

Factors Associated with Caregivers Burden of Breast Cancer Patients – Review

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Abstract

Caring for a patient with a disease such as breast cancer, which requires prolonged and sophisticated treatment modalities, can cause a significant burden on the caregiver, which cannot be measured or explained in depth with existing scientific evidence. Caregivers play a vital role in caring for family members with breast cancer from the beginning until the patient's outcome. Although caregivers have been part of many studies conducted to assess the severity of their burden, also they receive less care from others and the health care team members. Research findings depict that majority of the caregivers experienced a significant amount of caregiver burden. The review has found that many factors may influence a caregiver's burden. The manifestation of burden may vary depending upon the stage of cancer diagnosis, disabilities in the patient, emotional and physical capabilities, financial and social support available, and many more factors. The caregiver burden impacts the patient's and caregivers' life and well-being. Research focusing on interventions to reduce the burden is needed in today's scenario. Early, appropriate, and timely interventions help the caregiver utilize their potential effectively to balance their dual responsibility.

Keywords: Breast Cancer, family Caregiver, Caregiver Burden, Concept analysis, Antecedents, Consequences Factors associated with caregiver's burden of breast cancer patients Review

1. Background

Breast cancer has become the most commonly diagnosed cancer, surpassing lung cancer with an estimated 22,61,419 new cases in 2020^{1,2}. The diagnosis of cancer has a dyadic effect among patients and caregivers. Apart from the emotional stress, fear, and pain following the surgical intervention induced in the patient, the vast responsibility of family and taking care of cancer patients falls upon the primary caregiver, which produces a disastrous effect. The caregivers of breast cancer patients often have extreme fatigue and burden. The ultimate factors contributing to caregivers' highest-burden are lack of time, social

and emotional dysfunction, pain, lack of sleep, and tiredness.³

The caregivers have a pivotal role in treating breast cancer patients compared to other debilitating illnesses such as neurotrauma or spinal cord injury. Breast cancer patients have few days of acute hospital admission, but the disease course has an extended duration after mastectomy. A caregiver than a health professional will care for the patient more effectively. During this period, they have to do many of the healthcare professionals' procedures, such as administration of medications, reassurance of the patient, encouraging mastectomy exercise, and other treatment aspects for managing the condition, for which they are inadequately trained.⁴

These challenges produce many physical, emotional, financial, social, and role changes that may affect the caregiver's quality of life. A cross-sectional study revealed a high level of burden experienced by the caregivers of breast cancer patients and needs intervention.^{6,7}

Hence, the diagnosis of breast cancer affects the patient and the caregivers. The darker side of this scenario reflects that the problems of caregivers are hardly understood. Therefore, this review has highlighted the difficulties faced by the caregivers of breast cancer patients and the core focus of the interventions to help them cope with their lifestyle and provide care to their loved ones.⁵

A concept analysis of caregiver's burden

A caregiver is a first-degree relative who is willing to participate in caring for the breast cancer patient.⁸ The burden is defined as the recognized effect on the caregiver's life from the workload of caring for a breast cancer patient.⁹ Caregiver burden is defined as the level of multifaceted strain perceived by the caregiver from the task of caring for a family member and or loved one over time.¹⁰ After a thorough literature search, the caregiver's burden was categorized under the headings of caregivers' antecedents, consequences, and attributes.

