

## Caregivers of breast cancer patients in north coastal : based cross-sectional study

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### ABSTRACT

**Background:** A large number of patients with chronic diseases like cancer are cared for in homes by the family members. The vital role that these family members play as “caregivers” is well recognized. However, the burden on them is poorly understood. The objective of the study was to assess the caregiving burden among family caregivers of breast cancer patients and to explore the factors associated with high levels of caregiving burden among family members of breast cancer patients.

**Methods:** A cross-sectional, hospital based study was conducted in a tertiary health care setting in Visakhapatnam A total of 45 primary caregivers who were accompanying the breast cancer patients to the Government Hospital were interviewed using Zarit burden interview. The socio demographic variables of the care givers like age, gender, occupation, income, relation with the patient were also obtained. Informed consent was obtained from the caregiver. Data analysis: Data was entered in the MS Excel spread sheet and it was analysed using SPSS software version 21.0.

**Results:** The study population consisted of 26 (57.7%) males and 19 (42.3%) female caregivers. Very few 4 (9%) caregivers reported with no or mild burden during care giving. Majority 18 (40%) of the caregivers reported with mild to moderate burden, whereas 18 (40%) of the caregivers reported with moderate to severe burden. Few 5 (11%) reported with severe burden. Financial factors and uncertainty regarding the illness of the patient are associated with more burden.

**Conclusions:** There is high burden among caregivers of cancer patients which should be addressed.

**Keywords:** Burden of caregiving, Family caregiver, Breast cancer, Zarit burden interview, Visakhapatnam

### INTRODUCTION

In India breast cancer is the most common cancer among women and accounts for 27% of all cancers. About 2000 new cases are diagnosed with cancer every day, 1200 are detected at the early stages. In 2017, India had the highest mortality rate globally for breast cancer.<sup>1</sup> The diagnosis and treatment of the breast cancer is multi-dimensional. It involves prolonged days of stay at the hospital, expenses for various investigations and psycho-social support services. There is an important role for care giving due to the chronicity and enormity of the disease. The facilities

to address the cancer patients are few and that too expensive. Therefore, a large number of such patients are cared for in homes by the family caregivers.

A caregiver is defined as any person, who was unpaid and willing to participate, whom the patient himself or herself identified as being in a close supportive role, and as sharing most in his/her illness experience.<sup>2</sup>

While providing care and treatment, the entire focus is on the patient and the need and demand of these family members and primary caregivers are often overlooked

and neglected. Family involvement has significant influences on decision-making processes, the receiving and sharing of information, and the provision of physical and emotional support for patients. This role commonly causes a substantial burden and caregivers often experience physical, psychological, emotional and financial distress while providing care. These stressful factors in turn disturb the equilibrium in the family directly and/or indirectly. However, their burden of care does not attract appropriate attention. Hence, the present study was undertaken.

### **Objectives**

The objectives of the study were to assess the burden of care giving among family caregivers of breast cancer patients and to identify the factors associated with high burden.

## **METHODS**

A hospital based observational, cross-sectional descriptive study was conducted in the department of Radiotherapy of King George Hospital, a teaching hospital attached to Andhra Medical College, Visakhapatnam. The study population were Family members of the breast cancer patients who fit the definition of primary care givers.

### **Operational definition of primary caregiver**

*Primary caregivers:* A person (male or female) may or may not be blood-related who stays along with or nearby the patient helping not only in various day to day activities of the patient but also providing psychological, emotional, and financial support to the cancer patient.

In the present study, primary caregivers were mostly family members. So, the terms primary caregiver or family caregivers were used interchangeably.

### **Inclusion criteria**

All primary family caregivers aged 18 years and above who were accompanying the breast cancer patients to the hospital and who were willing to participate in the study and gave consent were included in the study.

### **Exclusion criteria**

Those individuals accompanying the patient to hospital only for the sake of treatment or those who are not satisfying or meeting the criteria or definition of family caregivers were not included.

Not willing to participate in the study or those who did not give consent were excluded from the study.

### **Sampling frame**

All the caregivers attending the tertiary care hospital in the months of October to December of 2018 were to be included subject to their fitting their inclusion and exclusion criteria.

The sample was 45 care givers of breast cancer patients who attended the Department of Radiotherapy between October to December of 2018.

The sampling technique was convenience sampling. Zarit burden Interview was used as a study tool. Permission for using the tool was obtained from Steven H. Zarit through G-mail. Background information on Socio -demographic details of the caregiver were also included in the study tool.

