

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. Introduction

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.

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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.

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