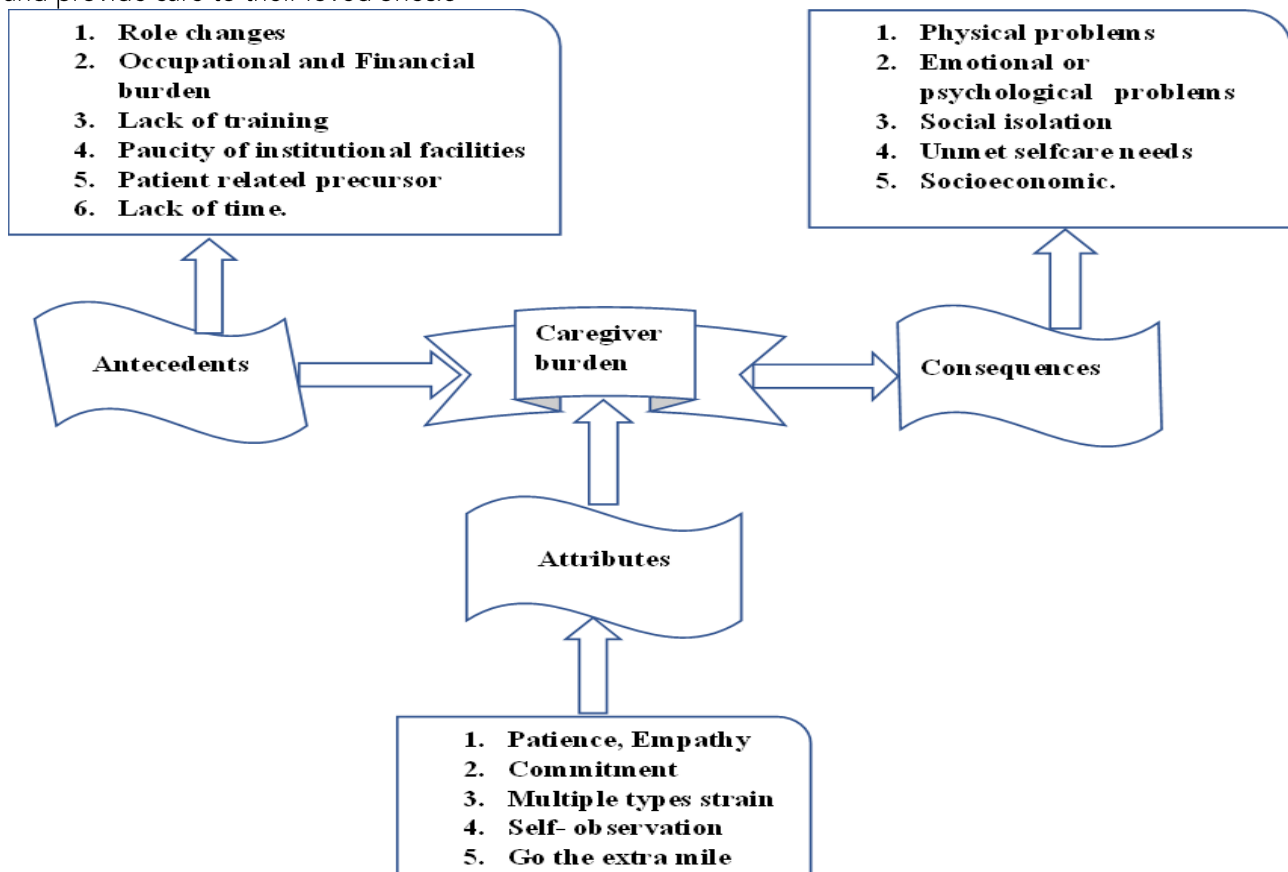


Figure 1 shows the schematic representation of the caregiver's burden.

Antecedents of caregiver burden

The antecedent is the events or attributes that must arise before the concept's occurrence.¹¹ After doing a detailed literature search, the following antecedent factors are identified.

