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A spectrum of hidden morbidities among spousal caregivers for patients with cancer, and differences between the genders: A review of the literature

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ABSTRACT

Objective: To explore the spectrum of hidden morbidities and gender differences in the spousal caregiving experience with regard to cancer patients across the cancer trajectory, and to discuss directions for future research and the implications for interventions to improve the caregiving experience.
Methods: A systematic search was conducted to identity articles published in English or Chinese from January 2000 to July 2012. Studies were located using an electronic search, a manual search, and an author search.
Results: A total of 19 articles were identified and included in this review. This review of the literature revealed that female spousal caregivers, in general, experienced more mental morbidity (higher levels of distress, depression, and anxiety, lower levels of mental health), physical morbidity (lower physical health scores, poorer physical functioning, and loss of physical strength), and social morbidity (lower marital satisfaction and less social support) than male spousal caregivers.
Conclusions: This review of the literature revealed that spousal caregivers, particularly female spousal caregivers for cancer patients, are at a high risk of falling victim to a wide spectrum of hidden morbidities due to their caregiving experience. The cultural influences on the couples and their patterns of communication that influence the caregiving experience for cancer patients should be further explored. A tailored-made intervention for spousal caregivers, both males and females, in the context of cancer care should be developed to cater to the needs of this population, which suffers from a spectrum of hidden morbidities.

Introduction

Cancer is a leading cause of death worldwide. In 2008, 7.6 million people died from the disease, accounting for 13% of all deaths, and 70% of these occurred in low- and middle-income countries (WHO, 2012a). Deaths from cancer worldwide are projected to continue rising, reaching a figure of 13.1 million in 2030 (WHO, 2012a). In China, cancer was estimated to account for 1.9 million deaths (20% of all deaths) in 2005, or about one fourth of all deaths due to chronic disease (7.5 million). The World Health Organization (WHO) has also estimated that deaths from chronic disease in China will increase by 19% in the ten-year period from 2005 to 2015 (WHO, 2012b).

A diagnosis of cancer and its treatment has an impact not only on the patient but also on the family caregivers (Kayser et al., 2007). With new and advanced medical treatment, 68% of adults diagnosed with cancer today can expect to be alive in five years' time (Jemal et al., 2011). Due to the good five-year survival rate for cancer, shorter hospital stays, limited discharge planning, and the expansion of home care technology, the burden of caring for cancer patients has been transferred to the family members of these patients, who are now being asked to shoulder greater burdens for longer periods of time (Chen et al., 2004; Schulz and Beach, 1999; Zivin and Christakis, 2007).

A review of the costs of family caregiving has shown that the caregiving role can be highly stressful and can lead to considerable psychological, social, economic, and health costs for the family caregiver (Haley, 2003). It has been reported that the spouse is the primary informal caregiver for cancer patients (Chen et al., 2004; Kurtz et al., 1995; Nijboer et al., 1998) Spouse caregivers of cancer patients can experience high levels of stress, potential burnout, depressive symptoms, marital distress, poor health, and unmet needs (Braun et al., 2007; Chen et al., 2004; Hagedoorn et al., 2008; Kurtz et al., 1995; Nijboer et al., 1998). Showing concern and

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support for spousal caregivers is important since their mental and physical status affects their capacity to continue to provide care for an ill spouse (Northouse et al., 2001).

Many studies have reported on the negative consequences of caregiving, such as fatigue, loss of sleep, loss of appetite, and illness (Blum and Sherman, 2010; Dhruva et al., 2012). There are also consequences that may not be readily recognizable by both caregivers and health professionals until the caregiver falls ill. Caregivers have been reported to suffer from physical, mental, and social problems (Braun et al., 2007; Hagedoorn et al., 2008; Kurtz et al., 2004; Matthews et al., 2004; Pitceathly and Maguire, 2003). According to the WHO's health model (Larson, 1999), health is 'a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity'. Where 'health' is lacking, but before illness has developed, a sub-optimal state of health – 'hidden morbidity' – can be considered to exist.

Although the term 'hidden morbidity' is not widely used in the context of cancer caregiving, the term 'hidden morbidity' is used in this study to refer to a sub-optimal physical, mental and social state in spousal caregivers. In web dictionaries (Proportional Morbidity, 2012), the term 'morbidity' has been defined as 'the relative incidence of a particular disease' and 'an abnormally gloomy or unhealthy state of mind'. Morbidity is also delineated as a 'departure from a state of physical or psychological well-being, resulting from disease, illness, injury, or sickness, specially where the affected individual is aware of his or her condition (Morbidity, 2012). The term 'hidden morbidity' used in this review refers to a condition that not known to health professionals and even to the person who is suffering from the sub-optimal condition (Braun et al., 2007).

A few studies have been conducted on the impact on the spouse of providing care to a cancer patient; however, an overall picture of the hidden morbidity among spousal caregivers is lacking. Gender has been recognized as the most predictive factor of negative experiences in caregiving (Hagedoorn et al., 2008), and there have been isolated studies reporting gender differences in the spousal caregiving experience for cancer patients. However, no review of the literature has been conducted to synthesize the findings related to the hidden morbidity and gender differences among spousal caregivers (Braun et al., 2007).

