

Family Caregivers' Perspective for Cancer Care in a Tertiary Care Centre of Assam

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Abstract:

Introduction: Family caregivers (FC) of patients with cancer has to undergo a lot of difficulties while taking care of the patients especially during advanced stage and often face burnout. **Objective:** To assess cancer patient's caregivers' perspective in a tertiary care centre of Dibrugarh, Assam. **Methods:** A Cross-sectional mixed method study was done among. Sample size was 180. Patients with cancer and their primary caregivers in a Tertiary Cancer Centre of Assam were enrolled between May-November 2024. Pretested and predesigned questionnaire was used to collect data from caregivers of cancer patients. Zarit Burden Interview (ZBI) format was used for assessing burden of caregivers. In depth interview of 20 caregivers (till saturation level) was done and the data collected was used for qualitative study. Analysis was done using SPSS 25 and Atlas TI. **Result:** A total of 155 participated in the study. Mean age of the caregivers was 42.26 ± 11.84 years and mean Zarit Burden score of caregivers was 36.44 ± 9.65 . Majority (103, 67%) caregivers reported mild-to-moderate burden, while 41 caregivers (26%) reported moderate-to-severe burden. Financial constrain, lack of social and emotional support, communication challenges emerged as major themes in qualitative study. **Conclusion:** Financial and emotional strain, dependency, anxiety and stress need to be addressed with holistic implementation of community-based interventions such as different welfare scheme, strengthened support system and communication interventions.

Keywords: Cancer, Caregiver Burden, Family caregiver, Mixed method study, Zarit Burden

Introduction:

Cancer is growing as a major cause of morbidity and mortality worldwide including India.^[1] As per the Global Cancer Observatory (GLOBOCAN) estimates, the total number of incident cancer cases in the year 2020 were 19.3 million worldwide with India ranking third after China and USA. GLOBOCAN predicted that cancer cases in India would increase to 2.08 million, accounting for a rise of 57.5 per cent in 2040 from 2020.^[2] India's largest cancer incidence is found in the North-Eastern (NE) area, which is also plagued by a higher prevalence of risk factors and a lack of effective cancer treatment

facilities.^[3] With advances in cancer treatments, the course and prognosis of cancer have changed, so the patients diagnosed with advanced cancer can live for a relatively long period.^[4] Family members and other unpaid caregivers are expected to increase as the number of patients with advanced cancer rises and their prognosis improves.^[5] Family members and caregivers are also affected by cancer and cancer treatment, not just the patients.^[6]

Informal or family caregivers are defined as those who provide essential support and medical care to persons with cancer, disability, injury, or chronic

Quick Response Code	Access this article online	How to cite this article :
	Website : www.healthlinejournal.org	Devi S, Mahanta T. Family caregivers' perspective for cancer care in a tertiary care centre of Assam. Healthline. 2025;16(2): 92-97
	DOI : 10.51957/Healthline_706_2025	

Received : 12-03-2025

Accepted : 19-06-2025

Published : 30-06-2025

condition in home and community-based settings. They are family members, friends, or neighbours that provide unpaid care for patients; they may lack the emotional readiness for caregiving and have little to no official training in it. By meeting patients' needs both inside and outside of the hospital, family caregivers play a crucial role in today's healthcare system. Informal caregivers for cancer patients may help with daily living activities (e.g., dressing, bathing, and feeding) and instrumental activities of daily living (e.g., cooking, cleaning, and managing finances) as well as managing the patient's medications, arranging medical visits, and keeping friends and family informed.^[7]

Caregivers of cancer patients providing higher levels of support are more likely to report negative outcomes, less likely to be effective partners in the patient's care, and are more likely to postpone their own health care needs.^[8] As caregivers are sometimes required to provide care which is beyond their personal resources or capacity, they are more likely to have poor wellbeing, financial challenges, and psychological consequences such as burden, anxiety, depression, and distress.^[9] With progression of disease, patients dependency on their FCs increases.^[7,10] Therefore this study was planned to assess the burden of caregivers of cancer patients attending the Dibrugarh Cancer Centre by using Zarit Burden Interview format.^[11]

Methods:

An observational cross-sectional study with mixed method design was conducted in a tertiary care hospital of Dibrugarh, Assam during May-Nov 2024.

For quantitative study: Consenting primary family caregivers of patients with cancer were interviewed using Zarit Burden Interview (ZBI).^[11] Consecutive sampling was used and those not being able to communicate due to language barrier were excluded.

Sample size: Sample size calculation was done based on previous study by Mishra et al.^[1] where, proportion of caregivers with mild to moderate burden was 70.22%. Hence, considering 95% confidence interval and assuming 10% non-response rate, the required sample size becomes 180.