Role changes

Family functions in a peculiar way wherein all the family members have responsibilities and roles in maintaining balance and fulfilling all development aspects. The family has six dimensions to achieve this goal, communication, social factors, problem-solving, affective response, affective involvement, and behavioural control. These dimensions bring about a balance within the family. This balance can sometimes be disturbed and results in a change of role dynamics. The family has to make and adapt to many changes when there is a cancer patient in the family. Here the caretaker takes a dual role in caring

for the patient and fulfilling the responsibilities. If a family member is diagnosed with cancer, it can bring many changes in the family. It changes priorities and interactions among family members and results in an excessive burden on the caregiver. Cancer is a chronic and unpredictable disease. It changes the caregiver's life plans who has to put the patient on priority. Sudden changes may affect the stability of the functioning of the family. Cancer diagnosis also affects the external functioning of the family and disrupts their social life.¹²

The number of informal caregivers has also increased due to the global increase in cancer patients. They receive new responsibilities and are confronted with role transitions. Randomized control trials revealed that psychological psychoeducation, skill training, and therapeutic interventions have significantly reduced caregivers' burden, though with minor to moderate effects. These interventions are hence encouraged for those caring for cancer patients.¹³

Occupational and Financial burden

Family is essential in supporting and caring for the patients, helping them manage and adapt to their disease. Many factors such as increased duration of care at home, decreased family size, and decreased hospitalization have increased the disease's burden. Most caregivers have to leave their job to care for the cancer-affected family member, which leads to a high financial burden.¹⁴ Thus, the caregivers require immense support to overcome this challenge in their social and family life. They require financial support to help them manage the burden of this disease. Training them with appropriate skills and palliative care has been found to lessen the burden of breast cancer among informal caregivers ¹⁵.

Lack of training

A common challenge caregivers face today is psychological problems like anxiety, depression, and other psychological disturbances. The caregivers need training on administering medications, handling the equipment, managing the complications of chemotherapy and radiation therapy, procedures related to treatment, providing comfort to the patient, and when and how to report to the healthcare facility. Most caregivers have low health literacy, leading to an increased burden resulting in adverse consequences¹³. Emotionally supporting themselves and getting proper training can help to overcome this challenge. The health system can help the caregiver obtain this training with proper guidance. The existing research could only reach the tip of the iceberg, and the rest is yet to be explored¹⁶.

A paucity of institutional facilities

Breast cancer requires specialized surgery, chemotherapy, radiation therapy, and palliative treatment. These facilities are not available in all hospitals, especially in developing countries. To avail effective treatment options, the caregiver must approach various hospitals or travel miles and miles with the patient. Also, the caregiver is exhausted in case of any emergency because of inadequate transportation facilities, longer distances to the treating hospital, and unavailability of effective care services nearby.¹⁷ Rising incidence rate, prolonged survival period, decreased stay in acute care facilities, and transformation of care to ambulatory care services lead to increased informal caregiver responsibility.¹⁸ Some studies state that a lack of workforce and poor organizational facilities also disturbs informal caregivers¹⁷.

Patient-related precursor

Many patient factors can influence the extent of the caregiver's burden. The diagnosis of cancer and its treatment can be overwhelming for the caregiver. Despite this, the unfavourable psychological reaction in the patient, such as melancholy, worry, mood swings, and social withdrawal, increases the depth of the caregiver's burden. Additional patient-related

factors are age, gender, treatment modality and duration, cancer symptoms' impact on the patient's daily life, and the patient's ability to cope with the diagnosis.¹⁹

Lack of time

The major challenge faced by family caregivers is a lack of time. The family caregivers need to find more time to meet the needs of the caregivers, apart from their daily routine from work and family life. Also, they must be physically and mentally involved in caring for patients. The majority of their routine tasks and other work remain unsettled, which causes the feeling of exhaustion and burnout among the caregivers.

Health consequences

The existing research shows breast cancer patients' caregivers have depression, fatigue, stress, and anxiety. The inadequacies and burdens experienced by caregivers are exhibited in various ways. The primary symptoms manifestation exhibited by caregivers are as follows :^{20,21,22}

