



Caregiving burden and the quality of life of family caregivers of cancer patients: the relationship and correlates



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A B S T R A C T

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Purpose: Family caregivers of cancer patients become responsible for many elements of cancer care, usually without preparation or training in provision of care. Their efforts of care generate caregiving burden, which could deteriorate caregivers' quality of life (QOL).

Method: A secondary data analysis of a cross-sectional descriptive study was conducted to describe the influence of caregiving burden on the QOL of family caregivers of cancer patients with consideration of correlates (N = 212). The Korean versions of Zarit Burden Interview and the World Health Organization QOL BREF were used. Multiple regression analyses were applied to analyze the relationship between the caregiving burden and QOL.

Results: Caregiving burden explained 30.3% of variance of the QOL ($\beta = -0.534, p < 0.001$). Caregivers caring for patients with functional deterioration experienced higher burden. Caregivers providing care for hospitalized patients demonstrated lower QOL. The caregiver's educational level was a positively contributing factor for the QOL.

Conclusions: Caregiving burden was the influential, negatively affecting factor for the QOL. Assessment of caregiving burden with special attention being paid to caregivers caring for patients with functional decline would help to identify caregivers in need of support. Supportive care needs to be sought to alleviate caregiving burden and improve the QOL of caregivers, especially for the caregivers of hospitalized patients.

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Introduction

Cancer is a chronic disease that is associated with considerable, continuing, and fluctuating needs and problems for patients (Nijboer et al., 1998). Advances in cancer treatment and current trends toward outpatient cancer treatment enables care to be implemented in the home setting, and the engagement of family members to assume important roles as caregivers (Given et al., 2001; Teschendorf et al., 2007). Caregiving is typically something that people neither anticipate nor choose; In confrontation with cancer diagnosis and treatment, family members feel responsible

for providing care (Senden et al., 2015) and committed to provide limitless care (Coolbrandt et al., 2014).

Family caregivers take on this responsibility with little or no training and with limited resources (Ferrell et al., 2013). Nevertheless, family caregivers are required to provide a broad range of assistance, including disease and treatment monitoring, symptom management, medication administration, emotional support, assistance with personal and instrumental care, and financial support (Given et al., 2001; Yun et al., 2005). Family caregivers experience a considerable amount of distress in their efforts to provide care for cancer patients.

Caregiving burden is defined as the distress that caregivers feel as a result of providing care. It is specific to the care and varies from anxiety and depression to other emotional and more general responses (Given et al., 2001). Caregiving burden includes physical (Fletcher et al., 2008; Mosher et al., 2013; Osse et al., 2006; Stenberg et al., 2010), psychological (Braun et al., 2007; Deshields et al., 2012; Grunfeld et al., 2004; Mosher et al., 2013; Osse et al., 2006; Song et al.,

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2011; Stenberg et al., 2010; Williams and McCorkle, 2011), social (Desheids et al., 2012; Goldstein et al., 2004; Song et al., 2011), and financial domains (Desheids et al., 2012; Song et al., 2011; Yun et al., 2005). Physical burden such as sleep disturbance, fatigue and pain were often experienced by caregivers (Fletcher et al., 2008; Osse et al., 2006). Helping cancer patients to deal with their feelings about cancer and providing emotional support for cancer patients were considered as difficult psychological tasks (Desheids et al., 2012). Missing work because of caregiving responsibility (Grunfeld et al., 2004) and caring others besides cancer patient (Desheids et al., 2012) could be considered as social burden. Financial burden could be derived from paying high medical expenses and losing income and savings (Desheids et al., 2012; Song et al., 2011; Yun et al., 2005).

Caregivers of cancer patients are prone to deterioration of their quality of life (QOL) due to the caregiving burden (Song et al., 2011; Tang et al., 2008; Yun et al., 2005). A high caregiving burden and low QOL were found to be common among caregivers of non-small-cell lung cancer patients (Grant et al., 2013). Family caregivers of leukemia patients regarded caregiving burden as the most influential factor for their QOL (Tamayo et al., 2010). The factors contributing to caregiver burden (Coristine et al., 2003; Goldstein et al., 2004; Kim et al., 2006; Papastavrou et al., 2012; Park et al., 2012; Schumacher et al., 2008) or QOL (Alptekin et al., 2010; Wadhwa et al., 2013; Weitzner et al., 1999) have been explored extensively, but few studies have simultaneously evaluated the caregiving burden and QOL of caregivers of cancer patients (Grant et al., 2013; Son et al., 2012; Song et al., 2011; Tamayo et al., 2010; Tang et al., 2008; Yun et al., 2005). In the studies utilizing the Caregiver QOL Index–Cancer (CQOLC), burden was measured as one of the domains of QOL, thus analysis about the relationship was limited (Son et al., 2012; Tamayo et al., 2010; Yun et al., 2005). The complex and multifaceted concept of QOL (Ferrell et al., 1995; Kitrungroter and Cohen, 2006; Padilla et al., 1990; Padilla and Grant, 1985; Padilla et al., 1983) was not fully represented by simplified measures such as the EQ-5D or EQ-VAS (Song et al., 2011). Grant et al. (2013) applied the Caregiver Burden Scale (Montgomery et al., 1985) and the City of Hope QOL Scale–family version (Ferrell et al., 1999); however, the relationship between two variables while controlling for factors that might have contributed to the caregiving burden and QOL requires further exploration.

