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Original Research Article

Other side of breast cancer: caregiver burden and its associated factors in Jammu region of UT of J and K

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ABSTRACT

Background: In recent scenario across the world, ever rising number of cancer cases are emerging as one of the leading cause of morbidity and mortality both in developing and developed countries. Breast cancer patients need care and support for which family members are the primary caregivers. The study aimed to assess caregiver burden and its associated factors amongst family caregivers of breast cancer patients.

Methods: This analytical cross-sectional study was conducted among 177 eligible caregivers of women with breast cancer attending the Radiation Oncology Clinic in a tertiary care teaching hospital in Jammu city of UT of J&K, using consecutive sampling technique. The caregivers were administered a questionnaire comprising of socio-demographic data and the Zarit- Burden Interview (ZBI). Data was analyzed using SPSS Version 23.0.

Results: In majority of cases, spouse was the caregiver (80.3%). Mean Zarit Burden score was 26.7 ±10.18, and about 2/3rdof respondents reported mild level of caregiver burden. Age, marital status, type of family, literacy status, caregiving intensity were found to be significantly associated with caregiver burden ($p<0.05$).

Conclusions: Though majority of the respondents outlined moderate caregiver burden, yet identification of both vulnerable caregivers and care-recipients as a dyad would go a long way in mitigating this burden.

Keywords: Caregiver, Caregiver burden, Breast cancer, Zarit-burden interview

INTRODUCTION

As per the WHO, 2.3 million breast cancer cases were diagnosed with 6, 85,000 deaths in 2020 globally.[1] Indian council of Medical Research (ICMR) has projected that one in nine Indians is likely to develop cancer in their lifetime.[2] The available data indicates a rising trend of breast cancer in India which is the leading cause of cancer in women. In most of the instances, the breast cancer disease strikes during the peak of women's family responsibilities and the career.

Family is the cornerstone during disease treatment helping patients to adapt and manage the disease. Decreasing family size has made it incumbent on family members to take care of these patients on domiciliary basis. In the scenario with cancer patients in the family, the needs of the family caregivers- who have been called hidden patients- often go unnoticed.[3]

Caregiver burden, as defined by Zarit is physical, psychological and social response of the caregiver which is usually due to imbalance between care needs and several care tasks. The resultant imbalance is reflected in social roles, physical and emotional state, personal time and financial resource of the caregiver. Caregiver burden also manifests as anxiety and depression besides as low quality of life.[4]

Cultural factors do play a part as modifiers of caregiving burden as traditional and religious norms enhance the formation of extended family protective networks. It is pertinent to identify the effective protective factors based on culture of each society.[5] Although many studies have been conducted in western countries, yet the Asian culture is different and caregiver burden need to be estimated in this region of the world.

Caregivers with their communication and understanding of feeling of patients help motivate patients in their day to day struggle in their critical illness, and hence their physical and mental health is of concern to all of us. This study aimed to assess the burden of caregiving among the attendants who are accompanying breast cancer patients in a tertiary care center in Jammu city of UT of J&K, India. Also, to identify various factors in these caregivers associated with the burden of caregiving.

METHODS

This observational study was carried out at Outpatient clinic of a Radiation Oncology Department in a tertiary care hospital after obtaining a due permission from the Institutional Ethical Committee (IEC/GMC/2020/339). Study population included the caregivers of all the females diagnosed with breast cancer (new cases and follow up cases) aged 18 years and above confirmed by histopathology reports who attended the OPD over a 6 months period. Caregivers for our study purpose were spouse/family member/close relative/friend/others above 18years of age who accompanied the subject (breast cancer females) to hospital most of the times for seeking the healthcare, handled all the medical problems of the subject and took care of them at home.

However, caregivers of the breast cancer patients with present or past history of any psychological/medical illness were excluded from the study.

Sampling technique

The patients were enrolled using Consecutive sampling technique.

Sample size

All the patients enrolled during the stipulated time period fulfilling the eligibility criteria using Consecutive sampling technique constituted sample size which was 177 patients.

Study period

Three months i.e. from 1st October to 31st December 2020

Study design and data collection

An analytical cross sectional study design was adopted for the research purpose. All the study participants were assessed for the burden of caregiving. Informed consents were taken separately from breast cancer patients and their caregivers before commencing the study. The caregivers who gave informed written consent were included in the study. A total of 190 breast cancer patients were identified during the study period who were accompanied with their caregivers. Around 13 caregivers refused to participate in the study, thus only 177 caregivers were included in the study. The caregivers were selected for interview using consecutive sampling procedure.

