

Quality of Life among Primary Caregivers of Women with Breast Cancer: A Review

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Abstract

Background: Cancer diagnosis has a significant impact not only on women, but also on their Primary caregivers. Understanding the effects of a breast cancer diagnosis on physical and mental health outcomes in caregivers is important because these variables are key components of quality of life. Quality of life is a multi-dimensional construct measuring overall enjoyment of life. This study intends to describe the impact of caring for women with breast cancer on the quality of life among their primary caregivers.

Method: We conducted a comprehensive search in PubMed, MEDLINE and CINAHL. In addition, we used the web search engine "Google" for abstracts from 2007 to 2012. A total of eight studies were reviewed that met the following inclusion criteria: adult women with breast cancer, research conducted in English. Studies ranged from 2007-2011. The total sample size in the eight studies on adult caregivers totaled 789 participants. The average age of participants in all of the studies was 49.55 years. There were seven studies that had a quantitative focus, which mainly used a questionnaire and survey to estimate quality of life among primary caregivers. The qualitative approach included in-depth interviews and a focus group.

Results: Accumulating evidence has supported the concept that cancer affects not only the patients but also their primary caregiver's quality of life. They face multiple challenges in caring for women with breast cancer, including physical, emotional, social, and financial stress that affects the caregiver's quality of life.

Conclusion: Breast cancer diagnosis not only affects the patient's quality of life, but in parallel, also affects the quality of life of the primary caregiver. Thus more focus should be placed on providing moral and social support, and educational resources to improve the level of the caretaker's quality of life.

Keywords: Family caregiver, Caregiver burden, Breast cancer, Literature review

Introduction

Quality of life (QOL) for primary caregivers (PCs) is a major issue in

the treatment of their loved ones who have breast cancer. Understanding the effects of breast cancer diagnosis on

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physical and mental health outcomes in caregivers is important because these variables are key components of QOL. Quality of life is a multi-dimensional construct that measures overall enjoyment of life. It includes numerous domains such as physical, mental, spiritual, and socioeconomic well-being.^{1,2}

Breast cancer is the most common cancer overall as well as the most common malignancy afflicting women in Jordan. Breast cancer ranks first among cancer in females, accounting for 36.8% of all female cancers, and is the leading cause of cancer deaths among Jordanian women.³

The impact of a life-threatening illness such as breast cancer is not limited to the patient, but also affects family and caregivers.² Negative caregiver experiences can affect their ability to be attentive to the patient, resulting in restricted roles and activities, in addition to increased psychosomatic, anxious, or depressive symptoms.^{4,1} The impact of care giving on caregiver QOL is considerable.^{4,2}

The involvement of family caregivers is essential for the optimal treatment of breast cancer patients as involvement encourages treatment adherence, continuity of care, and social support. Preserving caregiver QOL is a noteworthy issue both for the caregivers themselves and the persons afflicted with breast cancer.⁴

The primary aim of this research is to establish an integrative review that describes the effect of care giving on the QOL of PC of women with breast cancer who are undergoing treatment.

This review, guided by the theory of stress and adaptation for Lazarus,⁵ provides a conceptual framework for the review of QOL in PCs of patients with breast cancer. Quality of life is the outcome variable in this review. Adaptation is the degree to which an individual adjusts both physiologically and psychosocially to stress. This review focuses on caregiver QOL. In this framework, the adaptation process is demonstrated by the PCs ability to cope with caregiver burden (level of ability of daily living and severity of breast cancer). Adaptation is achieved by applying personal coping strategies and ultimately reaching

the best possible QOL.

Materials and Methods

We conducted a comprehensive search in PubMed, MEDLINE, and CINAHL. In addition, we used the web search engine "Google" for abstracts from 2007 to 2012. A combination of the following keywords were used: caregiver, quality of life, women with breast cancer.

First, we screened all titles located by the search in the databases. After we removed duplicate articles (n=22), there were 69 articles that remained, of which 36 titles did not match the integrative review topic. The remaining 33 titles were reviewed by abstracts. We excluded 12 articles because they focused on other diseases, such as Diabetes mellitus, and chronic obstructive pulmonary disease.

We included eight studies after excluding thirteen articles that did not meet the following inclusion criteria: adult women with breast cancer, research conducted in English, and focused on caregivers to adults. The earliest studies were from 2007 and the last study was conducted in 2011. Most articles were published in nursing journals. Most studies focused on coping with breast cancer, coping with the cancer disease, impact of a terminal illness, caring for the terminally ill, palliative care, and family caregivers.

The eight studies that structured the integrative review comprised seven quantitative and one qualitative study. Six used quantitative methods had a descriptive, cross-sectional, and correlational design. The quantitative studies primarily focused on the use of a questionnaire and survey to estimate the emotional, physical, social, and psychological domains. Qualitative approach included in-depth interviews and focus groups.

The sample sizes in the eight studies in this review ranged from 6 to 249 adult caregivers, which comprised a total of 789 total participants in the studies. The average participant age in the total of the studies was 49.55 years. Two studies did not report the caregivers' ages.

The eight studies were conducted in the USA, UK, Sudan, Sweden, Finland, Brazil, and

Switzerland. Most focused on caregiver QOL; some focused on QOL for the patient and their caregiver. The relationship of the primary caregiver to the patient was most frequently mentioned as the husband/partner, sons and daughters, friends and parents.