The Zarit burden Interview tool consists of 22 items.

Responses are recorded on Likert scale. Response for each question ranging from 0-4 (0=never, 1=rarely, 2=sometimes, 3=quite frequently, 4=nearly always). Depending upon their overall experience during care giving, they were requested to respond to the interview schedule. For the purpose of study, the study tool was converted into local language (Telugu) and pre tested and validated.

Permissions from the Superintendent, Head of the Department of Radiotherapy and Institutional Ethics Committee was obtained before commencement of the study.

### **Data analysis**

Data was entered in the MS Excel spread sheet and was analysed using SPSS software version 21.

For the representation of data, key word of each item is presented in the tables.

### **Method of data collection**

Breast cancer patients attending the department of Radiotherapy were asked to identify and nominate their family member who was the primary care giver. If these family caregivers were accompanying the patient at the time of visit, they were interviewed. In case the caregiver as reported by the patient was not available on that day of hospital visit, the patients were followed up for next visit. However, if the caregiver was not available even in second consecutive visit, he/she was excluded from the study. The aim of the study was explained to all study subjects and a written informed consent was taken before the interview. Verbal consent and thumb impression were taken from the caregivers who could not read or write. Since the study centred around eliciting sensitive information about their experiences as caregivers, sufficient time was dedicated to each patient and his/her

caregiver. Caregivers were interviewed in privacy in a separate room in the hospital. Subjects were assured of complete and strict confidentiality of the information collected.

## RESULTS

The results were obtained from 45 caregivers of the patients, comprising of 26 (57.7%) males and 19 (42.3%) females. The mean age of the study participants was  $43.56 \pm 13.57$  years.

**Table 1: Socio-demographic profile of family caregivers of patients (n=45).**

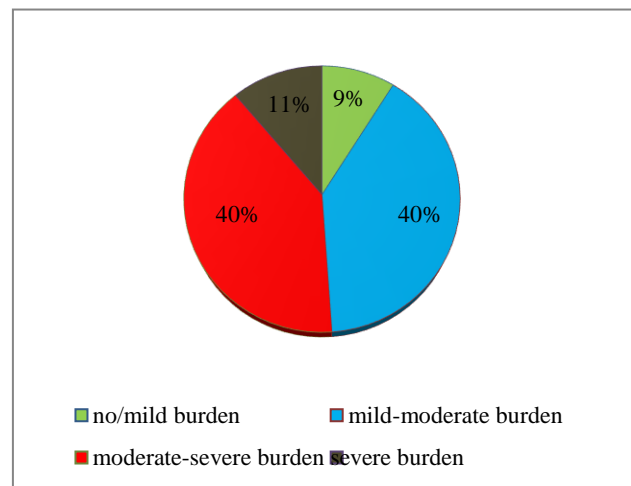
Socio-demographic profile	N (%)
<b>Gender</b>	
Males	26 (57.7)
Females	19 (42.3)
<b>Age of the caregiver (in years)</b>	
≤40	16 (35.6)
41-49	14 (31.1)
≥50	15 (33.3)
<b>Type of family</b>	
Nuclear family	41 (91.2)
Joint family	4 (8.8)
<b>Literacy status</b>	
Literates	32 (71.2)
Illiterates	13 (28.8)
<b>Employment</b>	
Employed	25 (55.6)
Unemployed	20 (44.4)
<b>Relationship with the patient</b>	
Spouse	17 (37.8)
Child	14 (31.1)
Parent	8 (17.8)
Others	6 (13.3)

Among the study participants, slightly more number of caregivers were employed (55.6%) as compared to un-employed (44.4%). Nearly two-thirds (71.2%) of them were literates. Majority i.e. forty-one (91.2%) were from nuclear families and only 4(8.8%) were from joint family. Around 17 (37.8%) caregivers were spouse of the patients,

Fourteen (31.12%) were patients' child, 8(17.8%) were parent and 6 (13.3%) were others such as mother-in-law and sibling etc.

It was observed that only few 4 (9%) caregivers reported no or minimal burden while 18 (40%) caregivers reported mild to moderate burden and another 18 (40%) moderate to severe burden. Only 5 (11%) caregivers reported severe burden.

Mean burden scores as assessed by ZBI was  $43.51 \pm 13$ .



