

## Review Article


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**Abstract**

**Objectives.** Cancer does affect not only the lives of the patients but also that of their spouses. The aims of this systematic review are to (i) explore the gender differences in the impact of caregiving for cancer on spousal caregivers, (ii) facilitate the conceptual understanding of gender differences in caregiving, and (iii) identify directions for future research and clinical practice targeting spousal caregivers.

**Methods.** A comprehensive search was conducted of the electronic databases of MEDLINE, PsycINFO, EBSCO, and CINAHL Plus for papers published in English between 2000 and 2022. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were used to identify, select, appraise, and synthesize the studies.

**Results.** A total of 20 studies from seven countries were reviewed. Findings of the studies were presented using the biopsychosocial model. Spousal caregivers of cancer patients suffered from physical, psychological, and socioeconomic morbidities, with female spousal caregivers reporting a higher level of distress. The gendered positioning of spousal caregivers in the societal context had further brought about over-responsibility and self-sacrifice among women.

**Significance of results.** The gendered positions of cancer spousal caregivers further illustrated the gender differences in the caregiving experiences and consequences. Health-care professionals in routine clinical practice should be proactive in identifying physical, mental, and social morbidities among cancer spousal caregivers, particularly female ones, and providing timely interventions. Health-care professionals should recognize the pressing need for empirical research, political engagement, and action plans to address the health status and health-related behaviors of patients' spouses along the cancer trajectory.

**Introduction**

Cancer is undoubtedly a leading cause of death worldwide. In 2018, cancer accounted for 9.6 million deaths or about one in six deaths (Cancer Research UK 2019; WHO 2019). It was also projected that deaths from cancer across the world would continue to increase, escalating to 27.5 million in 2040 (Cancer Research UK 2019). Epidemiological studies estimated that 17 million people were diagnosed with cancer worldwide in 2018 (Cancer Research UK 2019). Both the patients and their spouses have to cope with cancer and its gradual progression starting from the time of the initial cancer diagnosis. Living with cancer requires continuing care and multidisciplinary management by health-care professionals. Since most treatments are provided through regular visits to outpatient facilities rather than hospitalization, family caregivers have to tackle the significant burden associated (Hagedoorn et al. 2008; Wilkie and Farber 2012).

**Spousal caregiving in cancer**

Caregiving is an evolving concept, both within and beyond the health-care arena. In a published qualitative concept analysis on caregiving, that caregiving is defined as the process of helping another person who is unable to care for themselves in a holistic (physically, mentally, emotionally, and socially) manner (Hermanns and Mastel-Smith 2012). The study further stated that caregiving is facilitated by a number of factors, namely character traits, emotions, skills, knowledge, time, and emotional connection with the care recipient. The combined impact of change in health-care delivery and technological advancement have made cancer patient care more complex than ever; such impact has placed unprecedented demands on family caregivers. A study of cancer caregivers' experiences described informal family caregiving experience as a complex one and the relationships are dynamic, evolving and changing in both predictable and unintended ways (Blum and Sherman 2010). As a result, family caregivers are at risk of adverse consequences on

their physical, mental, social, and spiritual well-being (Applebaum and Breitbart 2013; McCorkle et al. 2012).

It had been reported that spouse is the primary family caregiver for cancer patients in the Western world (Nijboer et al. 1998; Thomas et al. 2002). The same phenomenon had been observed in the Chinese world (Chen et al. 2004). A study argued that spousal care has been taken for granted as a form of fulfillment of marriage vows (Taylor et al. 2008). In Hong Kong, the incidence of cancer is higher in males; one in four men and one in five women are likely to develop some form of cancer before the age of 75 years (Hong Kong Cancer Registry 2021). A literature review pointed out that spousal caregivers of cancer patients, as impacted by their caregiving experience, are at high risk of succumbing to a wide range of hidden mental, physical, and social morbidities (Li and Loke 2013). Among factors influencing the experience of caregiving, gender is suggested to be the most significant factor (Hagedoorn et al. 2008; Ussher and Sandoval 2008). Gender disparity appeared to emerge in the body of literature. Female spousal caregivers perceived higher levels of negative experience in caregiving (Li et al. 2013). Prior systematic reviews on family cancer caregivers covered prevalence of depression among caregivers (Pan and Lin 2022), quality of life of caregivers (Ochoa et al. 2020), factors associated with distress among caregivers (Cochrane et al. 2021), psychosocial interventions for family cancer caregivers (Applebaum and Breitbart 2013), resilience-promoting interventions among cancer caregivers (Opsomer et al. 2022), and comparison of psychosocial interventions delivered to caregivers (Treanor et al. 2019). However, none of the prior reviews addressed the gender differences in cancer spousal caregiving. The present study is the first systematic review to fill the knowledge gap by characterizing gender differences among cancer spousal caregivers.