Discussion

Accumulating evidence has supported the concept that cancer affects not only the patients but also their PCs. A review of the literature on the QOL of PCs of acute and middle- to long-term survivorship phases and during the grief phase provided solid evidence about the psychological impact of cancer on PCs.

Understanding the effects of a breast cancer diagnosis on physical and mental health outcomes in caregivers is important because these variables are key components of QOL. Quality of life is a multi-dimensional construct measuring overall enjoyment of life. It includes many domains such as physical, mental, spiritual, social, and socioeconomic well-being.^{1,2} Studies have shown an impairment of QOL in diverse samples of caregivers who have a specific relationship status with the cancer patient, such as spouses,² parents¹ or children.⁴ A lower QOL in caregivers of women with breast cancer has been associated with more caregiver burden, use of more emotional-focused coping and lower social supports.²

The primary caregiver faces multiple challenges on their treatment for women with breast cancer physical, emotional, social, and financial stress, and they should be oriented to the medication time, route, side effects, and complications of patients. They are also responsible for food selection and shopping. Therefore, the caregivers have limited time and privacy for themselves.

Cancer influences the emotional, social, and physical well-being of persons providing care as well as those diagnosed with the disease. Cancer can affect caregivers' social well-being, especially in areas related to discussions about the illness, family roles and responsibilities, and maintaining an individual's social support systems, which can

be difficult. Although caregivers' health status is initially similar to that of the normal population, caregivers often report more problems with fatigue, sleep disturbances, and impaired cognitive function than non-caregivers.^{6,4,2} The anticipated loss, prolonged psychological distress, and the physical demands of caregiving can seriously compromise the QOL of a family caregiver attending to a person with breast cancer.⁷

Primary caregivers of cancer patients experience multiple physical health problems as a consequence of their role. The most prevalent problems include sleep disturbance, fatigue, pain, anorexia and weight loss.

Chang⁸ have mentioned the effect of being a caregiver for women with breast cancer, on physical status that focused on the term of sleeping pattern. He observed that 89% of caregivers have difficulty sleeping which affected their physical, mental, emotional, and psychological status. The severity of sleep difficulties was found to negatively predict QOL.⁸

In addition, Sherman,⁹ have found that the PCs, whether a partner, family member, intimate, or non-family member, all face the challenge of being a PC. These challenges include physical, psychological, and emotional concerns. However there are varying degrees of impacting of these effects on the role of the PCs quality of life and the quality of life of women with breast cancer.⁹

Primary caregivers experience social problems or challenges associated with role of caring, finances, employment/education, isolation, and managing the environment. When a family member is suffering from cancer, roles change. Primary caregivers become stressed when a family member is terminally ill, particularly when this member is the wife, mother, partner, or sister; this lead them to seek information and education for coping. The discussion that has been conducted by Benzein¹⁰ focuses in depth on sharing feelings and experience being PCs as well as the role, challenge, and stress they have faced in their role.^{10,11} Thus nurses have an important role, that they should listen and answer questions for PCs and their patients.

Awadalla¹² focused on caregivers for women with breast cancer who suffered from stress and anxiety more than those who cared for patients with chronic diseases and psychiatric cases. He stated that demographic factors, physical, and educational level of the caregivers and patients reduced the level of stress, anxiety, and the limited role entrusted to them. For this reason they have increased QOL.¹²

However, QOL for PCs is affected by social, psychological, and physical demands. According to Lindholm et al.¹³ PCs have reported a need for more information about diagnosis, treatments, and management of symptoms, side effects, and physical care, particularly regarding home care after discharge. Often the PCs described not knowing what their information needs were until a crisis occurred. When information was not provided by the nurse, PCs felt frustrated and helpless.

Depression is the only factor that affected QOL. The stamina and PCs have a large role in the ability of women with breast cancer to cope and adapt to their disease, treatment stages and decision-making.¹⁴

Finally, husbands as PCs face depression and they need social support and family intervention when caring for women with breast cancer. The lack of social and family support may lead to maladaptive coping styles such as escape-avoidance, distancing, and confrontive coping. PCs also tend to suffer from higher levels of depression that affect their QOL.¹⁵

Diagnosed with breast cancer not only affects the patient's QOL, but in parallel, it also affects the QOL of a primary caregiver. We should focus on providing physical, psychological, and social support and provide educational resources to improve the level of their QOL.

Although, numerous research emphasize the importance of the role played by the caregiver, there are no studies conducted in Jordan that have focused on the primary caregiver role. Thus it is very important to conduct descriptive and interventional studies of PC for women with breast cancer.

This review has many applications for nursing practice, research and administration. In nursing the provision of physical, psychological, and social support can enhance patient and caregiver outcome by decreasing stress levels and increasing QOL. In nursing research, the result of this review encourage to do interventional study in order to enhance Primary Caregiver's QOL. Nursing administrators can utilize the result of this review in establishing policies that provide caregivers with resources to enhance their caring ability.

Review results will influence the field of caregiver QOL by providing the foundation for further QOL studies with broader populations such as those caring for persons with varying types of cancer and other chronic illnesses, such as HIV. The establishment of a coping skill training may enable the development of an effective model for assisting with the preparation of PCs in the home setting. Ultimately the outcomes of the review will seek to improve the QOL for those persons caring for their loved ones with breast cancer.

There are many limitations faced in this review, the most important is the lack of studies in Jordan in this area. Worldwide, there are no studies that focus on the psychological status and QOL for the caregiver.

There are no interventional studies in this area, but it is expected that these findings and recommendations provide an incentive to work on this area.

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