**Figure 1: Burden among family caregivers as per Zarit burden interview (n=45).**

**Table 2: Item wise caregivers responses to Zarit burden interview (items 1-18).**

S. no.	Item	0 (%)	1 (%)	2 (%)	3 (%)	4 (%)	Mean	SE
1	Health has suffered	4 (8.9)	6 (13.4)	4 (8.9)	12 (26.6)	19 (42.2)	2.80	0.203
2	Uncomfortable having friends	6 (13.3)	23 (51.1)	7 (15.6)	6 (13.3)	3 (6.7)	1.49	0.164
3	Currently affecting other relationships in the family in a negative way	21 (46.7)	14 (31.1)	2 (4.5)	2 (4.4)	6 (13.3)	1.07	0.207
4	Don't have enough time for self because of your relative	6 (13.3)	13 (28.9)	7 (15.6)	7 (15.6)	12 (26.6)	2.13	0.215
5	Don't have enough money to care about their relative	5 (11.1)	2 (4.4)	4 (8.9)	5 (11.1)	29 (64.5)	3.13	0.207
6	Your relative asks for more help than required	12 (26.7)	18 (40.0)	6 (13.3)	4 (8.9)	5 (26.7)	1.38	0.191
7	Stressed	4 (8.9)	15 (33.3)	10 (22.2)	4 (8.9)	12 (26.7)	2.11	0.204
8	Embarrassed	12 (26.7)	22 (48.9)	3 (6.6)	7 (15.5)	1 (2.3)	1.18	0.160
9	Strained	4 (8.9)	8 (17.8)	6 (13.3)	14 (31.1)	13 (28.9)	2.53	0.197
10	Fear of losing patient	4 (8.9)	8 (17.8)	3 (6.7)	10 (22.2)	20 (44.4)	2.76	0.211
11	Feel to do more for the patient	19 (42.2)	15 (33.3)	1 (2.2)	7 (15.5)	3 (6.67)	1.11	0.194

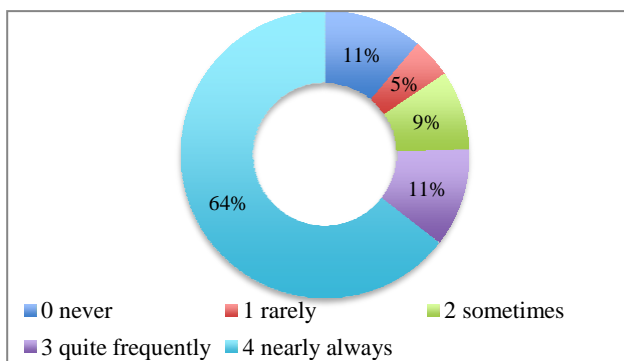
Continued.

S. no.	Item	0 (%)	1 (%)	2 (%)	3 (%)	4 (%)	Mean	SE
12	Social life has suffered	8 (17.8)	15 (33.3)	8 (17.7)	2 (4.4)	12 (26.8)	1.89	0.218
13	Loss of privacy or personal time	9 (20)	12 (26.7)	6 (13.3)	3 (6.7)	15 (33.3)	2.07	0.237
14	Angry when around the patient	23 (51.2)	16 (35.6)	2 (4.4)	2 (4.4)	2 (4.4)	0.76	0.156
15	Uncertain about the future of the patient	4 (8.9)	8 (17.8)	3 (6.7)	10 (22.2)	20 (44.4)	2.93	0.197
16	Dependence of your patient	12 (26.7)	18 (40)	6 (13.3)	4 (8.9)	5 (11.1)	1.38	0.191
17	Wish to run away from the situation	10 (22.2)	10 (22.2)	5 (11.1)	13 (28.9)	7 (15.6)	1.93	0.214
18	Unable to take care much longer	7 (15.6)	10 (22.2)	5 (11.1)	10 (22.2)	13 (28.9)	2.27	0.221

0-never, 1-rarely, 2-sometimes, 3-quite frequently, 4-nearly always.