The aims of this systematic review are to (i) explore the gender differences in the impact of caregiving for cancer on spousal caregivers, (ii) facilitate the conceptual understanding of gender differences in caregiving, and (iii) identify directions for future research and clinical practice targeting spousal caregivers.

## Methods

### Data search strategy

A comprehensive search was conducted of the electronic databases of MEDLINE, PsycINFO, EBSCO, and CINAHL Plus. A line-by-line search strategy was first developed for the MEDLINE search. The keywords that were searched included (“cancer” OR “oncology” OR “carcinoma”) AND (“caregiver” OR “caregiving” OR “carer”) AND (“gender differences” OR “gender”) AND (“spouse” OR “couple” OR “partner”). The search strategy was constructed with the help of a librarian to include free-text terms (e.g., in the title and abstract) and relevant subject indexing (e.g., MeSH). The search was limited to papers published in English between 2000 and 2022. The year 2000 marked the year when UN Women launched the flagship publication of *Progress of the World's Women* to promote gender equality; the research team found it relevant to search for studies published from 2000 to better understand the gender differences in cancer spousal caregiving entering the 21st century. The same search strategy was adopted in subsequent searches conducted in PsycINFO, EBSCO, and CINAHL Plus. A citation search was also performed to retrieve relevant articles.

A total of 340 papers were retrieved from database search and citation search. The Preferred Reporting Items for Systematic

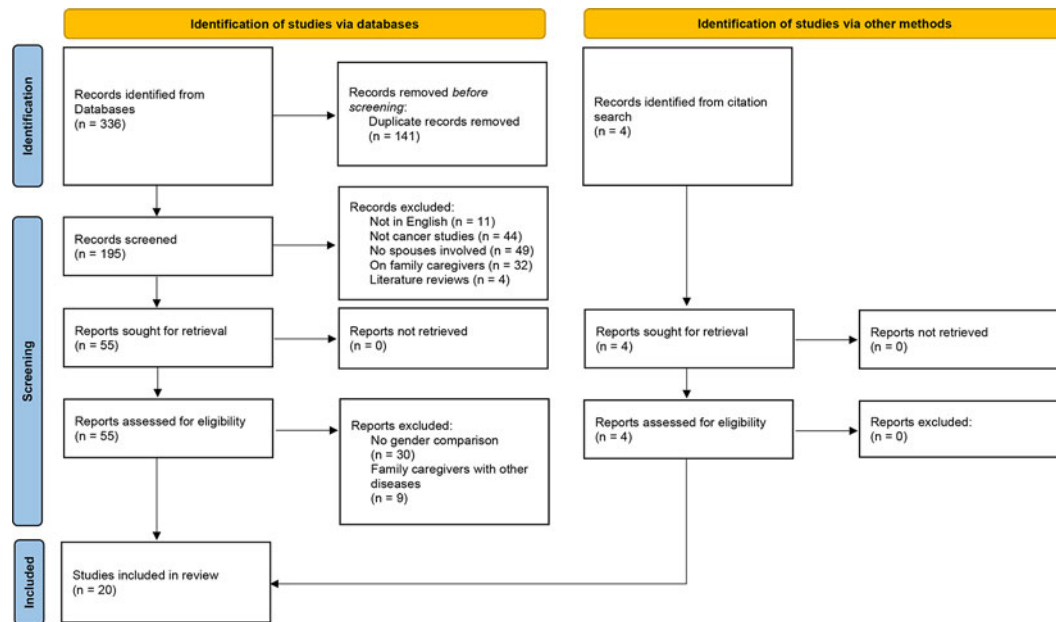
Reviews and Meta-Analyses (PRISMA) guidelines, a framework to identify, select, appraise, and synthesize studies, were employed to facilitate comprehensive reporting of the current study (Page et al. 2021). A reference management software, Mendeley, was used to import the searching records and remove duplicates. After removing duplicates, the first (J.H.Y.N.) and second (B.H.K.L.) authors of the current study independently screened the titles and abstracts of the remaining 199 studies to identify studies investigating spousal caregiving for cancer partners. The two reviewers compared their findings and discussed on any discrepancies to achieve agreement during this initial phase of screening. Studies included in this review met the following criteria: studies published in peer-reviewed journals in the English language and the study population is spousal caregivers caring for cancer partners. Quantitative studies should include statistical testing of gender differences; for qualitative studies, data synthesis must include gender differences. To envisage the multifaceted nature of cancer spousal caregiving from primary investigations, review articles were excluded. A total of 59 full-text articles were retrieved for further eligibility screening based on the inclusion and exclusion criteria. The first (J.H.Y.N.) and second (B.H.K.L.) authors independently reviewed the studies. The two reviewers subsequently compared their findings, and the third author (N.P.M.L.) participated in the discussion to resolve differences until a consensus is reached. This systematic eligibility review process brought a final data set of 20 studies on cancer spousal caregiving, with 19 being quantitative studies and 1 being a mixed-methods study. The flow diagram depicting the flow of information through different phases of the systematic review is presented in Fig. 1.

