, et al. Attitudes towards Alzheimer's disease as a risk factor for caregiver burden. Int Psychogeriatr 2011;23:1451–1461.

[66] Jones C, Edwards RT, Hounsome B. A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people with dementia residing in the community. Int Psychogeriatr 2012;24:6–18.

[67] Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. Health Technol Assess 1998;2:i–iv. 1–74.

[68] Patrick DL, Erickson P. Health Status and Health Policy. Oxford: Oxford University Press; 1993.

[69] Logsdon RG, Gibbons LE, McCurry SM, Teri L. Quality of life in Alzheimer's disease: patient and caregiver reports. J Ment Health Aging 1999;5:21–32.

[70] Vickrey BG, Hays RD, Maines ML, Vassar SD, Fitten J, Strickland T. Development and preliminary evaluation of a quality of life measure targeted at dementia caregivers. Health Qual Life Outcomes 2009; 7:56.

[71] Doward LC. The development of the Alzheimer's carers' quality of life instrument. Qual Life Res 1997;6:639.

[72] Knapp M, Comas-Herrera A, Somani A, Banerjee S. Dementia: International Comparisons. London, England: Personal Social Services Research Unit; 2007.