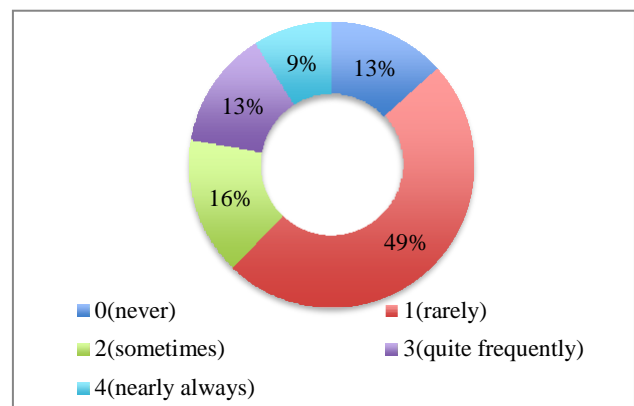
Almost 19 (42.2%) reported that their health had suffered. About 35.6% reported that they were uncomfortable having friends. Few reported that because of their friends, they have come out of the stress by sharing their doubts associated with the course of illness, providing food during hospital stay, taking care of other responsibilities at the house during the hospital stay. Nearly half (46.7%) of the caregivers responded that their relationships with other family members never affected them in a negative way. More than half (57.8%) reported that they do not have enough time for self because of providing care to their relative. Nearly 2/3rd (84.5%) of the caregivers responded that they don't have enough money to take care of their relative and to meet the other family responsibilities. This factor was mainly imposing greater burden on the caregivers. Nearly 1/4<sup>th</sup> (24.4%) felt that they were embarrassed because of their relative behaviour. More than half (57.8%) of the care givers revealed that they were always stressed up and strained being around the patient and providing the care.

Nearly 3/4<sup>th</sup> (73.3%) of the caregivers felt distressed due to fear of losing the patient and uncertain about their future. About half of them felt 15 (48.9%) that their social life has suffered. More than half (53.3%) felt that they are losing their privacy/personal time and wish to run away from the situation by being the caregiver. Very few (13.3%) were angry when they were around the patient. About (33.13%) reported that their relative was dependent on them. About (62.2%) reported that they were unable to take care of their relative much longer.



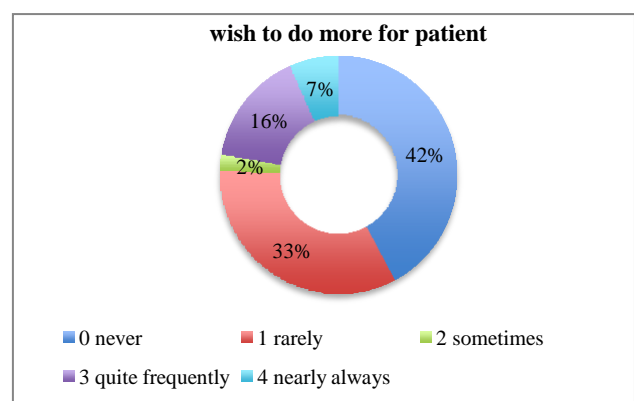
**Figure 2: Caregivers responses to Zarit burden interview for item 20 (n=45).**

More than half of the caregivers reported that they were nearly always burdened because of financial component. This may be due to the dual role played by the caregivers which make them more vulnerable to distress.



**Figure 3: Caregivers responses to Zarit burden interview for item 19 (n=45).**

Nearly half (49%) of the caregivers reported that either nearly always or quite frequently didn't lost control on their life because of the patient.



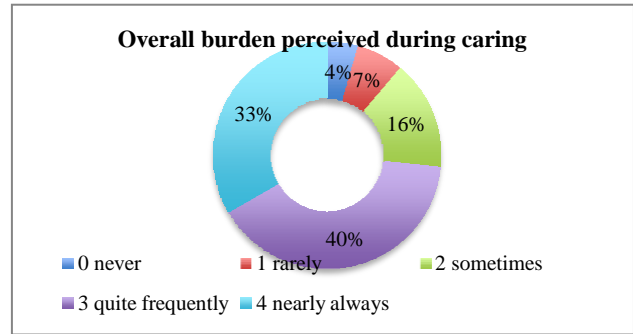
**Figure 4: Caregivers responses to Zarit burden interview for item 21 (n=45).**

About 19 (42%) of the caregivers reported that they wish to do more for the patient in maximum possible ways and also satisfied with the facilities at the hospital.

One third of the caregivers 15 (33%) reported that they felt burdened nearly always and very few 2 (4%) reported that they did not perceive any distress during caregiving.

In fact, they felt that it was their responsibility of the caregivers to provide care for healthier outcome of the patient.

Severe burden was seen to be higher among females, those aged less than 50 years, among literates and among employed. However, on testing Association between various socio demographic variables and the burden using chi square test, no significant association was found.