Physical problems

The family caregivers of cancer patients suffer many physical problems that can affect the quality of care provided. It includes fatigue, high blood pressure, back pain, weight changes, arthritis, and headache. The previous research showed that informal caregivers have a lower immune function, delayed wound healing, increased blood glucose levels, and deranged lipid profiles, putting them at high risk of cardiovascular disease²⁴. These problems occur due to decreased sleep, poor diet, and continued physical and emotional stress. Apart from this, due to the demands of caregiving and lack of time, informal caregivers cannot take adequate rest, maintain adequate nutrition, perform the exercise, and often neglect their physical health²⁵. Some studies reveal that when the patient has to undergo particular treatment procedures, it causes caregivers to struggle to meet their own needs and the patient's needs simultaneously²⁶. When they have prolonged physical issues, the quality of care decreases, leading to poor patient outcomes. As the patient requires continuous attention from the caregiver, they have limited time to seek medical attention. There is a significant relationship between the family caregivers and patients' behavioural characteristics, indirectly affecting the caregivers' burden ²⁷.

Emotional or psychological problems

The challenges faced by family caregivers in caring for breast cancer patients cause enormous emotional and psychological problems. The caregivers are concerned about their capacity to balance the care demands with other routine tasks. They are also scared about their future and the outcome for the patient¹⁶. To some extent, the caregivers are worried about their health which causes anxiety, fear, and depression among many informal caregivers. The main reasons for these psychological issues are fear

of cancer recurrence, interrupted family function, wrong perception of disease prognosis, and lack of adequate caregiver support and care²⁸. These issues can hurt their quality of life²⁹. Also, studies have proved that psychological issues increase as the caregivers gradually decline in their functional status³⁰. Some studies show that women and their husbands have significant psychological stress after mastectomy, which affects their relationship. Since the husband undertakes the domestic role too, he continues to experience stress in the future³¹. It may lead to adopting health risk behaviours such as smoking and the use of eliciting drugs²⁴. Many times, conversations regarding patient disease conditions with healthcare personnel are another cause to induce distress among caregivers. Factors such as lack of knowledge regarding the care methods, unavailability of various resources for patient care, and inability to cope with disease conditions add to this emotional stress^{32,33}. Studies show that caregivers anticipate voluntary participation in emergencies and guidance and seek compassion from their friends, extended family members, and even care recipients .³⁴ Providing care for elderly cancer patients creates a multifaceted burden on caregivers. Identifying factors causing the burden is vital for providing critical support to caregivers ³⁵.

Social isolation

Social isolation is common among breast cancer survivors and their caregivers. It happens because of the patient's fear of facing society due to marked body image disturbances after cancer treatment. As the cancer survivor is not going out of the home, the caregiver is forced to remain at home to avoid emotional and psychological loneliness for the patient. The caregivers also avoid social gatherings, meetings, public functions, and family activities. Hence, social relationships are disrupted and may lead to significant social isolation, which can neither be vented to the patient nor anyone else. In providing care to breast cancer patients, the caregiver's responsibilities inflict a considerable burden on the caregiver, and studies suggest that social support offers excellent support to the caregiver of cancer patients³⁶.

Unmet self-care needs

One of the difficulties that come across the family caregivers in performing their role in dealing with breast cancer patients is maintaining a balance in their caregiving role and meeting their wants. Providing care for patients with cancer is a complex and sequential process and can lead to an unstable and stressful life for a family caregiver and subsequently affect the person's holistic health. When this state persists for a distant future, it can reduce caregivers' standard and quality of living. Some studies state that caregivers of patients with cancer have broad and comprehensive unmet needs³⁷. Most studies of primary caregivers of cancer patients state various problems lining up from

reduced physical and mental health distress to unfavourable impact on professional life. These circumstances can lead to a rise in burden and a reduced standard of living for caregivers. Earlier cancer diagnosis and favourable response to therapy were productively correlated with the caregiver's standard of living. The long period of caregiving role and adverse effects of providing care in the caregiver's lives are also associated with decreased caregiver's standard of living. Most family caregivers take up their role unexpectedly without adequate preparation, leading to a poorer standard of living³⁸. Unmet wants of patients can raise the burden on the caregiver; and in turn, the difficulties faced by caregivers are closely related to the patient's comfort³⁹.

