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# Caregiving burden and health-promoting behaviors among the family caregivers of cancer patients



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#### ABSTRACT

Keywords: Caregivers Caregiving burden Health behavior

*Purpose:* The role of family caregivers in cancer care continues to expand, and it has been suggested that the caregiving influences health-promoting behaviors. The purpose was to describe the caregiving burden and health-promoting behaviors of the family caregivers of cancer patients and to determine the relationship between caregiving burden and health-promoting behaviors.

*Method:* A cross-sectional descriptive study was conducted involving 227 family caregivers of adult cancer patients. Caregiving burden was measured using the Korean version of the Zarit Burden Interview (K-ZBI), and health-promoting behaviors were determined using structured questionnaires.

Results: Considerable burden was experienced by the caregivers of cancer patients (K-ZBI score of  $36.51 \pm 12.54$ , mean  $\pm$  SD). However, caregiving burden did not influence caregivers' physical activity, diet, smoking, alcohol consumption, or adherence to cancer screening tests. When the caregivers were compared to controls from the Korea National Health and Nutrition Examination Survey V utilizing adjusted proportions, caregivers were less likely to perform physical activities (16.0% vs. 29.1%, p < 0.001), but more likely to adhere to alcohol consumption recommendations (76.3% vs. 35.0%, p < 0.001) and receive cancer screening services for stomach (68.5% vs. 56.8%, p < 0.001), breast (81.4% vs. 58.8%, p < 0.001), and cervical cancer (75.3% vs. 55.0%, p < 0.001).

*Conclusions:* The caregivers of cancer patients reported considerable caregiving burden. However the burden was not associated with health-promoting behaviors. Physical inactivity among caregivers may require interventions to promote health of caregivers.

*Implications for practice*: Relieving caregiving burden and improving caregivers' physical activities need to be considered as separate care issues in planning interventions for caregivers of cancer patients.

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#### Introduction

The burden of cancer continues to increase: 14 million new cases were estimated per year in 2012 worldwide, and the figure is expected to rise to 22 million annually over the next two decades (International Agency for Research on Cancer, 2014). It is predicted that 36.4% of Koreans will develop cancer in their lifetime (Korea Central Cancer Registry, 2011). Family members become caregivers at the time of cancer diagnosis, and accompany the patient on their journey to cancer survivorship. Family caregivers become responsible for many elements of cancer care, such as scheduling

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visits, providing accommodation, monitoring treatment compliance, symptom management, emotional support, meal preparation, housekeeping, and providing financial support (Given et al., 2001; Stenberg et al., 2010), but this usually occurs with insufficient preparation or training in the provision of care. Caregivers often neglect their own needs, and are even often required to give up their usual daily activities due to their caregiving responsibilities (Beesley et al., 2011; Molassiotis et al., 2011). These efforts to care for their loved ones burden family caregivers.

The caregiving burden experienced by the caregivers of cancer patients is as high as that of caregivers to those with dementia (Kim and Schulz, 2008). Caregivers experience various types of burden; including physical (Fletcher et al., 2008; Osse et al., 2006; Stenberg et al., 2010), psychosocial (Braun et al., 2007; Deshields et al., 2012; Grunfeld et al., 2004; Osse et al., 2006; Song et al., 2011; Stenberg et al., 2010; Williams and McCorkle, 2011), and financial burden

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(Deshields et al., 2012; Song et al., 2011; Yun et al., 2005). Performing caregiving is known to influence the health-promoting behaviors of caregivers. Less-than-optimal physical activities were attributable to their caregiving (Beesley et al., 2011; Mazanec et al., 2011). The physical health of family caregivers of lung cancer patients was shown to deteriorate as a result of their caregiving responsibilities (Milbury et al., 2013; Mosher et al., 2013). They also had issues regarding their diet, such as consuming less-than-optimal amounts of fruit and vegetables (Beesley et al., 2011). Chronic diseases were more prevalent among caregivers, most commonly hypertension and arthritis (Mazanec et al., 2011). Caregiving responsibilities lead caregivers to forget to take medications and even prevent them from seeing a doctor when they need to, or delay getting a medical test or screening (Burton et al., 2012; Mazanec et al., 2011).

It was hypothesized that caregiving burden would negatively influence caregivers' health-promoting behaviors (i.e., primary prevention behaviors such as physical activity, healthy diet, no smoking, and consuming adequate amount of alcohol; secondary prevention behaviors such as receiving cancer screening tests; tertiary prevention behaviors such as managing chronic disease). However, the relationship between the burden and three levels of health-promoting among caregivers of cancer patients has not been reported previously. A comprehensive understanding of caregiving burden and its relationship with health-promoting behaviors among caregivers of cancer patients would provide helpful information regarding the issues that they face and enable the planning of care for caregivers as recipients of care.

