# Predictors of caregiving satisfaction in informal caregivers of people with dementia

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## A R T I C L E   I N F O

## A B S T R A C T

Objective: The prevalence of dementia is increasing and consequently the demands from families, institutions and healthcare system. Although a substantial amount of research on caregiving has emphasized the negative aspects of caregiving, specifically on caregiver burden and depression, less attention has been paid to the positive aspects of caregiving. The aim of the present work was to study the phenomenon of caregiving satisfaction in informal caregivers of people with dementia by assessing their likely predictors.
Methods: A stress process model was used to study caregiver's satisfaction (measured using the Revised Caregiving Satisfaction Scale) on 101 informal caregivers of patients with dementia in relation to the caregiver's background and context, stress-related factors, and mediators.
Results: The regression model has an adjusted $R^2$ of 0.20, which indicates that having a consanguinity relationship with the care recipient, suffering from lower levels of subjective burden, and managing individuals with severe cognitive impairment are the most important predictors of higher caregiving satisfaction.
Conclusion: Interventions focused on the enhancement of the caregiving satisfaction by increasing the understanding of the disease, should be especially addressed to caregivers without a consanguinity relationship and with high levels of subjective burden, and to those managing care recipients with mild or moderate stages of dementia.

## 1. Introduction

That the world's population is aging is a well-recognized fact. According to current estimations, 35.6 million of people worldwide live with dementia, and this number will likely double by 2030 (World Health Organization and Alzheimer's Disease International, 2012).

People with dementia generally require a high level of care, and informal caregivers, primarily spouses and daughters, are the ones who provide this type of care (Brodaty & Donkin, 2009), playing a very important role in this process. Providing daily care to someone with dementia is not only time consuming, but also a stressful and demanding task. Literature has found many characteristics related with negative aspects of caregiving. There is consistent documentation that caregivers become ill more often compared with those who do not perform this type of service (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Vitaliano, Zhang, & Scanlan, 2003) and that caregivers have more physiological and/or psychological problems. Among physiological changes, increased stress hormones and inflammatory markers (Vitaliano, Murphy, Young, Echeverria, & Borson, 2011; von Känel et al., 2012), hypertension (Roepke et al., 2011), and metabolic syndrome

(Mausbach et al., 2010) were found. As regards psychological problems, depression (Alspaugh, Stephens, Townsend, Zarit, & Greene, 1999; Kiecolt-Glaser et al., 1991; Schulz, Martire, & Klinger, 2005) and anxiety (Anthony-Bergstone, Zarit, & Gatz, 1988; Cooper, Balamurali, & Livingston, 2007; Schulz et al., 2005) have been recurrently reported in caregiver's research.

Although these negative outcomes constitute an important part of caregiving research, an area of investigation on caregiving showing the positive potential consequences of the caregiving experience has not been as well researched as negative aspects (Andrén & Elmståhl, 2005). Many studies addressing these positive experiences have shown how a large number of caregivers could describe one or more positive aspects of caregiving (PAC) when asked (Cohen, Colantonio, & Vernich, 2002). PAC are typically defined as the rewards and satisfaction derived from the caregiver relationship (Hilgeman, Allen, DeCoster, & Burgio, 2007). Different aspects of positive consequences have been previously identified: caregiver sense of mastery (Cohen, Pushkar Gold, Shulman, & Zucchero, 1994; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Pearlin, Mullan, Semple, & Skaff, 1990); caregiver enjoyment derived from the present relationship (Cohen et al., 1994; Pruchno, Michaels, & Potashnik, 1990); caregiving gratification in observing desirable outcomes, such as the care receiver remaining at home rather than in a specialized facility or appearing to be happy (Motenko, 1989); and satisfaction, sense of meaningfulness and fulfillment from caregiving (Cohen et al., 1994; Lawton et al., 1989; López, López-Arrieta, & Crespo, 2005; Noonan & Tennstedt, 1997; Tarlow et al., 2004). An overview of studies on PAC indicates consistent positive associations between the positive feeling and variables such as the quality of the relationship before the illness (López et al., 2005), the fact that the caregiver is satisfied with the social support he/she receives (Schulz, Newsom, Fleissner, de Camp, & Nieboer, 1997), and a negative association with the caregiver's perception of burden (Hilgeman et al., 2007).