Data collection was carried out by means of interviewer-administered questionnaire. Each questionnaire consisted of three sections. Section A sought information on socio-demographic characteristics of the respondents like age, gender, marital status, type of family, literacy status, employment status, duration of caregiving, relationship with patient, caregiving intensity, status of caregivers co-residing with patient, using a predesigned, pre-tested, semi structured proforma. Section B contained Zarit Burden Interview (ZBI), a standard 22-item scale, to assess the experience of burden of caregiving by caregivers of the breast cancer patients.[6] The caregivers indicate the level of discomfort they feel in particular items and it is rated on a 5-point scale ranging from 0 (never) to 4 (nearly always). The sum total of score determine the level of burden perceived by the caregivers. Level of burden is categorized as no burden (0-20), mild burden (21-40), moderate burden (41-60) and severe burden (61-88). Section C assessed Dependency for activities of daily life using a Barthel Scale Index.[7] Barthel Index is an ordinal scale used to evaluate the patient’s ability to perform and function independently in ADL. The questionnaire includes ten variables for describing ADL and mobility: Feeding, toileting, bathroom, dressing and undressing, getting on/off a toilet, control of bladder, moving from a wheelchair to a bed and back, walking on level surface and propelling a wheelchair (if unable to walk). A 100point score is obtained by multiplying the final score by 5, which is categorized as 0-20 (total dependency), 21-60 (severe dependency, 61-90 (moderate dependency), and 91-99 (slight dependency). The higher the number, the more likely the patient is able to function independently. This scale was applied on the breast cancer patients after obtaining the informed consent, to assess their ability to perform and function independently in ADL.

A pilot study was conducted on 5-10 caregivers of breast cancer patients before commencement of actual study to estimate the approximate time for interview and for refining of the study questionnaire. The feedback so obtained was incorporated into the final version of questionnaire. These subjects were not included in the final assessment.

Statistical analysis

The data thus collected was analyzed using a SPSS version 23.0. Qualitative data was presented as percentages, while quantitative data was presented in Mean±SD. Chi- square test was used to show any statistical significance of any apparent association or differences. A p value <0.05 was considered statistically significant. All the p values reported were two tailed.

RESULTS

Table 1 shows the socio-demographic profile of the caregivers of breast cancer patients. It is seen that majority (44.6%) of the subjects belonged to the age group of <40 years followed by ≥50 years (32.8%). The mean age of the participants was found to be 39.38±19.72 years. Most (54.8%) of the respondents were male and majority (81.9% and 89.2% respectively) of the caregivers were married and living in the nuclear families. As seen from the table 1, 80.2% of the caregivers were the spouses of the patients. The average duration of caregiving was 7-12 hours in majority (42.4%) of the respondents and almost 80.2% of the caregivers were co-residing with the breast cancer patients. Most (50.3%) of the patients were diagnosed with stage II breast cancer, thus majority of the caregivers belonged to this group.

Table 1: Association between socio-demographic characteristics of the caregivers of breast cancer females and burden of caregiving.

Socio-demographic variable	Total (N=177) N (%)	No burden (N = 47), N (%)	Mild burden (N=117), N (%)	Moderate burden (N=13), N (%)	χ^2	p value
Age (years)						
≤ 40	79 (44.6)	34 (43.04)	41 (51.9)	4 (5.06)	22.03	<0.001 (sig.)
41-49	40 (22.6)	7 (17.5)	31 (77.5)	2 (5)		
≥ 50	58 (32.8)	6 (10.3)	45 (77.6)	7 (12.1)		
Gender						
Male	159 (89.8)	41 (25.8)	108 (67.9)	10 (6.3)	3.504	0.173
Female	18 (10.2)	6 (33.3)	9 (50)	3 (16.7)		
Marital status						
Married	145 (81.9)	41 (28.3)	103 (71)	1 (0.7)	52.21	<0.001 (sig.)
Single/divorced	32 (18.1)	6 (18.8)	14 (43.7)	12 (37.5)		
Type of family						
Nuclear	158 (89.3)	42 (26.6)	107 (67.7)	9 (5.7)	6.03	0.04 (sig.)
Joint	19 (10.7)	5 (26.3)	10 (52.7)	4 (21)		
Literacy status						
Literates	111 (62.7)	35 (31.5)	74 (66.7)	2 (1.8)	15.24	<0.001 (sig.)
Illiterates	66 (32.3)	12 (18.2)	43 (65.2)	11 (16.6)		
Employment status						
Employed	134 (75.7)	40 (29.9)	85 (63.4)	9 (6.7)	44.12	<0.001 (sig.)
Unemployed	43 (24.3)	7 (16.3)	32 (74.4)	4 (9.3)		
Relationship with patient						
Spouse	142 (80.3)	34 (23.9)	95 (66.9)	13 (9.2)	7.509	0.27
Child	22 (12.4)	9 (40.9)	13 (59.1)	0 (0)		
Parent	10 (5.6)	4 (40)	6 (60)	0 (0)		
Others	3 (1.7)	0 (0)	3 (100)	0 (0)		
Duration of caregiving						
≥ 1 year	159 (89.8)	38 (23.9)	109 (68.6)	12 (7.5)	5.657	0.05
< 1 year	18 (10.2)	9 (50)	8 (44.4)	1 (5.6)		
Caregiving intensity (hours/day)						
0-6	62 (35)	23 (37.1)	39 (62.9)	0 (0)	32.68	<0.001 (sig.)
7-12	75 (42.4)	22 (29.3)	50 (66.7)	3 (4)		
≥ 12	40 (22.6)	2 (5)	28 (70)	10 (25)		
Co- residency with the patient						
Yes	142 (80.2)	34 (23.9)	95 (66.9)	13 (9.2)	5.116	0.07
No	35 (19.8)	13 (37.1)	22 (62.9)	0 (0)		