### Quality assessment of the reviewed papers

The quality of each included study was appraised by the three reviewers independently. To appraise studies involving qualitative and quantitative methodologies, the Quality Assessment Tool for Studies with Diverse Designs (Sirriyeh et al. 2012) was selected as the quality assessment tool in the present review. It consists of 16 items; each could be rated on a 4-point scale from 0 to 3. The criteria include the use of theory, the appropriateness of the study design, the methods of collecting data, stringency in the sample size and in reporting outcome measures, analytical strategies and rigor, user involvement, and critical analysis. The studies that were included were considered to be of good quality, with scores ranging from 28 to 40 out of a possible total score of 48. It can be concluded that these studies were fairly strong and rated highly in terms of descriptions of the study design, methods of collecting data, sampling, and critical analysis. The respective ratings for each included study are shown in Table 1.

### Biopsychosocial model adopted for scrutinizing the results

The biopsychosocial model (Engel 1977) would be used as the framework to present the findings of this review. The model suggested that should we consider not only the biological factors for understanding a person's medical condition but also the psychological and social factors. It offers a dynamic view to determine a holistic picture of the health of an individual. Biological (physical), social, and psychological factors can all play a role in affecting an individual's health, such as attributing to or changing a person's stress levels. Applying in the context of a cancer caregiver's experience, mental (psychological) stressors could pose an impact on the physical body, the same way that the stress upon the physical body



**Figure 1.** The flow diagram depicting different phases of the systematic review.

could pose an impact on mental processes (Trudeau-Hern and Daneshpour 2012). The social stress on lives and choices brought about by extended periods of caregiving will also lead to income loss and reduced employment opportunities. Since financial status is a significant factor associated with caregiver burden, socioeconomic stress can adversely affect caregivers' quality of life (Girgis et al. 2013).

## Results

Twenty studies were included in this systematic review. The characteristics of these studies are summarized in terms of author, aims, study sample, study design, main findings, and quality assessment in Table 1. All of the 20 studies included in this review were published in peer-review English journals. There were 13 cross-sectional studies, one case-control study, two retrospective studies, three longitudinal studies, and one mixed-methods study. The included studies represented a diverse population from seven countries, with nine studies from the United States, five studies conducted in Europe (Sweden, the Netherlands, and Switzerland), three studies from Israel, two studies from Australia, and one from Korea. The total number of participants represented in this review was 288,300 from 20 studies, with the sample size ranging from 50 to 283,970.

Based on the biopsychosocial model (Engel 1977), the impact of cancer spousal caregiving synthesized from the 19 quantitative studies could be discussed as stressors of three categories, namely physical health stressors, psychological stressors, and socioeconomic stressors. One study included a qualitative approach to investigate spousal caregiving and gender.

### Physical health stressors

Three studies showed that spousal caregivers of cancer patients experienced physical distressing symptoms as the result of their caregiving role, and it led to an array of negative consequences such as fatigue, accumulative sleep disruption, appetite change, weight

loss, and illnesses (Colgrove et al. 2007; Ji et al. 2012; Nijboer et al. 2000). Female spousal caregivers, when compared to their male counterparts, experienced greater loss of physical strength, both at the time of the cancer diagnosis and 6 months post-diagnosis (Nijboer et al. 2000). Behaviors such as inadequate rest, insufficient exercise, and neglecting their own health and quality of life were more often noted in female spousal caregivers (Colgrove et al. 2007; Nijboer et al. 2000). Female spousal caregivers' physical health might also be compromised since caregiving could have made them adjust some of their preventive care practices. A study in the United States revealed that the female spousal caregivers 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 (Colgrove et al. 2007).

In a Swedish study investigating the risks of coronary heart disease and stroke among spousal caregivers of cancer patients, it was found that such risks had significantly increased over time, irrespective of the gender of the caregivers (Ji et al. 2012). Spouses of cancer patients, compared to unaffected spouses, were more vulnerable to poor cardiovascular health, including risks of coronary heart disease (13% increase) and stroke (26% increase), up to 20 years after their spouse's cancer diagnosis (Ji et al. 2012).

