Research Article

Other Side of Breast Cancer: Factors Associated with Caregiver Burden

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ARTICLE INFO

SUMMARY

Purpose: This study aimed to determine factors associated with caregiver burden among primary caregivers of women with breast cancer in Iran.
Methods: This was a descriptive correlation study conducted in 2012 on 150 main caregivers of patients with breast cancer who came to the oncology clinic of the X hospital in X, Iran. A questionnaire which included caregiving-related factors and the Zarit Burden Interview was used for data collection after its validity and reliability were determined. Data was analyzed using SPSS 13.0 software with descriptive and analytic statistics. The association between significant variables and the dependent variable with an observation of the effects of other variables was assessed using the multiple linear regression model.
Results: The mean age of caregivers was 39.60 ± 13.80 years old, and 77 (51.3%) of them were men. The mean score of the Zarit Burden Interview was 30.55 ± 19.18. In the regression model, the mean score of activities of daily living, level of education, gender, and financial status were identified as the determining factors of the burden of caregivers.
Conclusion: Primary caregivers need to be financially supported by the relevant organizations. Care skills training and providing palliative care seem helpful in reducing the pain and the burden of family caregivers for patients with breast cancer.

Introduction

Breast cancer is the most common cancer in women worldwide [1]. Breast cancer in Iran includes 21.4% of all reported cases of cancer. The crude incidence rate of breast cancer in Iran was 4 per 100,000 women. Available data showed that this illness has taken on a raising trend across the country, and from 1999 onwards has recorded the first place among other cancers [2]. Iranian women, compared to other women, are diagnosed with the disease a decade earlier. The highest incidence of this illness in Iran is observed at the ages of 40–49 years [3]. In fact, this disease occurs at the height of the women's family responsibilities and career.

During the disease and treatment, the family is the most involved in caring for the patient; helping them adapt and manage their disease [4]. Today, factors such as decreased family size, reduced presence of family members at home, reduced length of hospitalization of patients at medical centers have increased the length of care at home, and the responsibility of families for taking care of the patient has become more difficult [5]. Therefore, caregivers experience a high burden of care caused by greater responsibilities and changes in their family and social life.

Lu et al [5] quoted that Zarit defined the caregiver burden as a physical, psychological, and social response of the caregiver, which arises from the imbalance between care needs and the several care tasks. This imbalance relates to social roles, personal time, physical and emotional state, caregivers' financial resources, and official care resource.

A few frameworks have been presented on caregiver burden. Some have described caregiver burden from both an objective and subjective point of view. Objective caregiver burden is observable

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and is introduced as a needed effort to provide for the patient's needs. It is identified by the number of hours spent on giving care, types of treatment, service and any imposed financial matters due to giving care. Subjective pressure rises from beliefs, assumptions, and feelings about the role of caregiver [6].

Care, as a source of stress, can severely threaten mental, physical, and social health. Evidence indicates that caregiver burden is a predictor of anxiety, depression, and the low quality of life of caregivers [7]. However, caregiver burden will exist either overtly or covertly, therefore identifying the underlying factors seem to be helpful in modifying it.

Various studies have described diverse factors for caregiver burden including personal and social characteristics of the patient and caregiver [8,9], characteristics of care such as duration of care [8], health status of the caregiver [9] and patient's characteristics [10]. In Eastern cultures, cancer is known as an incurable disease, and in some cases, the concept of death itself. It seems that it can affect the amount of burden on patients and their families; however, very few studies have examined the burden experienced by this group of caregivers in Iran.

Cultural issues seem to also be among modifiers of caregiver burden. The relationship of background factors and caregiver burden has been investigated in western countries, yet the Asian culture is different from the western culture [6]. There is a strong family bond in Iran. Traditional and religious norms enhance the formation of extended family protective networks, and influences the expectations of the amount of caregiver's involvement in giving care. Therefore, effective factors must be identified based on the culture of each society.

This study aimed to determine factors associated with caregiver burden among primary caregivers of women with breast cancer admitted to the oncology clinic of the X hospital, X, Iran.