Table 2: Association between socio-demographic characteristics of breast cancer patients and burden of caregiving.

Socio-demographic variable	Total (N=177) N (%)	No burden (N = 47) N (%)	Mild burden (N=117) N (%)	Moderate burden (N=13) N (%)	χ^2	p value
Age (years)						
< 40	47(26.6)	25 (53.2)	18 (38.3)	3 (6.4)	26.03	<0.001 (sig.)
≥ 40	130 (73.4)	22 (16.9)	98 (75.4)	10 (7.7)		
Residence						
Rural	136 (76.8)	29 (21.3)	96 (70.6)	11 (8.1)	8.278	0.015 (sig.)
Urban	41 (23.2)	18 (43.9)	21 (51.2)	2 (4.9)		
Number of children						
Nil	18 (10.2)	2 (11.1)	13 (72.2)	3 (16.7)	14.7	0.005 (sig.)
1	50 (28.2)	6 (12)	39 (78)	5 (10)		
≥2	109 (61.6)	39 (35.8)	65 (59.6)	5 (4.6)		
Family income INR/month)						
<50,000	164 (92.6)	45 (27.4)	111 (67.7)	8 (4.9)	26.01	0.001 (sig.)
50,000-1,00,000	11 (6.3)	2 (19)	4 (36.5)	5 (45.5)		
>1,00,000	2(1.1)	0 (0)	2 (100)	0 (0)		
Registration status						
New registration	26 (14.7)	18 (69.2)	6 (23.1)	2 (7.7)	29.44	0.001 (sig.)
Follow up	151 (85.3)	29 (19.2)	111 (73.5)	11 (7.3)		
Staging of cancer						
Stage 1	9 (5)	5 (55.6)	3 (33.3)	1 (11.10)	22.5	0.004 (sig.)
Stage II	89 (50.3)	32 (36)	51 (57.3)	6 (6.7)		
Stage III	30 (17)	1 (3.3)	28 (93.4)	1 (3.3)		
Stage IV	45 (25.4)	9 (20)	32 (71.1)	4 (8.9)		
Unknown*	4 (2.3)	0	3 (75)	1 (25)		
Type of facility						
IPD	137 (77.4)	29 (21.2)	97 (70.8)	11 (8)	9.036	0.01 (sig.)
OPD	40 (22.6)	18 (45)	20 (50)	2 (5)		
ADL dependency						
Absent	108 (60.4)	41 (38)	61 (56)	6 (6)	18.67	0.001 (sig.)
Present	69 (39.6)	6 (8.7)	56 (81)	7 (10.1)		

#unknown: breast cancer females, who were diagnosed with cancer through histopathology reports but staging was not confirmed

The analysis of sociodemographic characteristics of breast cancer patients with the burden of caregiving revealed that majority (73.4%) of the breast cancer patients aged >40 years and most (76.8%) of the patients belonged to rural area. Although, most (61.6%) of the breast cancer patients had ≥2 children, moderate level of burden of caregiving was felt in majority (72.2%) of the caregivers of those with no child (Table 2).