### Psychological stressors

Spousal caregivers could suffer from mental morbidity of various presentations, such as high levels of psychological distress, anxiety, depression, and poor mental well-being (Girgis et al. 2013; Li and Loke 2013; Pinquart and Sorensen 2006). In a study using the Epidemiological Studies Depression Scale to compare depression between male and female spousal caregivers, it was found that female spousal caregivers experienced a higher level of psychological distress than male ones (Hagedoorn et al. 2000). Other studies also recognized that female caregivers reported a higher level of depressive and anxiety symptoms and a lower level of subjective

**Table 1.** Characteristics of 20 included studies

Author, year (country)	Aims	Sample	Design <sup>a</sup>	Main findings	QA <sup>b</sup>	
Quantitative studies						
Physical	Colgrove et al. (2007) (USA)	To examine the moderating effects of spirituality on the relation between caregiving stress and spousal caregivers' mental and physical health.	403 spousal caregivers	CS	Female gender was associated with poorer mental health. Caregiving stress was also associated with poorer physical functioning.	38
	Ji et al. (2012) (Sweden)	To examine the incidence of coronary heart disease and stroke in the spouses of cancer patients after they were diagnosed with cancers at different sites.	122,683 male, 161,287 female	R	After the cancer diagnosis in wives, the risks of coronary heart disease, ischemic stroke, and hemorrhagic stroke in husbands were 1.13 (95% CI, 1.10–1.16), 1.24 (95% CI, 1.21–1.27), and 1.25 (95% CI, 1.18–1.32), respectively. The corresponding risks in wives with an affected husband were 1.13 (95% CI, 1.10–1.16), 1.29 (95% CI, 1.26–1.32), and 1.27 (95% CI, 1.19–1.34). The increases were consistent over time and were more pronounced if a cancer with a high mortality rate, such as pancreatic and lung cancers affected the spouse.	28
	Nijboer et al. (2000) (The Netherlands)	To describe the overall patterns of caregiver experiences in partners of cancer patients over time, across different groups (i.e., according to gender, age, and SES), and within individuals over time.	148 spousal caregivers (94 female, 54 male)	L	Female caregivers perceived a more negative impact on loss of physical strength as compared to male caregivers; this difference had been observed over time.	31
Psychological	Baider et al. (2003) (Israel)	To identify and compare the variables that characterize couples where both spouses are in high psychological distress with couples where the psychological distress of both spouses is within the normal range.	118 male, 169 female	CS	The husbands were significantly more distressed than the wives, and their distress was as high as that of patients of both genders.	33
	Hagedoorn et al. (2000) (The Netherlands)	To further knowledge on gender and role (i.e., patient versus partner) differences in psychological distress and quality of life as a consequence of dealing with cancer.	173 spousal caregivers and 80 control	CC	Female partners perceived more psychological distress and a lower quality of life than male partners.	35
	Hagedoorn et al. (2002) (The Netherlands)	To examine a possible explanation, specifically self-efficacy and personal accomplishment with respect to caregiving, for the frequently reported finding that female caregivers perceive more psychological distress than do male caregivers.	68 spousal caregivers (32 female, 36 male)	CS	Only among female partners were self-efficacy and personal accomplishment regarding caregiving found to be positively linked to distress. Higher levels of distress were reported in female partners, as compared with male partners.	35
	Ketcher et al. (2019) (USA)	To (i) identify potential differences in the amount of spousal caregiving provided by males and females; (ii) examine how gender influences caregiver stress, burden, anxiety, and depression, as well as patient psychosocial outcomes; and (iii) explore how caregiver gender influences coping styles.	88 spousal caregivers (63 females and 25 males)	CS	Female caregivers reported significantly higher levels of perceived stress, depression, anxiety, social strain compared with male caregivers, and female patients of male caregivers were more likely to use social support as a coping style compared with male patients of female caregivers.	28
	Kim et al. (2006) (USA)	To examine potential psychosocial mediators of gender differences in caregiving stress among spousal caregivers of cancer survivors.	429 spousal caregivers	CS	Husband caregivers reported higher caregiver's esteem, which resulted in reporting less stress from providing care to their wife with cancer. On the other hand, when husband caregivers provided care to their wives with poorer psychosocial functioning, they reported greater stress from caregiving.	28

(Continued)