Purpose

The purpose of this study was to identify factors contributing to the caregiving burden and QOL, and to describe the influence of caregiving burden on the QOL of family caregivers of cancer patients with consideration of correlates.

Methods

Design

A secondary data analysis of the cross-sectional descriptive study about caregiving burden, health promoting behavior and quality of life (Rha et al., 2014).

Sample

A total of 227 family caregivers of 226 adult cancer patients receiving care at the oncology inpatient wards and outpatient clinics of 2 university hospitals in Korea participated in the parent study. The inclusion criteria were: (1) family caregiver of an adult cancer patient (aged ≥ 18 years) and (2) main caregiver for the cancer patient. Main caregiver was defined as a family member who was the

most responsible for the care of the cancer patients. The main caregiver participated in many elements of cancer care and usually spent more time with patients when compared to other family members. Family caregivers who accompanied patients' clinic visit or were providing care at bedsides were considered as potential participants. A research nurse approached caregivers who were initially identified as main caregivers of patients by clinical nurses. The research nurse explained the purpose of the study, checked eligibility, and invited main caregivers to participate in the study. The study protocol was approved by Institutional Review Boards (4-2012-0503 and 12-129) and all participants provided informed consent. For the current study, data from 212 caregivers who responded to caregiving burden and quality of life questionnaires were selected.

Measurements

The Zarit Burden Interview (ZBI; Zarit et al., 1980) was the measurement of caregiving burden with domains of burden in the relationship, emotional wellbeing, social and family life, finances, and loss of control over one's life. The Korean version of the ZBI (K-ZBI) comprised 22 items with responses on a 5-point Likert scale. The K-ZBI total score could range from 0 to 88. The Cronbach's alpha of the original ZBI was reported to be 0.920 (Hérbert et al., 2000), and that of the Korean version used in the present study was 0.883.

The caregiver's QOL was measured using the Korean version World Health Organization QOL–BREF (K-WHOQOL–BREF) with physical health, psychological, social relationship, and environmental domains, comprising 26 items with responses on a 5-point Likert scale (Min et al., 2002). Each domain score could range from 4 to 20, and the total score could range from 1 to 5. The Cronbach's alpha for the K-WHOQOL BREF was reported to be 0.898, and that of the K-WHOQOL BREF in this study was 0.903.

To explore which factors contribute to caregiving burden and QOL, the caregiver factors and the cancer patient factors (disease- and treatment-related information) were collected using structured survey questionnaires. The Eastern Cooperative Oncology Group (ECOG) performance status was used to describe functional status of cancer patients. ECOG performance status assesses how patients' daily living abilities are affected by the disease. ECOG 0 denotes fully active status, ECOG 1 means ambulatory but restriction of physically strenuous activity, ECOG 2 status is ambulatory and capable of self-care, but unable to carry out any work activities, ECOG 3 status is capable of only limited self-care, and ECOG 4 denotes completely disabled status (Oken et al., 1982).

Statistical analysis

Descriptive statistics were used to describe the characteristics of the caregivers and their cancer patients. The *t*-test, ANOVA with Scheffe's test and Pearson's correlations were used to identify potential correlates of caregiving burden and QOL. Correlates identified through bivariate analyses were included for multiple linear regression analyses to describe the relationships between caregiving burden and QOL. Statistical software IBM SPSS Statistics 21.0 was used to analyze the data.

Results

General characteristics: caregivers

The caregivers were middle aged (age = 46.2 ± 11.84 years, mean \pm SD, range 20–75 years), mostly female (79.2%), and most (69.3%) were residing with cancer patients. About half of the caregivers were spouses (48.6%) and many caregivers were the sole

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