Various socio demographic variables of caregivers like Age, marital status, type of family, literacy status, employment status and caregiving intensity were found to be significantly associated with burden of caregiving ($p<0.05$). Among the socio demographic characteristics of breast cancer patients, Age of the breast cancer patients, their residence, number of children, family income per month, registration status, staging of cancer, type of facility where the breast cancer patients are treated, all were found to have a significant association with the burden of caregiving on their caregivers ($p<0.05$) (Table 1 and 2).

DISCUSSION

With the increasing burden of non-communicable diseases, it is imperative to study the experiences of family members of such patients, especially those suffering from cancers. In this context, breast cancer patients and their caregiver's were studied living in diverse socio-cultural milieu. The present study aimed to determine the burden of caregiving among caregivers of women suffering from breast cancer attending a tertiary care oncology clinic in Jammu city of UT of J&K, India.

The mean Zarit Burden Score of caregivers in the present study was 26.7±10.18 which was comparable to the results documented by Vahidi et al and Jite et al.[8,9] The results are also in agreement with those reported by Mishra et al.[10] However contrasting results were outlined by Gabriel et al and Kajana et al who recorded higher mean burden scores to the tune of 37.1±12.3 and 43.51±13.16 respectively.[11,12] The lower burden scores in the present study were likely due to strong family ties in

India where caregivers are overwhelmingly involved in holistic care of the patient. Different results by authors in different geographical locations may be related to sampling methods based on stages of the disease, different levels of socio-economic status and cultural differences among the caregivers.

The present study revealed that about two-third of the caregivers reported mild burden while only 7% reported moderate burden and this could be ascribed to younger age of the caregivers. Also, most of the breast cancer patients were diagnosed at the initial stages of cancer, so the burden perceived by the caregivers is comparatively low. The robust joint family system as well as cultural practices still prevalent in Indian culture can also be the reason for lesser caregiver burden. These results corroborate with the findings of Mishra S who also reported mild to moderate level of burden in 70.2% of the respondents.[10] On the other hand, Kajana et al and Unnikrishnan et al reported 40% and 37% moderate to severe burden in their respective studies.[12,13]

In this study, almost four-fifth of the caregivers happened to be the spouses and majority of them outlined little or no burden to mild burden. In contrast, Vahidi et al from Iran reported higher caregiver burden among spouses of breast cancer patients.[8] A disease like cancer which frequently affects daily routine of the family and in this context, Bigatti et al indicated the spouses of cancer patients incur, the highest caregiver burden.[14] The dominant role of male partners as caregivers in this study may be suggestive of moral and marital obligation to a life partner who happen to be suffering from a chronic disease like breast cancer.

Regarding severity of caregiver burden, rural caregivers and the caregivers of the breast cancer patients with no children reported higher level of caregiver burden. Whereas caregivers residing in urban areas and caregivers of breast cancer patient diagnosed with stage III cancer reported lowest burden of caregiving. Among the socio-demographic variables; age, marital status, type of family, literacy status, employment status and caregiving intensity were significantly associated with caregiver burden. Jite et al outlined age and educational status as the variables associated with caregiver burden.[9] Vahidi et al also found gender, marital status, relation to patient and lower levels of education significantly associated with caregiving burden.[8] Literate family caregivers are likely to have better knowledge of coping strategies and disease trajectory, economic advantage besides having a good social network. They are likely to leverage more assistance from family and friends as a stabilizing factor, the less literate caregivers may perceive patients illness as a threat and are likely to report higher burden.[15,16] Gabriel et al and Jite et al also found that longer time spent in care for patients is also associated with higher caregiver burden.[11,9]

The results of the present study have also revealed that perceived dysfunction in ADL of the care recipients was significantly associated with caregiver burden which are in consonance with those outlined by Jite et al.[9] On the other hand, some authors have found weak or no association between care recipients functional decline and burden of caregivers.[17-19] Decline in ADL usually requires a higher level of caregiver engagement as daily life management of the patients gets more and more dependent on the caregivers.

Limitations of the study include a small sample size and its cross-sectional nature. It is recommended that longitudinal studies to assess true predictive value of factors associated with caregiver burden be conducted across multiple centres. Another limitation was inability to assess economic burden among the caregivers by the tool used in the present study.

CONCLUSION

This study suggests that psychological health of the caregivers of the breast cancer patients should be assesses regularly for timely detection and treatment of mental health problems. Also, the findings of the present study elucidate that early interventions to increase social support and self-efficacy for caregivers are of critical importance. To alleviate the problem of financial distress in these families, health policies by government like Ayushman Bharat- Pradhan Mantri Jan Arogya Yojana (AB-PMJAY) are steps in the right direction. Integration of palliative care in primary care settings is likely to achieve better outcomes in these patients.

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