**Table 1.** (Continued.)

Author, year (country)	Aims	Sample	Design <sup>a</sup>	Main findings	QA <sup>b</sup>
Kim et al. (2008) (USA)	To examine the dyadic effects of psychological distress on the quality of life of couples dealing with cancer.	168 spousal caregivers	CS	Difference in psychological distress between the couples found, with wife caregivers reporting poorer mental health.	34
Kuenzler et al. (2011) (Switzerland)	To examine the impact of gender, role, and relationship status on male and female patients, their spouses, and non-partnered patients.	137 spousal caregivers	CS	Female spouses of cancer patients were at high risk of deteriorated quality of life immediately after diagnosis.	34
Rhee et al. (2008) (Korea)	To explore the prevalence of and to identify the predictors of depression in family caregivers of cancer patients.	165 spousal caregivers	CS	Being female, being the spouse of the patient, being in poor health status, or having a low monthly income or high medical costs was associated with caregiver depression.	35
Socioeconomic Bookwala and Schulz (2000) (USA)	To examine gender differences in the experience of primary and secondary caregiving stressors, depressive symptoms, and their interrelationships.	283 spousal caregivers (145 female, 138 male)	CS	Caregiving husbands experienced fewer stressors and depressive symptoms than their female counterparts. Multiple group analysis revealed that the primary stressors were more useful in explaining variance associated with the secondary stressors for women than men and that the path coefficients linking the amount of caregiving assistance to caregivers' activity restriction were significantly different across men and women.	35
Carey et al. (2012) (Australia)	To (i) describe support persons' perceptions of personal, financial, and social impacts associated with this role; (ii) explore strategies that may reduce the financial and social impact of the support role; and (iii) identify factors associated with experiencing a greater number of personal, social and financial consequences, and endorsing a greater number of solutions to reduce these impacts.	148 spousal caregivers	CS	While male support persons reported a greater number of expenses than did female support persons, women felt a larger financial impact.	36
Goldzweig et al. (2009) (Israel)	To assess the levels and intercorrelations of psychological distress, coping, and social support among older couples, where one of the partners was diagnosed with colon cancer.	231 cancer patients spouses	CS	Men reported receiving more support from their wives than did the female spouses. The gender differences found implied that men (healthy or sick) tended to receive more support than they give to their wives. It also implied that men did not use the support they received as effectively as their wives.	38
Hasson-Ohayon et al. (2015) (Israel)	To explore the relationship between attachment styles, social support, gender, and finding meaning in caregiving among spousal caregivers of colorectal cancer patients.	60 caregivers (30 females and 30 males)	CS	No significant gender differences were found with regard to attachment styles, social support, and finding meaning in caregiving among spousal caregivers of colorectal cancer patients.	37
Kavanaugh et al. (2015) (USA)	To examine the predictors of economic burden reported by lung cancer spousal caregivers.	138 spousal caregivers (112 females and 26 males)	CS	Younger spouses provided care for patients with more symptoms and reported greater economic burdens. The direct effects between contextual variables and economic burden revealed that caregivers with less education and those with more children at home reported more adverse economic outcomes.	32

(Continued)



**Table 1.** (Continued.)

Author, year (country)	Aims	Sample	Design <sup>a</sup>	Main findings	QA <sup>b</sup>	
Langer et al. (2003) (USA)	To (i) describe changes over time with respect to negative affect and marital satisfaction; (ii) examine dyadic differences over time; and (iii) identify predictors of change in marital satisfaction among patients and spousal caregivers.	131 spousal caregivers	L	Couples' marital satisfaction matched prior to stem cell transplantation but grew mismatched over time, with spousal caregivers reporting lower levels of marital satisfaction relative to their patient counterparts 6 months and 1-year post-transplant. The change was predicted only by gender but not by the physical or psychosocial characteristics.	36	
Northouse et al. (2000) (USA)	To (i) compare colon cancer patients' and their spouses' appraisal of illness, resources, concurrent stress, and adjustment during the first year following surgery and (ii) examine the influence of gender (male versus female) and role (patient versus spouse caregiver) on study variables.	56 couples	L	Female spouses tended to report less support than male spouses, as shown by female spouses reporting the lowest level of support at all three assessment times.	36	
Van Houtven et al. (2010) (USA)	To better understand the costs for caregivers from a retrospective analysis of economic burden based on a survey of informal caregivers of cancer.	1,039 spousal caregivers	R	Spouses faced higher economic burdens than other relatives or friends.	33	
Mixed-methods study						
Gendered positioning	Ussher and Sandoval (2008) (Australia)	To (i) examine cancer-carer distress, burden of care, unmet needs, time spent caring, and support received, using questionnaires, and (ii) examine the ways in which caring is positioned by carers, using interviews.	50 caregivers (35 female, 15 male)	MM	Women described being positioned as all-encompassing expert carers, expected to be competent at decision-making, a range of physical caring tasks, and provision of emotional support for the person with cancer. The consequences of this positioning were over-responsibility and self-sacrifice, physical costs, and overwhelming emotions, which were self-silenced. In contrast, men carers positioned caring as a competency task which they had mastered and which provided them with satisfaction, with the emotions of the person with cancer or their own emotions, being negative aspects of caring.	40

<sup>a</sup>CC = case-control, CS = cross-sectional, L = longitudinal, R = retrospective, MM = mixed-methods.

<sup>b</sup>QA = quality assessment. SES=social economic status

well-being and life satisfaction than male caregivers (Ketcher et al. 2019; Kim et al. 2008; Rhee et al. 2008).

