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# Primary caregivers of cancer patients in the palliative phase: A path analysis of variables influencing their burden☆

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## Abstract

Research has shown that several variables influence the burden of primary caregivers of cancer patients staying at home in the palliative phase, but the associations between these variables have hardly been explored. The aim of this study was to examine the associations of theory-driven variables with the caregivers' burden by means of path analysis. The sample consisted of 96 caregivers of cancer patients in the palliative phase staying at home recruited from a hospital trust in Norway. The dimensions of burden from the Caregiver Reaction Assessment, namely self esteem, lack of family support, impact on finances, and impact on daily schedule, were used as the dependent variable. The following independent variables were tested in the models: the patients' levels of pain, fatigue, and nausea; and the caregivers' physical quality of life, anxiety and depression, and social support.

The Partial Least Squares approach to structural equation modelling was used for the path analysis. Model 1 shows the direct associations between the independent variables and the dependent variable, explaining 16% of the variance in caregiver burden. Model 1 supports the finding that only caregivers' depression has a direct significant association with caregiver burden, and shows further that the effects of the other independent variables on burden are mediated through depression. In Model 2, anxiety and depression are mediating factors between three other independent variables and caregiver burden, and 12% of the variance is explained. Model 2 supports none of the independent variables as antecedents of burden. Testing of the models suggested that caregivers' depression was the main factor associated with caregiver burden, but also an important mediator of indirect associations of indirect associations of caregivers' anxiety and physical health.

*Keywords:* Primary caregivers; Caregiver burden; Cancer; Home care; Norway

## Introduction

Primary caregivers (caregivers) are essential supporters of cancer patients in palliative phase who are staying at home, since they provide practical and emotional help and care. Research has shown that caregiving for severely ill patients

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over long periods can have a negative impact on caregivers both mentally and physically (Grov, Dahl, Moum, & Fossa, 2005; Grunfeld et al., 2004; Mor, Allen, & Malin, 1994; Weitzner, McMillan, & Jacobsen, 1999). The caregiver reaction is usually divided into the dimensions of burden and well-being. In this study 'caregiver burden' refers to overall consequences associated with a demanding and stressful caregiver situation (Given, Given, Helms, Stommel, & DeVoss, 1997; Hoffmann & Mitchell, 1998; Ivarsson, Sidenvall, & Carlsson, 2004; McCorkle & Pasacreta, 2001).

In cancer patients, termination of curative treatment defines the start of the palliative phase, when the patient increasingly is in need of palliative treatment and care. Current definitions of palliative care provided by the World Health Organization (World Health Organization (WHO), 2005) and the European Association for Palliative Care (European Association for Palliative Care (EAPC), 2005) do not include any estimation of expected duration. The palliative phase can last from a few days to several years. We defined the time period from the start of the palliative phase until inclusion in the study, as the patients' 'palliative pre-study time'.

### *Patient factors*

Increased symptoms and physical needs as well as poorer performance status of patients are associated with more negative impact on caregivers' family support, impact on finances, and caregiver schedule (Given et al., 1997). The patients' well-being is strongly influenced by symptoms and side-effects, especially pain (Kaasa, Loge, Knobel, Jordhoy, & Brenne, 1999; Vallerand, 1997), fatigue (Barsevick, Whitmer, & Walker, 2001; Smets, Garssen, Schuster-Uitterhoeve, & de Haes, 1993; Smets et al., 1998; Stone, Richards, A'Hern, & Hardy, 2000; Stone et al., 2000; Wolfe, 2000), and nausea (Cohen & Mount, 2000; Davis & Walsh, 2000; Kinghorn, 1997; Smets et al., 1993). The importance of caregivers' support in symptom management is highlighted (Given, Given, & Kozachik, 2001; Hileman, Lackey, & Hassanein, 1992; McCorkle & Pasacreta, 2001), and the levels of such symptoms may, therefore, be associated with caregiver burden.

Theoretically, the patients' gradual impairment and deterioration influence caregivers' quality of life and perceived burden (Grunfeld et al., 2004; Weitzner et al., 1999). However, in one study patients' health had limited impact on female caregivers' level of depression (Raveis, Karus, & Siegel, 1998), and on the 'caregiver reaction' of both genders in another report (Grov, Fosså, Tønnessen, & Dahl, 2006).

### *Caregiver factors*

Various caregiver factors have been investigated. Caregivers' level of education (Cameron, Franche, Cheung, & Stewart, 2002) have been shown to influence their experience of emotional distress. Previous studies have also shown that the levels of anxiety and depression in caregivers usually are elevated when they are caring for a cancer patient in a palliative setting (Given et al., 1993; Grov, Dahl et al., 2005; Grunfeld et al., 2004; Higginson, Wade, & McCarthy, 1990; Payne, Smith, & Dean, 1999).

### *Social factors*

When caregivers rank factors of importance for their well-being, social needs are ranked highest (Soothill et al., 2003), and caregivers with strained family relations are more at risk of experiencing burdens (Raveis et al., 1998). Social support to the caregivers has rarely been studied as a factor associated with caregiver burden. However, the highest caregiver burden is reported among those with more limited social network (Biegel, Sales, & Schulz, 1991; Goldstein et al., 2004; Soothill et al., 2001, 2003).

### *Path analysis of caregiver burden*

Because so many variables/factors showed significant associations with caregiver burden, an exploration of their relative strength was considered relevant, and path analysis was considered as an appropriate statistical method for such an explorative study. To our best knowledge the only path analysis of caregiver burden has been published by Given et al. (1993). These authors reported significant associations between caregivers' level of depression, and the patients' dependency concerning activities of daily life and patients' level of depression, as well as between the caregivers' daily schedule and the patients' health status.

Based on a selection of variables with documented empirical associations with caregiver burden, the aims of this path analytic study were threefold: (1) to examine the direct associations between the