Therefore, it is the objectives of this review to (i) synthesize the results of empirical research on the hidden morbidities of spousal caregivers across the cancer trajectory; (ii) identify differences between the genders; and (iii) illuminate the directions for future research and implications for interventions. By providing a better understanding the caregiving experience and the hidden morbidities of caregivers, and providing a basis for designing related interventions to support and improve the spousal caregiving experience according to gender differences, if any, the findings in this literature review may be helpful to healthcare professionals who work with couples dealing with cancer.

Methods

A systematic search was conducted to identity articles published in English or Chinese from January 2000 to July 2012. Studies were located using electronic searches, a manual search, and an author search. The following computerized databases were searched: MEDLINE, CINAHL, Science Citation Index Expanded, Scopus, PsychINFO, and China Academic Journals Full-text Database. The key search terms used were 'cancer' or 'oncology' or 'carcinoma' AND 'caregiver' or 'caregiving' or 'carer', AND 'gender differences' or 'gender' AND 'spouse' or 'couple' or 'partner'.

Initially, a total of 177 records were identified from the literature search of the six databases using the keywords, a manual search of review articles and reference lists, and from the author search. Given that the six databases were searched, one hundred and twenty records were found to be duplicated; only 57 remained after removing the duplicate records. Data and literature were extracted from each of the included studies using a standard format: information on the literature, study method, study aims, samples/settings, and findings. To be included in this review, the study population had to be largely comprised of couples coping with cancer, on the caregiving experiences of spouses caring for patients with cancer, and to report on findings that included both male and female spousal caregivers in the same study. After records were screened and articles assessed, thirty-eight records were excluded for not meeting the criteria for inclusion (Fig. 1). In the end, a total of 19 articles met the criteria and were included in this review.

Results

Quality and characteristics of the selected studies

All of the 19 articles included in this review were published in peer-review journals. The impact factor of these journals ranges from 1.849 to 4.200. With exception of two journals, one is an official journal published by the European School of Oncology, and the other is a journal that "offers reviews of key neuropsychiatric topics for clinicians, with the aim of tying research findings to the needs of clinical practice" (JAMA, 2012). In all of these 19 studies, the study design were well defined; time point of data collection was specified; characteristics of the targeted couples and sample size were clearly described; the analysis for confounding variables were properly adjusted; the outcomes and estimated significances were stated without obviously bias. Overall, the 19 articles included in this review were considered of high quality.

All of the 19 articles included in this review were quantitative studies (Table 1). There were 9 cross-sectional and 10 longitudinal studies, with observation times ranging from 2 weeks to 5 years from baseline. The studies were conducted in the United States (8) (Colgrove et al., 2007; Haley et al., 2003; Kim and Carver, 2007; Kim et al., 2006; Langer, 2003; Langer et al., 2003, 2010; Northouse et al., 2000), the Netherlands (5) (Hagedoorn et al., 2000, 2002; Nijboer et al., 2000, 2001; Tuinstra et al., 2004), Israel (3) (Baider et al., 2003; Barnoy et al., 2006; Goldzweig et al., 2009), Germany (2) (Luszczynska et al., 2007; Pinquart and Duberstein, 2005), and Finland (1) (Gustavsson-Lilius et al., 2007). Of the 19 studies, 16 (84.2%) were conducted in Western countries.

The couples in the study were coping with colorectal or colon cancer (5) (Goldzweig et al., 2009; Nijboer et al., 2000, 2001; Northouse et al., 2000; Tuinstra et al., 2004), lung cancer (2) (Haley et al., 2003; Pinquart and Duberstein, 2005), prostate or breast cancer (1) (Baider et al., 2003), and gastrointestinal cancer (1) (Luszczynska et al., 2007). Over half (10/19, 52.6%) of the studies involved multiple types of cancer: colon, lung, liver, brain, skin, and bone (Barnoy et al., 2006; Colgrove et al., 2007; Gustavsson-Lilius et al., 2007; Hagedoorn et al., 2000, 2002; Kim et al., 2006; Kim and Carver, 2007; Langer, 2003; Langer et al., 2003, 2010).

The sample size in these studies ranged from 40 to 429 couples, and the total number of male and female spousal caregivers was 1569 and 1894, respectively. The caregivers were between the ages of 43 and 69.2, and the patients between 43.5 and 70.7. The time that had elapsed since the diagnosis of cancer varied considerably from newly diagnosed to 5 years or more, with nearly half (10, 52.6%) of the studies involving subjects who had been diagnosed for over 2 years. Stages of cancer also varied across the studies from Stages I/II/III, with one study specifying that no patient was in a terminal condition (Barnoy et al., 2006), while another specified that all of the patients had a life expectancy of less than 6 months (Haley et al., 2003).