

Factors associated with carer quality of life of people with dementia: A systematic review of non-interventional studies

Dr Nicolas Farina¹, Dr Thomas E Page², Dr Stephanie Daley¹, Dr Anna Brown², Prof Ann Bowling⁴, Mr Thurstine Basset³, Prof Gill Livingston⁵, Prof Martin Knapp⁶, Ms Joanna Murray⁷ and Prof Sube Banerjee¹

¹Centre for Dementia Studies, Brighton and Sussex Medical School; ²School of Psychology, University of Kent; ³Health Sciences, University of Southampton, ⁴Lived Experience Advisory Panel, Sussex Partnership NHS Foundation Trust; ⁵Division of Psychiatry, University College London; ⁶Department of Social Policy, London School of Economics; ⁷Institute of Psychiatry, Psychology and Neuroscience, King's College London.

Introduction

Family carers of people with dementia are their most important support in practical, personal and economic terms. They are vital to maintaining their quality of life (QOL). Given the importance of the family carer, it is important to ensure that their own QOL is satisfactory. A necessary first step in monitoring and acting to improve QOL is to determine what good QOL looks like in carers.

Aim:

This review aims to identify factors related to the QOL of family carers of people with dementia.

Methods

We systematically searched a series of research databases (e.g. PubMed, Scopus) for terms related to carers, dementia, family, and quality of life.

We included any quantitative, qualitative or mixed-methods article that explored the factors that effect the QOL of family carers of people with dementia. However, we did exclude interventional studies. Quality of the identified studies were assessed using the Mixed Methods Appraisal Tool.

A narrative synthesis method was used to described the results, divided into thematic headings.

Results

909 studies were identified. Following, screening lateral searches and quality appraisal, 41 studies were included for synthesis. A total of 10 themes were identified (See Figure Below).

The amount and quality of evidence varied between themes. 'Carer health' and 'carer independence' was consistently associated with carer QOL.

Unsurprisingly, 'carer burden' was also closely linked with carer QOL. Themes such as 'carer emotional wellbeing', 'future' and 'carer self efficacy' are all emerging themes that may impact carer QOL.

In contrast, there was little evidence that the demographics of the person with dementia or the carer (e.g. age, education) affected carer QOL.

Discussion

This review identifies that the QOL of carers of people with dementia is a complex construct affected by a number of factors.

Further research is needed to explore these factors and carer type in more detail, in well designed studies. Importantly, there is a need for studies to use psychometrically sound condition-specific measure of QOL for carers of people with dementia as there is a clear gap in the evidence base.