Methods

Study design

The present study was a descriptive correlation study, conducted in 2012 to determine factors associated with caregiver burden among primary caregivers of women with breast cancer in Iran.

Setting and sample

The participants in this study were 150 primary caregivers of patients with breast cancer admitted to the oncology clinic of the X hospital in X. The study inclusion criteria for the patients were as follows: (a) being at least 18 years of age, (b) able to identify the primary caregiver and (c) included after at least 8 weeks from her diagnosis. A primary caregiver was defined as a family member, relative, or friend of the patient, who was considered by the patient as the main provider of unpaid care (i.e., spent the most time with the patient, providing the main needed day-to-day care, assistance, and support) to her. Caregivers fitting the inclusion criteria included those who were 18 years of age or older, not receiving any payment for providing care, participated in the study willingly, and understood the Persian language. Participants were excluded if cancer was diagnosed in caregivers within the prior year or they were receiving cancer treatment, had a known mental disorder or were taking care of more than one patient. The sample size was estimated using G*Power Analysis version 3.1 for a power level of .80, a significance level of .05, and moderate effect size to enable the planned analyses. A sample size of 110 subjects was calculated. Given the probability of a 10% loss of samples and for a higher accuracy, at least 125 participants were being considered. For a higher

assurance, 150 caregivers participated in the study. A convenient sampling method was used in the present study.

Ethical consideration

This research was done after acquiring approval from the Research Council (EC130-5/4/11445-11-30) of Tabriz University of Medical Sciences. After coordinating with officials, authors introduced themselves to the participants and explained the purpose of the study. In addition, we assured them confidentiality and the right to withdraw from the study at any time.

Measurements

The data collection tool was a questionnaire consisting of two parts; the first part included demographic characteristics and factors associated with caregiving. Demographic information included age, gender, marital status, educational level, employment status, perceived income adequacy, perceived health status over the past year, hours dedicated to patient's care during the week, coresidency status, treatment method, patient's source of income, and a patient's dependency in performing activities of daily living (ADL).

In this study, dependency in ADL was assessed based on the Katz Index of Independence in Activities of Daily Living and the Lawton Instrumental Activities of Daily Living Scale [11,12]. Both were validated in Iranian culture [13,14]. This scale has 9 items (including dressing, eating, bathing, medication, going outdoors, walking, financial affairs and shopping) based on the 4-point Likert scale (*completely independent* to *completely dependent*). It takes about 2 minutes to complete. A higher score means that the patient is more dependent. The second part included the Zarit Burden Interview (ZBI) which measures the degree to which caregivers perceive care responsibilities as having an adverse effect on their physical health, emotional well-being, social life, financial status, and interpersonal relations. ZBI is a self-report questionnaire including 22 items based on a 5-point Likert scale. Questions from 1 to 21 are answered based on the following levels of frequency: $0 = never$, $1 = rarely$, $2 = sometimes$, $3 = quite\ frequently$, and $4 = nearly\ always$. Question 22 assesses the overall burden that a caregiver feels; it is scored based on the following possibilities: $0 = not\ at\ all$, $1 = a\ little$, $2 = moderately$, $3 = quite\ a\ bit$, and $4 = extremely$. The sum of individual item scores ranges from 0 to 88 (total score). Higher scores indicate higher levels of burden or distress felt by a caregiver. Although some authors proposed cutoffs to interpret the results [15,16], we chose to avoid categorizations by cut-offs that were not yet culturally or clinically validated. The time to administer was stated in the main version, but in our experience it took about 5—15 minutes to complete.   Q5

ZBI is widely used in North America and Europe to measure the burden experienced by family caregivers in caring for the elderly with disabilities [5]. However, this tool has also been used for patients with cancer [17]. In Iran, this questionnaire has been validated by Navidian et al [18], and its reliability has been determined at .94. In the present study, the face and content validity of the questionnaire was reassessed, and through Cronbach α, the ZBI and independency in ADL reliability was estimated at .86 and .87, respectively.

Data collection/procedure

Data collection was carried out conveniently in the oncology clinic in 2012 by a trained researcher. Caregivers who fulfilled the including criteria were allowed to participate in the study. Copies of the questionnaires were distributed among participants. Sufficient