Ethical approval: Obtained from Institutional Ethics Committee (Human) of Assam Medical College, Dibrugarh, Assam and written informed consent of all participants were taken.

Data collection: Pretested and predesigned questionnaire was used to collect data from caregivers of cancer patients.

Study tool: To assess the burden of the caregivers, Zarit Burden Interview (ZBI) format was used. The scale consists of 22 items. Each item on the interview was a statement which the caregiver was asked to endorse using a "5-point scale". Response options were "0 (Never)", "1 (Rarely)", "2 (Sometimes)", "3 (Quite frequently)", "4 (Nearly always)". Scoring key was "0-20 = little or no burden", "21-40 = mild to moderate burden", "41-60 = moderate to severe burden" and "61-88 = severe burden". The ZBI-22 is a widely used and well validated test in numerous previous studies, with a Cronbach's α of 0.92 in the original scale.^[12] English version translation of ZBI was used for the study. ZBI was self-administered. However, patients who were unable to read or write were interviewed by the first author.

For qualitative study: Those caregivers identified as having moderate to severe and severe burden from the ZBI scores of the quantitative study were selected for qualitative study. Data were collected through in-depth semi-structured and face-to-face interviews. A total of 20 interviews were conducted in total, till data saturation was achieved.

Data analysis: The information so collected was fed into a computer using SPSS 25 version. Uni-variate analysis was carried out. Qualitative study results were analysed using Atlas Ti.

Results:

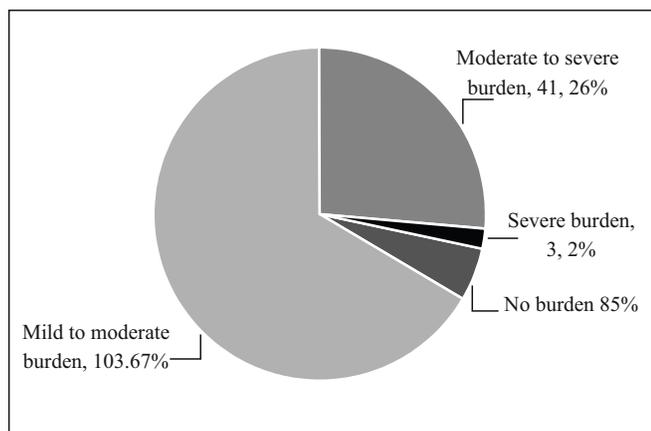
A total of 155 caregivers of patients were included with response rate of 86%; comprising of 67 (43.2%) males and 88 (56.8%) females. Reasons for non-response was not consenting and language barrier as in Northeast India many languages and dialect was used and all comes to this tertiary care center for health care. Average age was 42 years, ranging from 18 to 65 years. Majority of caregivers (116,74.8%) were married and 72

(46.5%) were living in joint families, Hindu (147,95%) by religion, residing in rural areas (110,71%) with socioeconomic class III or IV as per BG Prasad classification. The average age of patients was 51.60 ± 11.22 years and majority were female by gender (98,63.2%). Mean duration of cancer of the patients since diagnosis was 10.59 ± 10.76 months.

The most common cancers among the sampled patients were breast cancer (78, 50.3%), colon cancer (30, 19.4%), gall bladder cancer (20, 12.9%) and stomach cancer (14, 9%). Other cancers like oral cancer, leukaemia etc. were also found.

Quantitative part: Burden among family caregivers was calculated using Zarit Burden Interview (ZBI) format. Little or no burden was reported in 8 (5%) caregivers while 103 (67%) caregivers reported mild to moderate burden and 41 (26%) caregivers reported moderate to severe burden. Severe burden was found only in 3 (2%) caregivers. Mean burden scores as assessed by ZBI was 36.44 ± 9.65 (median=37). On univariate analysis, no statistically significant association of burden on caregivers with caregivers' (and patients') characteristics was seen.

Figure 1: Caregivers burden based on Zarit Burden Interview score (ZBI) (n= 155)



From qualitative study: Data collected from the in-depth interview conducted with twenty participants were analyzed. Data collection done till saturation level attained. Core themes that emerged were: Emotional and Psychological Effect, Effect on Personal Life, Coping Strategies and Barriers and Challenges

Theme 1: Emotional and Psychological Effect

Sub-themes:

- **Financial Strain:** Caregivers reported financial burden due to medical expenses and loss of employment opportunities. These add to the financial woes which according to the caregivers is a cause of concern.

“I have already spent most of my savings on her treatment and now I am afraid that I might not be able to afford her further treatment.” - 47 years old husband.

- **Burnout and Constant Care Demands:** Many caregivers experience exhaustion from 24/7 caregiving responsibilities. They express that the constant nature of care giving responsibilities cause physical as well as psychological exhaustion among them which take a toll on their overall health.

