



Unravelling positive aspects of caregiving in dementia: An integrative review of research literature



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ARTICLE INFO

Keywords:

Family caregiving
Persons with dementia
Positive aspects of caregiving
Research review
Stress and coping process
Meaning-making model
Cognitive emotional regulation

ABSTRACT

Background: Family caregiving is the crucial informal care resource to lessen the burdens associated with dementia. Research in this field has focused on reducing the caregiver's burden, but little attention has been given to promoting the positive aspects of caregiving.

Objectives: To conduct a systematic critical review of research on the nature of positive aspects of caregiving, and the factors predicting this phenomenon among family caregivers of dementia patients, with the ultimate purpose of gaining insights to explain how and why it emerges.

Review methods: A systematic search of the literature was undertaken in the databases OvidMedline, CINAHL, PsycINFO, Web of Science and Scopus, using the keywords 'care* AND Alzheimer OR dementia AND 'positive aspect' OR 'positive experience' OR 'positive perceptions' OR reward OR gain OR 'satisfaction with care*' OR 'care* satisfaction' OR benefit OR uplift OR meaning OR enjoyment OR pleasure OR growth OR hope OR gratification. The Critical Appraisal Skills Programme checklists for qualitative and cohort studies were used to evaluate data quality. Narrative data synthesis was undertaken using the five-stage Whittermore and Knaf method.

Results: A total of 3862 articles were identified, of which 41 were included in this review. The key findings are that positive aspects of caregiving among family caregivers of dementia patients form a multi-dimensional construct which covers four key domains: a sense of personal accomplishment and gratification, feelings of mutuality in a dyadic relationship, an increase of family cohesion and functionality, and a sense of personal growth and purpose in life. By integrating the findings about the nature and conditions predicting positive aspects of caregiving, the presence of three conditions was identified as promoting the emergence of such qualities i) personal and social affirmation of role fulfilment, ii) effective cognitive emotional regulation and iii) contexts which favour finding meaning in the caregiving process.

Conclusion: The findings of this review provide insight into catalysing the paradigm shift from 'reducing stress' to 'optimising positive experience' in developing caregiving support services for dementia, and may guide future empirical study to explain this unique dimension of caregiving experience.

What is already known about the topic?

- Family caregiving for dementia patients is known to be burdensome. Great emphasis has been placed on how to lessen the burden and the associated detrimental health consequences.
- Increasing evidence suggests that the adaptation process of caregiving is characterised by the coexistence of both positive and negative experience.
- Positive aspects of caregiving have been found to be associated with protective health effects on family caregivers.

What this paper adds

- By integrating research findings about the nature of positive aspects of caregiving and the conditions predicting their emergence, the review identifies this construct as multidimensional and as being best understood from a multi-paradigm perspective.
- Positive aspects of caregiving encompass four key domains: a sense of personal accomplishment and gratification, feelings of mutuality in a dyadic relationship, an increase of family cohesion and functionality, and a sense of personal growth and purpose in life.

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- Positive caregiving experience is more likely to exist in the presence of three conditions: personal and social affirmation of role fulfilment, effective cognitive emotional regulation and contexts which favour finding meaning in the caregiving experience.

1. Introduction

Dementia is a global public health pandemic, its prevalence increasing exponentially with age. (Ferri et al., 2005) In 2015, it was estimated that 46.8 million people worldwide were living with dementia, and population aging will double its prevalence over the next 20 years. (Prince et al., 2015) Dementia is a progressive debilitating syndrome characterised by multiple cognitive deficits, mood and behavioural problems, and subsequent disability and dependency. Caring for persons with dementia (PWD) exacts tremendous costs. (Prince et al., 2015) Family caregiving becomes the backbone of informal care and plays a crucial role in supporting dementia care in the community. However, with the need to handle a wide range of physical tasks and distressing emotional and behavioural symptoms, the process of caregiving has been described as progressively more demanding, stressful and frustrating. (Papastavrou et al., 2007) Promoting the effective adaptation of family caregivers to this process is considered to have a high priority in sustaining this valuable resource of informal care for dementia patients.