The positive aspects of caregiving have been conceptualized differently across studies. It is difficult to define the positive aspects of caregiving since there is no clear definition of this construct (Carbonneau, Caron, & Desrosiers, 2010; Kramer, 1997). Among all of the PAC, the phenomenon of satisfaction derived from the caregiving relationship seems to achieve a high level of importance (Kramer, 1997). Lawton et al. (1989) were the first to introduce the term "satisfaction" as one of the major dimensions of caregiving general positive appraisal, representing subjectively perceived gains from desirable aspects of caregiving. They developed a scale to measure this general appraisal, the Caregiving Satisfaction Scale (CSS) that comprises several aspects that have been included in the literature about PAC: feeling closer to the patient, enjoying being with the patient, boosting the caregiver's self-esteem, delighting in the patient's pleasure, and giving meaning to the caregiver's life.

However, although satisfaction with caregiving has been reported in the literature (Lawton et al., 1989; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; López et al., 2005; Lundh, 1999), little is known regarding its actual predictors. Using the CSS, López et al. (2005) conducted a study with the aim of determining several factors that could be considered predictors of caregiving satisfaction. They found that higher satisfaction was associated with better previous relationships between the caregivers and the elderly with dependence, with being caregivers voluntarily, with maintaining leisure time, with less need for venting emotions, and with caregivers not working outside the home.

Consistent with this investigation and with the aim of extending our knowledge concerning PAC, the conceptual framework guiding this study is adapted from the stress process model (SPM) of Pearlin et al. (1990) to examine the predictive factors associated with caregiving satisfaction. According to this conceptual model, the caregiver's stress is considered a process that is composed of many conditions, and the outcomes are the result of the interaction of these different conditions. The conceptual framework for this study incorporates variables representing each of the four domains of the model of Pearlin et al. (1990), including the background and context within which the stress occurs, the actual stressors, the mediators, and the caregiver's outcomes or manifestations of stress (Fig. 1). The likely *outcomes* of the SPM of Pearlin et al. (1990) involve the well-being of the caregiver and their physical and mental health. The majority of research regarding caregivers of patients with dementia has employed the model linked to negative aspects of caregiving (Crespo & Fernández-Lansac, 2013). Therefore, our model incorporates a modification to the model of Pearlin et al. with the treatment of what they considered to be personal gain as a positive outcome represented by caregiving satisfaction (see Fig. 1). This variation is consistent with the two-factor model of Lawton et al. (1991), which postulates that the caregiving appraisal could be considered an outcome of caregiving.

The perception of family caregiving as satisfying may serve as a protective factor from the negative consequences associated with providing care (Robertson, Zarit, Duncan, Rovine, & Femia, 2007). Several studies have shown important relations between positive aspects of caregiving and less likelihood to report depression, burden or poor health (Cohen et al., 2002), positive affect (Lawton et al., 1991), improvement of caregiver well-being (Motenko, 1989; Noonan & Tennstedt, 1997), less possibilities to actually institutionalize their family members (Mausbach et al., 2004) or to feel the desire to institutionalize them (Cohen et al., 1994). Therefore, knowing the factors that predict caregiver's satisfaction will facilitate the design of interventions focused on these predictors to increase this positive experience, and thus buffering the negative consequences of caregiving.

In summary, the current study uses the caregiver's satisfaction as a potentially important output that is often missed in the literature concerning the SPM. Different aspects of caregiver's background and context characteristics, stress-related factors, and perceived social support were analyzed to examine which variables in each domain can act as predictors of the feeling of satisfaction in caregivers.

## 2. Materials and methods

### 2.1. Selection and description of participants

The sample included 101 informal caregivers of patients with dementia living in the community. The caregivers were recruited from local Alzheimer's associations or adult day care programs from 3 countries: Spain, Poland and Denmark. The inclusion criteria for the study were as follows: (a) taking care of a person diagnosed with dementia by a specialist or a neurologist, according to the criteria of the Classification of Mental and Behavioural Disorders, 10th revision (ICD-10, World Health Organization, 1992), or the Diagnostic and Statistical Manual of Mental Disorders, 4th edition, text revision (DSM-IV-TR, American Psychiatric Association, 2000), or the National Institute of Neurological Disorders and Stroke-Alzheimer Disease and Related Disorders Association (NINDS-ADRDA, McKhann et al., 1984); (b) being the primary caregiver in the following aspects: executing basic care tasks for a minimum of 6 weeks, receiving no remuneration for caregiving service, and devoting much time to patient care (Wilson, 1989); (c) suffering a burden according to the 22-item version of the Zarit Burden Interview (ZBI, Zarit, Orr, & Zarit, 1985), using a cut-off point of 24, which was determined to identify family caregivers who are at risk for depression (Schreiner, Morimoto, Arai, & Zarit, 2006); and (d) agreeing to participate in