Socio-economic impact

The rapid increase in population and increased lifespan in high and low-income countries directly result in increased incidence and mortality rate of breast cancer, increasing the burden on caregivers. The majority of studies in developed countries stated that informal caregivers are more prone to all kinds of intellectual and somatic burdens ⁴⁰. The incidence of cancer and the extent of the burden on caregivers have high significance on the country's economy. These can be influenced by the nation's socio-economic development, which may affect the availability of services for cancer caregivers. Studies showed that low socio-economic status could predict a high caregiver burden³⁶. Cancer caregivers suffer a high financial burden due to cancer treatment's duration, complexity, and cost ⁴¹.

Attributes of caregiver's burden

Attributes of a caregiver's burden can be classified into three domains ³⁸.

1. Caregiver-related attributes,
2. Patient-related attributes
3. Caregiver-patient dyadic attributes.

Caregiver-related attributes: These are the caregiver's socio-economic status, gender, and age, which may have an inevitable direct influence on the caregiver's burden. Female caregivers experience more caregiver burden compared to male caregivers ³⁸. Elderly caregivers experience a higher burden compared to young adults. The socio-economic factors include the caregiver's education, occupation, and income. Studies indicate that high income and high-level education are proportionate to the caregiver burden. The inherent qualities of the caregiver, such as empathy, patience, commitment, and self-observation, can also inversely affect the caregiver's burden. Low self-efficacy and resilience in caregiver results in a higher caregiver burden ³⁸.

Patient-related attributes: The age, health status, stage of cancer quality of life of the patient influenced the caregiver burden. Caring for a younger patient and having more dependent children in the family can produce more burdens on the caregiver ³⁸.

Caregiver-patient dyadic attributes: It involves the quality or type of relationship between the caregiver and the patient. Informal caregiving is a dyadic process. It requires harmony and mutual satisfaction among the caregivers for a positive outcome. Spousal caregivers with reasonable marital satisfaction have demonstrated good mental well-being 38.

Clinical manifestations of caregiver burden:

Few studies show that caregivers of breast cancer patients have a high level of depression, fatigue, stress, and anxiety. The inadequacies and burdens experienced by caregivers are exhibited in various ways. 39,40,41,42

