



Caregiving Burden among Family Caregivers of People with Advanced Cancer: A Literature Review

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Abstract

This literature review focus on the research methods, levels, influencing factors and types of family caregiver burden caring patients with advanced cancer; aiming to improve medical worker's understanding of caregiver burden, provide a basis for building their support system, and produce new insights for nursing practice and research in the future.

Keywords: Cancer; Caregiver burden; Review

Abbreviations: ZBI: Zarit Burden Interview; CRA: Caregiver Reaction Assessment; CASP: Critical Appraisal Skills Programme.

Introduction

With the improvement of diagnosis, treatment and the symptom-management of disease in the health care system, the life span of terminally ill cancer patients has been greatly extended. Cancer is gradually regarded as a chronic illness, which means a major shift in the model of care-delivering [1]. In the majority of cases, the care of cancer patients has transferred from a hospital setting to home care [2]. As a result, more and more family members are taking on the role of caregivers, providing daily life, emotional and medical support and assistance to patients with advanced cancer. It has been recognized that home-based care is a long-term backed project, and care providers in the family are the bedrock of the health assistance system [2].

Many evidence-based studies have stated that informal caregivers in the family undergo a heavy burden when caring for a sick family member [3-6]. As researches in developed countries shown, high levels of burden can lead to anxiety,

depressive disorder, fatigue, insomnia and risen mortality among informal caregivers [7-9]. Taking care of people in the late stage of cancer, in particular, is recognized as more challenging [10]. The main reason is that the symptoms of cancer vary with the phase of the disease, and the status of patients at the end of life is more uncertain [11,12]. Caregivers can suffer from great indignation, social isolation or other serious consequences [13,14]. Furthermore, the burden on family caregivers for patients with advanced cancer also has a significant impact on patients' psychological, physical, financial and community activities [15,16], which in turn affects their quality of life or self-reported well-being index in the end [17].

However, the research investigating the caregivers' burden and its impact on their lives appears to be limited. Interestingly, a study conducted by De Korte-Verhoef, et al. [18] found that although more than half of family caregivers reported a serious burden, only a quarter were aware that the burden had negatively affected their everyday lives. Due to the serious lack of attention and support, some authors consider the caregivers as "potential patients" or "secondary patients" [19-21].

Primary caregivers can be divided into two categories: formal and informal caregivers. The former mainly refers to nurses or nursing workers who are professionally trained and get paid to deliver care; the latter usually relate to family caregivers, such as spouses, children or relatives, who deliver care without pay [21]. According to the World Health Organization [22], there were more than 18 million new cancer cases worldwide in 2018. An increasing number of cancer cases will require greater nursing demands as well as more support from the family caregivers [21].

Studies have indicated that caregivers are likely to confront threats to their bodies and emotion during the process of caring for dying patients [2]. The caregiving tasks are usually diverse, especially for family caregivers, not only to tackle the routine household chores or assist patients in all aspects of daily life but also to provide emotional and financial support, such as participating in the discussion of treatment options and paying medical expenses [19,23,24]. Also, family caregivers tend to focus on patient-centered care and sometimes ignore their own needs. A recent study by Oedekoven, et al. [25] suggests that it is of great importance to recognize the strains caregivers face, so that the healthcare professionals can provide support in the right way to ease the burden on caregivers. In order to recognize the current body of knowledge related to the burden of caregiving in advanced cancer a literature review was conducted.

Search Strategy

An electronic search of four English databases was conducted: Academic Search Complete, Medline, CINAHL, and Health Source: Nursing/Academic Edition. To avoid unnecessary errors, the author consulted a librarian at the university about the search strategy. Keywords or free text were combined using Boolean operators (ie, "AND" and "OR") during retrieval to get all relevant studies about caregiver burden over the last three years. After deleting the duplicate article, the author re-examined the title and abstract in line with the exclusion criteria to exclude some articles. The author also conducted a manual search by evaluating the reference list of articles that strongly related to this topic. The limitations imposed included literature published (a) in the English or Chinese language, (b) between 2010 and 2020, (c) peer-reviewed, and (d) full text.

Results

The initial search revealed 509 studies, but fifteen articles were comprised in this review. The majority of the studies adopted quantitative methods (13/15), of which three were longitudinal studies and ten were cross-sectional studies. One study was qualitative design, with in-depth semi-structured interviews. The final one was a mixed

method design that combines quantitative questionnaires with semi-structured interviews. Six studies mainly assessed caregiver burden, five identified influencing factors or predictors of caregiver burden, and four focused on the relationship between caregiver burden and other outcomes. In terms of cancer types, nine studies (9/15) did not specify the type of cancer; three studies focused on patients with lung cancer and their caregivers, while the rest were on breast cancer, ovarian cancer, and head and neck cancer respectively. Moreover, most of the studies (11/15) did not specifically state the criteria of advanced cancer, and only four studies used phase III/ IV criteria based on the TNM staging system. In the light of geographical distribution, the major studies were conducted in developed countries (10/15), such as South Korea, Italy and the United States, and a few in developing countries.