A study on psychiatric morbidity of family caregivers further identified that female spousal caregivers were more likely to experience social pressure to assume the caregiving role, yet they were also more likely to stay in the caregiver role even when it became very stressful (Rhee et al. 2008). It is noteworthy that psychological distress could be a prolonged experience. It was shown that female spousal caregivers experienced higher anxiety than their male counterparts at diagnosis and at 8 and 14 months post-diagnosis (Kim et al. 2006). A study investigating distress in couples coping with cancer found a higher level of distress among the female spouses, regardless of whether they were the cancer sufferers or the partners of the sufferers (Hagedoorn et al. 2002). In addition, a Swiss study explored the quality of life differences with

regard to gender, role, and patient relationship status among cancer patients and their spouses immediately after diagnosis. The study found that female spouses appeared at risk for deteriorated mental and dyadic quality of life. Furthermore, they were more prone to greater distress, namely depression, anxiety, intrusions, and hyperarousal, compared with male spousal caregivers (Kuenzler et al. 2011).

An Israeli study (Baider et al. 2003) and an American study (Kim et al. 2006), however, reported results on the contrary. While both studies found that male spousal caregivers received more family support, they experienced a higher level of psychological distress than female caregivers. Notwithstanding, currently available evidence generally showed that female spousal caregivers had a higher level of distress and perceived caregiving more negatively than male spousal caregivers.

### Socioeconomic stressors

Social distress of a spousal caregiver includes both social support and marital relationship (Goldzweig *et al.* 2009; Hasson-Ohayon *et al.* 2015; Langer *et al.* 2003; Northouse *et al.* 2000). A study of 283 spousal caregivers' primary and secondary caregiving stressors, depressive symptoms, and their interrelationships in the United States found that female spousal caregivers experienced more restrictions in their personal and social activities; they also experienced a great loss of self and had a poorer ongoing relationship with the care recipients (Bookwala and Schulz 2000). Studies also reported that female spousal caregivers perceived less social support than their male counterparts and such social morbidity became worse over time (Langer *et al.* 2003; Northouse *et al.* 2000). In a mixed-methods study (Ussher and Sandoval 2008), it was found that female spousal caregivers were reluctant to ask for support from family members, friends, and neighbors. Also known was that female caregivers were unwilling to obtain professional support due to the uncomfortable feeling of being cared for by strangers. These barriers had resulted in increasing social isolation due to the loss of contact with family members, friends, or neighbors.

Since marriage is a long-term relationship that affords a central role identity and provides a fundamental resource of social support and coping assistance, it is often considered as a relationship that is distinct from other family relationships (Revenson 1994). A few studies had examined caregivers' marital satisfaction using the Dyadic Adjustment Scale (Langer *et al.* 2003; Northouse *et al.* 2000). It appeared that less marital satisfaction was reported in female spousal caregivers (Northouse *et al.* 2000). This finding was in line with a later study reporting marital satisfaction decreased over time among female spousal caregivers (Langer *et al.* 2003). In contrast, one Israeli study found that male spousal caregivers experienced lower levels of marital satisfaction than their female counterparts (Goldzweig *et al.* 2009).

The financial impact and hidden costs of cancer appeared to affect caregivers. Caregivers could suffer from financial burden brought about by insurance deductibles and co-payments, as well as by other services that were not covered by medical insurance such as transportation, home care, and lost salaries due to missing work (Carey *et al.* 2012; Kavanaugh *et al.* 2015; Van Houtven *et al.* 2010). It was observed that older spousal caregivers in many cultures experienced a set of gender norms and role expectations that emphasized women's homemaker role and men's breadwinner role. As a result, female caregivers' economic activities had been more affected when caregiving demands emerged (Kavanaugh *et al.* 2015). Quitting a job, retiring early, and changing a schedule or job role were some of the many adjustments that women made in their work situation. A study on caregivers of hematological cancer patients found that female caregivers felt a large financial impact although male caregivers reported a greater number of expenses (Carey *et al.* 2012). Male spousal caregivers reported experiencing more personal expenses and a greater number of social impacts.

### Gendered positions of spousal caregivers

One out of the 20 included studies used mixed-methods to analyze the gender differences in cancer spousal caregiving. The 50 family cancer caregivers, 35 women and 15 men, were examined using a critical realist approach and a combination of questionnaires and interviews (Ussher and Sandoval 2008). Women reported higher levels of depression and anxiety, unmet needs, and disruptions

from the burden of care than men, regardless of the time spent on caregiving. Semi-structured interviews with 13 spousal caregivers were used to identify gender differences in the experience and construction of caregiving. Female caregivers described being positioned as all-encompassing expert caregivers, with the expected competence to make decisions and to perform a range of quasi-medical tasks, and provide emotional support to their partners with cancer (Ussher and Sandoval 2008). The consequences of this positioning were physical costs of caring and overwhelming emotions, which were often followed by self-silencing with suppression of anger. In contrast, male caregivers positioned caring as a competency task which they could master and obtain satisfaction from, though difficulties dealing with the emotions of their partners with cancer and or their own emotions toward cancer were reported as negative aspects of caregiving (Ussher and Sandoval 2008). Central to the socially constructed positions as all-encompassing expert caregivers, the study concluded that cancer caregiving among female spousal caregivers had resulted in over-responsibility and self-sacrifice, which could be intensified by societal expectations and self-policing practices.