“Ever since he has been diagnosed with cancer, I have been constantly taking care of him. I am tired all the time and rarely get to sleep.” - 40 years old female

- **Emotional Toll of Dependency:** The emotional burden of providing care for a completely dependent individual was a recurring concern as mentioned by the caregivers.

- **Anxiety and Stress:** Participants expressed concerns about the stress of managing daily routines. These as mentioned earlier, takes a toll on not only their personal life but also on their health. Due to uncertainty of the disease and unpreparedness of how to deal with the disease, the caregivers develop symptoms such as shock, panic, fear, helplessness, denial, feeling overwhelmed, losing hope and anxiety.

“I dont know why he got this disease. Is God punishing me? I feel so helpless and dont know who will take care of my children now.” - 50 years old wife.

Theme 2: Effect on Personal Life

Sub-themes:

- **Social Isolation:** Caregivers experienced restricted social interactions and inability to attend family

- **Family and External Support:** Assistance from relatives and paid caregivers provided some relief to the caregivers. It also provided coping mechanism to them to deal with the stress.

“Sometimes, my relatives help me out with household chores like cleaning, washing etc. Their support is a great relief to me from being stressed and overburdened.” - 35 years old woman.

Discussion:

Findings from quantitative study documented mild to moderate burden in 67% FCs, while moderate to severe burden was found in 26% indicating the need to address this issue at both facility and community level. This correlates with the study done in Iranian caregivers by Mirsoleymani et al.^[13] where a significant percentage (48.1%) of caregivers reported high burden. In a study done by Kondeti et al.^[10] found that 51.65% FCs experienced moderate caregiving burden, 44.07% experienced high caregiving burden, and only 4.26% of FCs experienced mild caregivers burden.^[10] Likhmana et al.^[14] in a study conducted in Delhi reported 56.5% caregivers with no or minimal burden, 37.5% caregivers with mild to moderate burden and only 1% caregivers reported severe burden.^[12]

One of the main philosophies of palliative and hospice care is taking care of the patient and family as a single unit and addressing the needs of both parties to globally address their overall well-being and quality of life as a family unit. Caregivers face increased difficulties as the patient's cancer progresses into the terminal stage. They are thus under more stress, which has a negative impact on their physical, mental, emotional, and spiritual well-being. As the patient approaches the end of their life, becomes more dependent on them, and becomes more functionally handicapped, the demands placed on the caretakers increase, causing them to experience greater emotional distress.^[9]

Meta-analysis by Northouse et al.^[13] found that, psycho educational, skills enhancement (coping mechanism, communication, and problem-solving skills), and therapeutic counselling are three types of interventions that are usually offered to caregivers. Self-

help care supportive interventions have several advantages for caregivers, including making caregivers competent to select what, how, and when they give care at optimum level.

In the present study qualitative study result showed that high financial burden, lack of support system, coping strategy leading to burn out among caregivers. This needs to be addressed by provision of different welfare scheme by Government of India. In India, cost of treatment has been a significant barrier to accessing cancer care and PM-JAY has resulted in significant reduction in out-of-pocket expenditure and financial constrains.^[14] FCs play an essential role in ensuring health care to cancer patients especially during advanced stage, thus impacting the patients course of disease progression, survival, and quality of life. This often results in psychological burden on both patients and FCs. Thana et al.^[15] found that caregivers physical health, psychological factors, financial status, social isolation, and family or social support were frequently reported burden factors.

As it was a hospital-based study there is every possibility of those not coming to the hospital and not getting care not being included in this study. Time constraints for in-depth interview in hospital setting and absence of main care giver accompanying the patient to the hospital were the main weakness of our study. But every effort was given to extract rich information from the caregivers. Future community based operational research can be planned to know the effectiveness of different interventions.

Conclusion:

Most of the caregivers had mild to moderate burden, which needs to be addressed. Many rely on family caregivers for their care and management in this country as both cancer incidence and life expectancy is increasing in India. Therefore, strengthening family caregivers both in home and hospitals, linking facilities and home-based care by evidence-based communication interventions should be a priority in health planning and management.

Recommendation:

Family caregivers financial and emotional strain,

stress and anxiety needs to be addressed with better care and support integrating in our health care delivery model with public private partnership, so that emerging burden on family caregivers can be addressed. Death literacy and bereavement care also needs to be integrated to support FCs. Implementation research to assess the effectiveness of different interventions needs to be tried with local innovations.

This issue should be prioritized while preparing district health action plan with integrating social welfare Department and different community-based organizations.

Declaration:

Funding: Nil

Conflict of Interest: Nil

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