Before analysing the data, the author appraised the quality of the article using the Critical Appraisal Skills Programme (CASP) tool. Conveniently, the CASP appraisal checklists can be downloaded for free from the website at any time. What's more, this is a simple and effective instrument that covers the elements needed to evaluate evidence and could guide students in a critical assessment of the quality of selected literature [26]. Since there are versions of CASP checklist that apply to different methodologies, appropriate type was selected based on the methodology of each study.

Caregivers' Characteristics

Across all the 15 studies, the sample size ranged from 20 to 327. Most of the family caregivers were women (69.4%), nearly half (45.6%) were spouses, 44.1% were grown-up children, and the average age was 46.2 years. More than half of caregivers had a secondary school education or above (65.9%), 45.4% had occupation (including part-time jobs), and 69.5% of them provided more than 4 hours of care per day.

The Measurement of Caregivers' Burden

Of the 15 studies, the most commonly used tools to measure Caregiver Burden were the Zarit Burden Interview (ZBI) [27-30] and the Caregiver Reaction Assessment (CRA) [2,31-33]. Other studies used revised versions that were translated into the country language and tested for reliability and validity. ZBI is a self-rated scale for caregivers. The initial scale consisted of 29 items, which was later revised into a 22-item questionnaire. Each item was measured using a 5-point Likert scale. The score ranges from 0 (never) to 4 (almost always). The overall burden is the sum of the scores for all items, from 0 to 88. The higher the score, the greater the burden [28]. When it comes to CRA, which was first developed by Given, et al. in 1992 [34]. It consists of five core

domains with a total of 24 items that reflect the caregiver's positive and negative experiences according to the life of caregiving. The score also ranged from 1 (totally disagree) to 5 (totally consent). Only in the area of caregivers' self-esteem, the higher the score means the burden was lower. The higher the score in the other four areas, the greater the burden [2].

Themes Emerging from the Literature

This literature review has identified three main themes: 1. the level of caregivers' burden 2. The types of burden perceived by family caregivers 3. Factors influencing caregivers' burden. Each theme will now be described.

Theme 1: The Level of Caregivers' Burden

Across all studies included in this literature review, over half of caregivers of people with advanced cancer (67.8%) reported moderate to the severe burden. Data from a survey of informal caregivers of breast cancer patients in Nigeria showed that 86.7% of the 118 participants reported a "high" burden, with an average ZBI score of 37.1 [30]. In Seo and Park's [29] research, the ZBI score was 44.13. Although both studies had high self-rated ZBI scores, there were significant differences in the identities of participants, with the former mainly adult children and the latter mostly spouses. Researchers mentioned that under the influence of cultural teachings, they play the role of caregiver and are willing to take care of patients, despite the difficulties. This is a sense of responsibility, indicating the caregivers' positive experience of care. Therefore, the caregiver also scored a bit higher on the CRA subscale - self-esteem [31].

The vast amount of literature on this subject indicates that female caregivers report a higher level of burden and stress than male caregivers [21,28,35,36]. The findings were also supported by an Australian cross-sectional survey, which focused on gender differences in the burden on family caregivers of patients with advanced cancer [27]. However, in Canada, a study of caregiver burden based on palliative care at home came to the opposite conclusion, with a sample size of 327, although of which there are only 30 percent of male caregivers [37]. The difference in the findings of the two studies was probably due to the different scales used to assess caregivers' burden, and the response rate in the Australian study was only 50.3%, compared with 89.1% in the Canadian study. In general, caring for family is regarded as women's traditional duties, with many intimate nursing demands (ie, toileting) so that it is less likely to seek support [35,38-40]. In contrast, male caregivers are better at seeking community services, information support to fulfill their caregiving obligations [41,42]. Additionally, qualitative studies revealed that female caregivers feel guilty about the conflict between caregiving tasks and housework [27,35], which may lead to burdensome.

