



## Review

# Multivariate models of subjective caregiver burden in dementia: A systematic review



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## ABSTRACT

**Background:** Burden in dementia caregivers is a complex and multidimensional construct. Several models of burden and other representations of burden like depression or mental health are described in literature. To clarify the state of science, we systematically reviewed complex models that include both patient and caregiver determinants of caregiver burden.

**Objective:** A review of determinant models of caregiver burden.

**Design:** Systematic review.

**Data sources:** Electronic databases PubMed, PsycInfo and EMBase were searched in December 2013.

**Study selection and analysis:** Research studies with quantitative outcome measures of caregiver burden or burden-related concepts, including both patient and caregiver functional characteristics as determinants. We categorized the determinant variables in the models and calculated the percentages of proven determinants within each category.

**Results:** We found 32 studies with burden models and 24 depression and mental health models. Patient behavioral problems, caregiver coping and personality traits and competence are most consistent determinants of caregiver burden, depression and mental health. Behavioral problems are more significant than cognitive disorders or lack of self-care. Of all measured caregiver personality traits, neuroticism has the strongest impact on caregiver burden. Regarding caregiver competences, feeling competent or enjoying higher self-efficacy in general diminish caregiver burden and promote caregiver mental health.

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## 1. Introduction

Alzheimer's disease and related disorders, like vascular dementia, affect approximately 30–40% of the population aged 80 or older (RIVM, 2010). The majority of dementia patients are cared for at home by family members, mainly spouses and adult children. Providing care for a dementia patient over a longer period of time is associated with emotional and physical health problems. Research performed by Netherlands Institute for Health Services Research Nivel (Peeters et al., 2007, 2010) in the Netherlands revealed that the prevalence of high levels of burden in informal caregivers of dementia patients is 20%. These caregivers feel so heavily burdened that they are at risk for health problems. Another 58% run the risk of emotional distress as a result of caregiving.

The impact of dementia on the caregiver is frequently conceptualized in terms of caregiver burden. The burden concept has been the subject of research for several decades, distinguishing between objective aspects of burden, that is time spent on care and support, and subjective aspects of burden. Subjective caregiver burden is a complex and multidimensional construct, linked to caregivers' psychological and physical well-being (Zarit et al., 1986). In the literature subjective burden is therefore related to other psychological concepts such as mood disorders, e.g. depression and anxiety, or caregiver quality of life. Conceptual differences in the definition of subjective burden lead to a diversity of measurement approaches and consequently to the development and use of different measurement instruments.

Patient determinants of caregiver burden that are mentioned in the literature include cognitive function disorders, loss of autonomy and the related need of support in daily activities. However, most important are the neuropsychiatric symptoms accompanying dementia, like depression, agitation and apathy. Coping with behavioral problems has been reported to be one of the most stressful aspects of caregiving (Christie and Wood, 1988; Coen et al., 1997; Gaugler et al., 2000; Black and Almeida, 2004; Meiland et al., 2005; Allegri et al., 2006). Among the most heavily burdened caregivers, 86% of the experienced problems is connected to the disease-related behavioral changes in patients (Peeters et al., 2007). Caregivers vary widely in how they adapt to the demands of caregiving. Their characteristics make them more, or less, fit to deal with the challenge of caregiving and therefore also determine their susceptibility to stress, and burden (Pot et al., 1998; De Vugt et al., 2004; Helmes et al., 2005). Finally, the relationship between patient and caregiver can play a decisive role.

Several models of burden, describing the interaction of both patient and caregiver determinants, are presented in the literature. For example, Lazarus and Folkman (1984) provided a conceptual model for understanding the caregiver stress process, which was used in further empirical research into caregivers' adaptability by Haley et al. (1987). Pearlin's et al. (1990) stress process framework focuses on contextual variables and distinguishes between stressors that are directly related to the caregiving role (e.g. care recipient behavioral problems), and indirectly related sources of stress (e.g. financial problems). Since Lazarus and Folkman (1984),

a basic principle of these stress models is the assumption that an emotional event does not automatically provoke stress, but that it depends on the individual appraisal of the event, and is therefore also mediated by personal, illness-related, social and material factors. Insight into the multiple determinants of caregiver burden has both scientific and clinical relevance: It may contribute to theory development by the construction of more comprehensive and valid theoretical models, as well as to clinical practice, by providing a rationale for the development of specific interventions to reduce caregiver burden. We therefore drew up an inventory of the existing determinants of subjective burden models described in the literature and we systematically analyzed the determinants included in these models.

The central research question was:

- Which patient and caregiver characteristics are significant determinants of subjective caregiver burden or burden-related concepts like caregiver mental health or depression in the different models?

## 2. Method

### 2.1. Search strategy and selection criteria

An extensive search was performed of the literature on models of caregiver burden up to December 2013, utilizing the resources Medline (PubMed), PsycInfo and EMBase. The search strategy consisted of a combination of search items: burden, distress, stress, strain, overload, well-being, AND caregiver, family, spouse, informal, relative, home, AND psychogeriatrics, geriatric psychiatry, dementia, behavior, neuropsychiatric symptoms, OR theoretical, concept, predictors, prognostics, model, scale, limited by (old) age and human.<sup>1</sup>

The applied inclusion criteria were: (1) empirically tested models of burden in dementia caregivers, including both patient and caregiver determinant variables. We expected that this combination would provide more insight in their relative importance regarding caregiver burden. (2) Empirically tested models of burden-related concepts, such as (diminished) mental health or depression (as representations of burden) in dementia caregivers.

Studies were excluded when the tested models included only biographical and no other functional characteristics of patients and caregivers. Additionally, references were checked for relevant publications (snowball method) and experts were consulted.

Based on the content of the abstract the first inclusion of articles was performed by two independent reviewers. In case of doubt or disagreement, a third reviewer made the decision, after reading titles and abstracts. Finally, full articles were checked on the inclusion and exclusion criteria.

<sup>1</sup> The search strategy can be obtained from the author.

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