#### Objective

The purpose of this study was to describe the caregiving burden and health-promoting behaviors of family caregivers of cancer patients and to determine the relationship between caregiving burden and health-promoting behaviors among these caregivers.

#### Methods

Design

A cross-sectional survey was conducted for this descriptive study.

#### Sample

A total of 227 family caregivers of 226 adult cancer patients receiving care at 2 university hospitals located in Seoul and Daejeon in Korea participated in this study. There were two caregivers of one cancer patient who reported equally sharing caregiving responsibility, thus both were considered as main caregivers. Data were collected between August 2012 and January 2013. The inclusion criteria were (1) being a family caregiver of an adult cancer patient (age  $\geq$  18 years), (2) being the main caregiver for the patient (main caregiver denotes family caregivers who are the most responsible for the care of the cancer patents. They participate in many elements of cancer care and usually spend more time with patients when compared to other family members), and (3) possessing no physical, psychological, or cognitive problems that would preclude study participation. The sample size was estimated using G\*Power Analysis v. 3.1 for a power level of 0.80, a significance level of 0.05, and moderate effect size to enable the planned analyses. From the largest sample estimation of 192 for a 3-group mean comparison, a total of 227 caregivers participated. For the comparison of caregivers' health-promoting behaviors to representative sample of non-caregivers, age and gender matched controls were selected from the Korean National Health and Nutritional Survey V (KNHANES), a nationwide survey assessing health and nutritional status of Koreans (Korea Centers for Disease Control and Prevention, 2012). The number of controls does not have to be equal to the case, and the total sample size could improve the quality of the study. Grimes and Schulz (2005) suggested that up to a ratio of about 4 (controls) to 1 may be a cost-effective way to improve the study; four controls from the KNHANES V were matched to every caregiver resulting 908 controls.

The Institutional Review Board (IRB) of each hospital approved the study protocol (IRB numbers 4-2012-0503 and 12-129). A research nurse approached caregivers who were initially identified as main caregivers of cancer patients by clinical nurses. Caregivers at bedside or those who accompanied patients' clinic visit were approached. The research nurse explained about the details of the study and what their participation would entail. Eligibility of caregivers was confirmed and the caregivers were invited to participate in the study; all of them provided written informed consent. Only one caregiver dropped out of the study because of patient's condition deterioration.

#### Measurements

The Zarit Burden Interview (ZBI) (Zarit et al., 1980) is widely used in studies of the caregivers of chronically ill patients including cancer. It consists of 22 items for which the responses are scored on a 5-point Likert scale which total score ranges from 0 to 88 (higher score means higher burden). The ZBI enables the measurement of caregiving burden with subscales of 'burden in the relationship (6 items),' 'emotional well-being (7 items),' 'social and family life (4 items),' 'finances (1 item),' and 'loss of control over one's life (4 items).' The Korean version of the ZBI (K-ZBI) was used in this study. Cronbach's alpha of the ZBI was previously reported as 0.920 (Hérbert et al., 2000), and that of the K-ZBI in the present study was 0.883.

Health-promoting behaviors regarding primary, secondary, and tertiary prevention activities were measured using structured questionnaires (See Table 1). Primary prevention activities included physical activity, diet, no smoking, and adequate alcohol consumption. Type, time and frequency of physical activities during past 30 days were inquired. Diet assessment was performed using the self-dietary assessment index from the National Cancer Center of Korea, which was adapted from the Mini Dietary Assessment Index (Kim et al., 2003). The self-dietary assessment index comprises 20 items for which responses are scored on a 3-point Likert scale; the possible total score lies in the range 20-100, and a total score of <59 suggests the presence of dietary problems, and 60-79 suggests the need of improvement. Caregivers answered based on their diet during past 30 days. Current smoking, with amount and frequency, and type of alcohol consumption with amount and frequency during past 30 days were inquired. Caregivers were also asked whether caregiving had changed their physical activity, diet, and smoking and alcohol consumption behaviors. Secondary prevention activities referred to adherence to the recommended cancer screening tests, which were the components of the National Cancer Screening Program of Korea. For the screening of stomach cancer, participants aged  $\geq$ 40 years were asked whether they had undergone esophagogastroduodenoscopy (EGD) or doublecontrast upper-gastrointestinal tract (GI) series within the past 2 years. For colorectal cancer screening, caregivers aged  $\geq$ 50 years were asked whether they had undergone occult blood testing within the past year, or had received a barium enema within the past 5 years or colonoscopy within the past 10 years. For breast cancer screening, female caregivers aged ≥40 years were asked whether they had received a mammogram within the past 2 years. For cervical cancer screening, female caregivers aged ≥30 years

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