Records of caregiver' age and caregivers' burden varied in the literature. Some of literature claims that the burden on older caregivers was higher than on the younger [21,32], and Ramli and Pardi [2] have opposite views on this. Many previous studies have even shown that there is no correlation between caregivers' age and caregivers' burden [37,43,44]. In a cross-sectional study in Italy, 174 participants were divided into younger and older groups and found that caregivers aged 65 or over had a higher level of burden. There is often a conflict between caregiving tasks and personal development, with caregivers having to give up some hobbies or reduce their own expenses to provide better care [21]. On the other hand, qualitative data from a cross-national research in five countries illustrated that caregivers, especially older caregivers, often have an array of health problems, which is a leading cause of feeling more burdened [32]. Although a cross-sectional study in Malaysia also used questionnaires, among the 110 family caregivers, younger caregivers reported a greater self-perceived burden, possibly because providing care often disrupted their day-to-day arrangements. However, as caregivers grow older, they have more experience and ability to arrange their own lives as well as meet the needs of patients, the burden may become less accordingly [2].

Some authors believed that different relationships between family caregivers and patients will result in different levels of caregivers' perceived burden [28,45,46]. A Taiwanese study of the burden trajectory of family caregivers recruited 150 lung cancer patient-FC dyads and found that caregivers who are spouses have a heavier burden than caregivers who are adult children [35]. Of the 150 caregivers, 70 percent were female, and 50 percent were spouses. In Taiwan, it is believed that women should care for sick family members and assume family responsibilities, even without adequate preparation [31] or professional training. Therefore, their subjective burden may increase due to social expectations [33]. Researchers from several studies agreed with this finding [32,47,48]. On the contrary, a study of family caregivers for breast cancer patients came to another conclusion, with Gabriel [30] arguing that grown offspring caregivers are more burdensome than spouses. Because most of the caregivers in Gabriel's study were retired spouses, there was nearly no conflict between career and caring. Adult children who tend to come from low-income families had to support their parents as well as their own small family, suffer more [30].

Theme 2: The Types of Burden Perceived by Family Caregivers

In accordance with Akpan-Idiok and Anarado [49], caregiver burden can be classified as mental burden, social burden, and economic burden. Through the analysis of 15 studies, the perceived burden of caregivers is mainly

reflected in three dimensions: social life, financial issue, and physical and mental health.

Family caregivers' social life was seriously disturbed [31-33]. In a longitudinal study on the caregiver burden trajectory of lung cancer patients, Lee, et al. [33] found that "disrupted schedules" were an area where caregivers felt the greatest burden. The result was also confirmed in an anonymous investigation of 50 caregivers of ovarian cancer patients in the United States by Hartnett, Thom and Kline [31]. Caring for late-stage cancer patients can be a challenging and time-consuming job, which takes up a great deal of time [33] and limits caregivers' daily activities [50]. As a result, lots of caregivers have reportedly switched from full-time to part-time work or even resigned [51]. In in-depth interviews with caregivers, they usually mentioned that caregiving tasks led to disruption of social interactions and feelings of social isolation [32].

To the best of our knowledge, numerous studies have reported a link between financial issues and caregiver burden [45,52], which ranked second in the burden on caregivers [33]. Family caregivers not only provide assistance in patients' daily lives but also fund their medical treatments. Many families reportedly spend as much as a tenth of their income on caring for a sick family member and end up taking out loans [4]. A longitudinal study in Taiwan investigated caregivers of 150 patients with advanced-stage lung cancer, and found that nearly 20 percent had resigned from their jobs to offer care, resulting in financial distress after unemployment [33]. This is in line with another previous study [53]. Monthly medical costs [54], fewer available medical resources because of lower-income [30,31], more family expenses [29], and the unemployment of family caregivers [33] all bring heavy financial load to family caregivers. For that reason, it is conceivable that low-income people would feel especially stressed and burdened when caring for sick relatives.

The physical and mental health of caregivers can deteriorate as a result of the ongoing caregiving burden [55]. A substantial body of research stated that providing long-term care can lead to a host of health problems, such as pain [32], fatigue, serious lack of sleep [3,25,48,56], emotional restlessness [2], anxiety and depression [32,57]. Tang [58] conducted a qualitative study in the correlated field using semi-structured interviews in China. Data analysis showed that the psychological stress experienced by family caregivers of patients with advanced cancer also included the challenge of telling the truth and anticipated grief. It may have something to do with cultural background. Death is a taboo topic in China, where family caregivers often choose to hide the truth about the patient's condition and make major medical decisions at critical moments [58]. Anticipated grief

is a pervasive, inevitable emotional stress that can manifest as anger, silent crying, and so on [59]. Caring for relatives or a loved one is a highly individualized experience, with different levels of stress and emotion [60]. For caregivers whose patients are about to die, they are under greater psychological constraints. Sternthal and Dholakia [61] suggest that caregivers should not only take care of their patients but also learn to look after themselves.