### Discussion

As referred to the broad base of published studies, it was found that both male and female spousal caregivers had experienced considerable physical, psychological, and socioeconomic morbidities in association with caregiving. Notwithstanding, it was evidenced that female spousal caregivers in general perceived a larger burden of care and reported to suffer from higher levels of distress across all aspects. The current systematic review highlighted gender disparity between male and female cancer spousal caregivers. The gendered positions of female and male cancer spousal caregivers further illustrated the gender differences in the caregiving experiences and consequences.

The self-identity of a caregiver is constituted and negotiated in relation to the positions taken up by an individual or the positions within which they are put into by others. As different from the relatively static nature of roles, positioning is described as a dynamic, continuous, lifelong process (Harré and Van Langenhove 1999). Positioning theory studies what an individual "may do and may not do" with reference to the moral presuppositions of rights and duties (Harré *et al.* 2009). Once taken up a particular position, an individual inevitably interprets the world from the perspective of that position. The processes of adopting a position include recognizing oneself as a member of certain dichotomous categories (e.g., male and female, or good spouse and not good spouse) and participating in storylines that are made relevant within a particular category (Davies and Harré 1990). Viewing caregiving as a social episode, the actions of spousal caregivers can be seen as meaningful components of storylines and are determined by the positions they have taken up.

Women are expected to better suit the caregiving role than men and be competent at decision-making. Taking up the female spousal caregiver positions, women appraised various stressors by means of their own perception of moral rights and duties, as well as that imposed directly or indirectly by others. As positioning is a continuous process along the cancer trajectory, what women do, both publicly and privately, are subjected to moral assessments of proper and improper actions in connection with the female position. The results of this study revealed that the gendered positions of female spousal caregivers did give rise to physical, psychological, and socioeconomic stressors. The societal context appeared

to reinforce and perpetuate the gender differences, if not gender inequalities in cancer caregiving, between men and women, with more female spousal caregivers suffering from over-responsibility and self-sacrifice.

Gender is constructed by cultures and by individuals (Beall 1993). Social constructionists argue that human beings are actively engaging in perceiving social information and constructing their understanding of the world. As an individual, we perform according to others' cultural messages to conform to gender stereotypes in the prevailing culture. It has been argued that health-related beliefs and behaviors, as social acts, are also means of constructing and demonstrating gender (Courtenay 2000). In many cultures, gender stereotypes serve as a form of sexual division of labor and a rationalization for the current social order (Beall 1993). In many parts of the world, it is accepted that women's caregiving is the natural order of cultures (Chitayat 2009). It had been well documented that women are major contributors to health, through both their roles as primary family caregivers and their participation in the health sectors as formal or informal health-care providers (WHO 2009). Also known is that women's roles as family caregivers do not come with support, recognition, and remuneration. The socially constructed gender norms of female spousal caregivers further reinforced many social practices in spousal caregiving. The gendered positions of spousal caregivers would certainly pose a profound impact on an individual's functioning and health. The morbidities observed in female spousal caregivers for cancer patients discussed earlier are undoubtedly attributed to the perceptual biases linked with gender stereotypes.

The impact of informal caregiving has long been the focus of academic research. Much of the research on caregiving has come from literature on studies attempting to understand caregiver stress and coping strategies, including the Transactional Model of Stress and Coping (Lazarus and Folkman 1984) and the Stress Process Model (Pearlin et al. 1990). These early models listed contextual variables such as age, gender, socioeconomic status, and caregiver relationship to the patient and attempted to identify and rank stressors. Some models categorized stressors into primary and secondary stressors, with primary stressors referring to the direct caring needs of the patients. These models discussed the consequences of caregiving with reference to the caregiver's appraisal of the stressors, including positive and negative feelings, and the potential mediating variables, such as coping behaviors and social support. Theories of caregiving stress and coping had been further extended later by including sociocultural factors (Aranda and Knight 1997; Knight and Sayegh 2010). The Sociocultural Stress and Coping Model has incorporated the influence of cultural values characterizing ethnic differences in caregiving. Although gender has always been included as a background variable in caregiver research and the findings of the present study showed gender disparity between male and female cancer spousal caregivers, more empirical studies are needed to increase the explanatory power of gender in these models of caregiving. Viewing gender as a socially constructed concept instead of a constant demographic variable would allow a comprehensive understanding of the gendered positions in spousal caregiving. It is also becoming more pressing for sophisticated research to be conducted on gender to improve our knowledge on the heterogeneity within the female caregiver group and the potential interaction effect with other social and cultural variables.