Most research into the adaptation process of family caregivers focuses on identifying the stressful and negative aspects of the caregiving experience, placed great emphasis on lessening the burden and associated detrimental health consequences. Relatively little attention has been given to the positive aspects of caregiving. In fact, increasing evidence suggests that the adaptation process of caregiving is characterised by the coexistence of both positive and negative experience. (Andrén and Elmståhl, 2005; Narayan et al., 2001) Positive aspects are conceptualised as the extent to which the caregiving roles are experienced as inspiring and rewarding, yielding positive consequences and enriching one's lived experience. (Williams, 2005) The concept has been described as uplift, gratification, reward, growth and satisfaction in the literature. (Kramer, 1997; Duggleby et al., 2009) Instead of regarding the positive aspects of caregiving and its burden as bipolar ends on a continuum, these two dimensions can be regarded as a case of coexistence. Therefore, ignoring the positive aspects of caregiving would limit understanding of the overall adaptation process of family caregivers in dealing with PWD. Indeed, the protective effects on the health of this cohort of family caregivers have been widely reported. They are not only associated with less anxiety and depression, (Williams, 2005) a lower level of perceived disturbance of behavioural symptoms, (Rapp and Chao, 2000) better subjective health (Cohen et al., 1994; Gold et al., 1995) and a sense of role fulfilment (Hirschfeld, 2003; Mausbach et al., 2004) among family caregivers, but also reduce the risk of institutionalising PWD. (Hirschfeld, 2003; Mausbach et al., 2004) Promoting the effective adaptation of family caregivers therefore implies a need to look beyond reducing their burden to optimising the positive aspects of caregiving.

In line with this, a substantial body of knowledge has been generated to identify this phenomenon. However, studies attempting to explain the emergence of positive aspects of caregiving are at a relatively early stage. Though Lawton (Lawton et al., 1991) hypothesised, more than two decades ago, a two-factor model of caregiver appraisal in the hope that caregiving satisfaction (an indicator of its positive aspects) might be better understood as an independent outcome in the stress adaptation process, neither stressors nor coping resources (i.e., caregivers' health and social support) were found to predict such caregiving experience. And even though other studies identified significant predictors of positive caregiving aspects, they only explained a small proportion of their variance (Cheng et al., 2013a,b; Hodge and Sun, 2012; Liew et al., 2010; Lim et al., 2011; Quinn et al., 2012). This may be related to the lack of clear theoretical propositions to conceptualise

their emergence. Addressing this research gap may need a closer scrutiny of the literature, and the purpose of this review paper was hence to capture the nature of the positive aspects of caregiving through a systematic and critical review of the literature, and to identify conditions or factors relating to their emergence.

The research questions for this review were as follow:

1. What are the positive aspects of caregiving among family caregivers of PWD?
2. What are the conditions or factors relating to the emergence of positive aspects of caregiving among family caregivers of PWD?

2. Methods

2.1. Search strategies

The integrative review methods described by Whittemore and Knafl (Whittemore and Knafl, 2005) guided the literature search process. Relevant research studies were sourced using the databases OvidMedline, CINAHL, PsycINFO, Web of Science and Scopus. Keywords used were 'care* AND Alzheimer OR dementia AND 'positive aspect' OR 'positive experience' OR 'positive perceptions' OR reward OR gain OR 'satisfaction with care*' OR 'care* satisfaction' OR benefit OR uplift OR meaning OR enjoyment OR pleasure OR growth OR hope OR gratification. Studies were included if they focused on positive aspects of caregiving among family caregivers of PWD. Those concerned with family caregivers of people with other diseases were excluded. However, those comparing PWD caregivers with those of other patients were also included. The other exclusion criteria included: 1) research studies focusing on formal or paid caregivers, 2) publications not written in English or 3) reviews, abstracts or discussion papers.

2.2. Data evaluation

Data evaluation focused on evaluating the quality of the identified research evidence. This step was recommended as crucial to enhancing the rigour of an integrative review. (Whittemore and Knafl, 2005) The Critical Appraisal Skills Programme checklists for qualitative and cohort studies were used to provide a form of systematic quality appraisal of qualitative and quantitative studies respectively. (CASP International Network, 2016) These checklists covered the assessment of various aspects, including clarity of research questions, conceptual basis, methodological rigour, subject recruitment, control of threats to internal validity, accuracy of results, study implications and potential for application of the findings. The quality appraisal was carried out by the first and second authors independently, with '0' representing 'not fulfilled', '1' 'can't tell' and '2' representing 'good compliance' Tables 1 and 2. Summarise the results of quality appraisals for qualitative and quantitative studies, respectively.

2.3. Data synthesis

Data synthesis followed the five-stage method as recommended by Whittemore and Knafl. (Whittemore and Knafl, 2005) Data relevant to the review questions was extracted from the identified studies (data reduction), and organised into a matrix table (data display) to facilitate the comparison of studies according to their methods and findings. Findings addressing the same review question were compared and integrated, so that patterns and themes could be identified (data comparison). An interpretative effort was then made to use the integrated data to describe how positive aspects of caregiving emerge in the dementia context. The data synthesis was then verified by the findings from the identified studies for accuracy and confirmability (verification).

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