Theme 3: Factors Influencing Caregivers' Burden

To a certain extent, the illness of the patient is positively correlated with the burden on the caregiver; that is, the caregivers' burden increases with the aggravation of the patients' condition [29,32,37]. A longitudinal study in Canada examined the burden of caregivers at home for 327 patients with malignant tumors, the result is that the burden on caregivers increases when patients' functional status declines [37]. The possible reason is that as the patient's condition worsens, the number and extent of the patient's nursing needs increase correspondingly. Family caregivers, on the other hand, are identified as primary observers of the patient's illness progress and facilitators of symptom-management, thus encounter a greater burden [62,59]. Meanwhile, the qualitative research results of Tang [58] also confirm that the monitoring of patient progress is one of the core themes of caregivers' burden in China.

It is noted that social and family support is negatively correlated with caregivers' burden, which means that the more support caregiver receive, the lower burden the caregiver will have [2,30,54,58]. The result of a quantitative study of the informal caregivers' burden of breast cancer patients showed that the external support can help caregivers adapt to changing roles, thereby reducing the burden [30]. Since this study was conducted in the economically backward northern regions, the results may apply only to low-income areas. But the findings are consistent with many previous pieces of research [31,63]. For caregivers, the appropriate social support network is a buffer that can reduce or avoid the stress and burden they come across [64,65]. The different models of palliative care services established by European health systems, for example, is an effective way to relieve the burden on caregivers [32]. Additionally, good family support can reduce the burden on caregivers [2]. However, when another family member falls ill, relatives visit less often [50], and there is no alternative family caregiver [66], the burden perceived by the caregiver much heavier [54].

The duration of care is closely related to the level of the burden as well [2,30,37,57]. In their findings, Akpan-Idiok and Anarado [49] elaborated that more than 50% of care providers underwent high levels of care-time-related burden. Borges, et al. [57] investigated the burden between 91 lung cancer patient-caregiver dyads in Brazil. The results

of a survey indicated that almost one-half of the caregivers at home offered care for above four hours per day, in other words, exceed 28 hours per week. That's 3.6 hours a week more than the average nursing time, compared with the figures reported by the National Alliance for Caregiving [57]. Guerriere, et al. [37] studied the predictors of caregiver burden in palliative care at home with a sample of 327 caretakers. Of those participants, carers who spend more time caring for patients experience a greater subjective burden. This may be related to severe limitations in their daily activities. This finding is in line with other researches [30,50]. Some of these studies set their focus on caregivers of breast cancer patients or in other cultural settings. On the other hand, a cross-sectional investigation from Malaysia showed remarkable different consequences [2]. The survey was conducted among family caregivers of chemotherapy patients, and a scaled assessment illustrated that the burden on caregivers decreased over time. According to the stress adaptation theory, caregivers master various nursing skills step by step over time and gradually adapt to the pressure brought by caring tasks [2]. The study involved only one tertiary hospital of 110 participants and was limited to patients undergoing chemotherapy, so the findings may not be generalizable to a wider population.

Conclusion

The findings of this literature review suggest that the majority of family caregivers of patients with advanced cancer are undergoing moderate to severe burdens, with significant adverse impacts on their social life, physical and mental health, and financial well-being. Patients' condition, family and social support, and care duration were identified as predictors of caregivers' burden and could be changed. Hence, long-term care for patients with terminal cancer should include identifying and assessing vulnerable caregivers in the family who need support. These findings provide the theoretical basis for the health care system to continue to improve its medical support network and tools. For example, community health professionals can provide disease-related counseling and information to family caregivers and guide them in symptom management.

At present, most studies about the burden on caregivers are conducted in developed countries such as Europe, where hospice care started earlier and has relatively mature service experience and model. Family caregivers have easier access to the resources they need to relieve their burden. For developing countries, such as China, which has the world's largest population, hospice care providers are far from meeting market demand. Besides, under the influence of 5,000 years of traditional Chinese culture, family carers should take the responsibility of taking care of their relatives actively and initiatively rather than look for a hospice care

institution firstly. Otherwise, it will go against the principle of filial piety. In summary, the burden on caregivers in different countries, different cultures and different types of cancer patients cannot be generalized.

In the future, more research targeted on specific types of cancers should be carried out in developing countries with different national conditions. For further research, qualitative research is suggested to explore carers' burden under different cancer types and cultural, so as to update the existing cognition.

Conflicts of interest

There are no conflicts of interest.

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