Since the cancer trajectory could lead to changes in the nature of the marital dyad (Glantz et al. 2009), future research should also focus on the differential impact of caregiving and care-receiving on

both men and women. In addition, in order to address the evolving nature of gender in the contemporary world, it would also be desirable to conduct studies on caregiving practices and experiences on lesbian, gay, bisexual, and transgender (LGBT) caregivers to outline the full picture of spousal caregiving. The ultimate purpose of cancer caregiving research is to identify the groups of individuals who are at risk of the negative impact of caregiver distress and develop interventions that are sensitive to the needs of specific groups of caregivers identified. More empirical data on gender differences in caregiving experiences based on cancer types and caregivers' experiences of long-term survivorship and bereavement would certainly broaden the knowledge base to facilitate potential intervention planning for caregivers. While quantitative methodology is the dominant research method in health-care research and is useful in testing assumptions, it could not provide us with sufficient details of a phenomenon and its context. To better understand gender as a complex construct rather than simply another demographic variable, well-designed qualitative studies are needed. The exploratory nature of the qualitative methodology could significantly contribute to the understanding of gender as a concept and facilitate the future development of interventions addressing gendered positions.

### **Clinical implications**

Clearly, when analyzing the situation of cancer spousal caregivers from a gender perspective, evidence demonstrated that female spousal caregivers for cancer patients suffered from higher levels of distress in spousal caregiving. Based on the results of this review, highlighted here are the implications on working with cancer spousal caregivers in routine clinical practice:

- i. Spousal caregivers of cancer patients experienced physically distressing symptoms as the result of their caregiving role; these physical health stressors appeared to be associated with negative consequences of various severity over time, such as fatigue, sleep disorder, deteriorated physical health, coronary heart disease, and stroke. Health-care professionals should be proactive in identifying physical health problems among spousal caregivers, female ones in particular.
- ii. Mental morbidity among spousal caregivers could be manifested in various forms, including stress symptoms, anxiety, and depression. As quality of life is an important component in health and health-related domains, health-care professionals should direct spousal caregivers to timely interventions should mental morbidity be recognized in caregiver needs assessment.
- iii. The financial impact and hidden costs of cancer appeared to affect predominantly female spousal caregivers. Health-care professionals should be sensitive to the long-term implications of the economic burden on cancer patients and their families as a whole.
- iv. Gender stereotypes in the societal context appeared to underpin the gender differences in informal cancer caregiving. The gendered position of female spousal caregivers left many women suffering from over-responsibility and self-sacrifice with minimal support. With this understanding, health-care professionals should develop a clinical practice with a gender focus, including but not limited to recognizing gender bias in spousal caregiving.
- v. Health-care professionals inevitably take part in constructing gender in the societal context and should therefore act as



a catalyst for the transformation of cancer spousal caregiving. While providing health-care services to cancer patients, it is necessary to routinely consider the health status and health-related behaviors of patients' spouses along the cancer trajectory.

### Strengths and limitations

The current study explored the gendered positions in cancer spousal caregiving through the lens of social constructionism, allowing extensive understanding on gender disparity between male and female cancer spousal caregivers beyond the demographic labels of gender. The PRISMA guidelines were used to increase research transparency and ensure proper reporting of this systematic review (see Supplementary material for the PRISMA checklist). This review, however, has some limitations. Most of the studies (19 out of 20) included in this review were conducted in Western countries, and the only study from Asia was conducted in South Korea. In addition, language bias could not be avoided as only studies published in English were included. Considering gender is a socially constructed concept, cultural values are likely to vary the attributes of such concept. Although this systematic review represented a diverse population from seven countries, it is uncertain if we could extend the understanding of gender differences in caregiving from this study globally. Furthermore, the 20 studies included in this review were of a wide range of study designs, including cross-sectional and longitudinal studies. While all included studies had been critically appraised for quality assessment, such heterogeneous inclusion has created challenges for us to draw a conclusion about gender differences in caregiving at specific time points along the cancer trajectory.

### Conclusion

In reviewing the currently available evidence, this paper confirmed that spousal caregivers of cancer patients are at increased risk of developing physical, psychological, and socioeconomic morbidities. Although inconsistent findings on gender differences in spousal caregiving were noted, the vast majority of research evidence pointed out that female spousal caregivers suffered more than their male counterparts across dimensions. The knowledge obtained from the current inquiry could serve as a foundation for more sophisticated research on gender differences in spousal caregiving and studies focusing on the evolving nature of gender in the contemporary world. In addition to narrowing the knowledge gap described, health-care professionals should also recognize the strong need for empirical research, political engagement, and action plans to address the health status and health-related behaviors of patients' spouses along the cancer trajectory. It is beyond doubt that addressing female spousal caregivers' well-being would benefit not only women but also their families and the community at large.

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