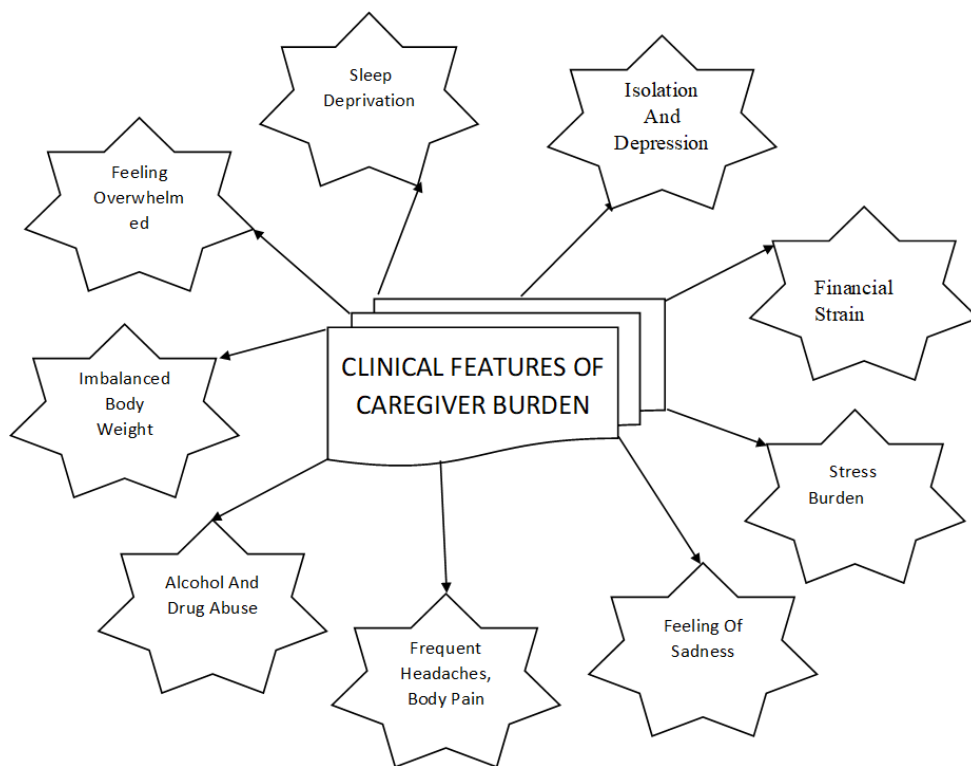


Fig 2 shows the symptoms experienced by the caregivers of breast cancer patients

Recommended interventions for caregivers of breast cancer patients

The caregiver burden significantly impacts breast cancer patients' physical and psychological well-being. Hence, an intervention must be implemented to support the caregivers and invoke positive

outcomes in the survivor. The intervention should address the caregiver's psychosocial, economic, and educational needs as they lack the preparation and knowledge to undertake the role of caregiver. The interventions offered for caregivers can be psychoeducational, skill training, and therapeutic 43,44.

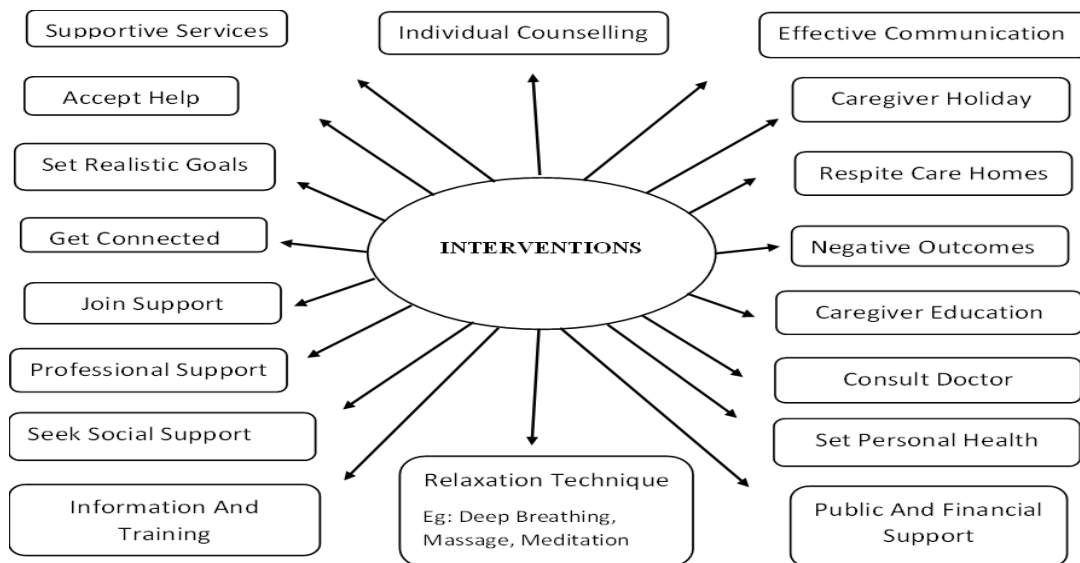


Fig 3 Illustrates the various interventions recommended for the caregivers of breast cancer

2. Conclusion

Caregivers have a significant role in the recovery of

breast cancer patients. They spend considerable time caring for the patient. The breast cancer diagnosis is an unexpected, deadly occurrence, so

they feel unprepared to accept the diagnosis by the patient and caregivers. The healthcare providers can educate the caregivers and provide little guidance regarding patient care. In addition, emphasis on the importance of the caregivers' health and its impact on the patient outcome.

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