**Figure 5: Caregivers responses to Zarit burden interview for item 22 (n=45).**

**Table 3: Association between various socio demographic variables and the family caregiver burden according to Zarit burden interview.**

Variable	No or mild (%)	Moderate (%)	Severe (%)	Total	Chi square
<b>Age (in years)</b>					
<50	15 (48.38)	13 (41.89)	3 (9.67)	31 (100)	0.9
>50	8 (57.14)	4 (28.57)	2 (14.28)	14 (100)	
<b>Gender</b>					
Female	10 (50)	7 (35)	3 (15)	20 (100)	0.695
Male	12 (48.78)	11 (44)	2 (8)	25 (100)	
<b>Type of family</b>					
Joint	2 (50)	1 (25)	1 (25)	4 (100)	1.00
Nuclear	20 (48.7)	17 (41.4)	4 (9.7)	41 (100)	
<b>Occupation</b>					
Employed	15 (55.55)	8 (29.62)	4 (14.81)	27 (100)	0.828
Unemployed	7 (38.88)	10 (55.55)	1 (5.55)	18 (100)	
<b>Education</b>					
Illiterate	7 (56.13)	6 (46.63)	0	13 (100)	0.419
Literate	15 (46.87)	11 (34.37)	6 (18.75)	32 (100)	

## DISCUSSION

The Diagnosis of cancer is distressing not only for the patient but also for the family members. In India, the role played by the family members is vital not only providing support in the form of attending to physical needs of the sick patient but also to provide emotional support. The treatment costs are also usually taken care of by the family. The sudden, unpreparedness for exposure to caregiving, uncertainty about the illness, unawareness about the expenses and unavailability of various facilities for treatment makes them more vulnerable to distress in addition to other responsibilities of the family.

In the present study, mean age of the caregivers was  $43.56 \pm 13.57$  years. Similar findings were observed ( $43.46 \pm 10.39$  years) in studies done by Unnikrishnan et al and Lukhmana et al indicating that the majority of the caregivers were in the reproductive age group where the productivity may be at risk by engaging them in dual role. i.e. as a breadwinner and care provider.<sup>3,4</sup>

In the present study, caregivers were predominantly males 55.56%. This is similar to findings of the studies by Unnikrishnan et al and Kazi et al.<sup>4,5</sup>

In the present study, majority of the care givers (37.15%) were related to the patient as spouse. The findings were similar to studies done by Vahidi et al, Lukhmana et al and Kulkarni et al where it was 38.16%, 38.03% and 33.5% respectively.<sup>4,6,7</sup>

In the present study, majority of the care givers (91.55%) were from nuclear families. The findings were similar to a study done by Sreeja et al.<sup>8</sup>

In the present study, majority (71.56%) of the care givers were literates and (55.56%) were employed. The study also revealed that being involved in care providing, made some of the caregivers to quit from their livelihood wages. The findings are similar to studies by Kulkarni et al, Malathi et al, Sreeja et al.<sup>7-9</sup>

The mean burden score in the present study was  $43.51 \pm 13.16$ , representing a moderate-severe burden among primary caregivers of breast cancer patients.

In the present study, about 40% of the study population reported that moderate to severe burden. Similarly, findings (37%) were noticed in a study done by Unnikrishnan et al.<sup>3</sup>

In the present study, mean scores for various questions related to health of the caregiver, financial compromise, uncertainty about the future of the patient, fear of losing the patient, feeling to run away from the situation was 2.80, 3.13, 2.93, 2.76 and 1.93 respectively.

Contrary findings were observed in the study done by Kulkarni et al.<sup>7</sup> where the values for the above components were 0.84, 1.76, 1.18, 3.18 and 0.55 respectively.

The differences in the above-mentioned questions may be due to difference in the study setting, study population and their psychological strength, site of cancer and stage of cancer and financial support for them also plays a crucial role. In the present study, majority of the study population were the bread-winners to the whole family.

It imposes a greater burden for them.

In the present study, the mean value for the question, social life suffered obtained was 1.89. Similar finding was observed in the study done by Kulkarni et al i.e. 1.35.<sup>7</sup>

Indicating that, in India, most of the times, social life revolves around the family. When any family member fall sick, the prime importance is given to the sick, and the family members strives hard to revive them rather than giving priority to privacy and social life. Hence, from the above findings it was observed that breast cancer is causes lot of psychological trauma not only to the patient but also to the family.

Majority of the caregivers reported that severe burden was felt due to insufficient money to provide care and to meet other family responsibilities. Health of the caregivers was also suffered because of their relative and majority of them also reported that uncertainty about the illness making them more distress.

In the present study, chi square test of significance was used to find out the association between various socio demographic variables and burden score. No significant association was observed between the various socio demographic variables and burden score. The findings was similar to a study done by Kazi et al.<sup>5</sup>

## CONCLUSION

The mean burden score in the present study was  $43.51 \pm 13.16$ , representing a moderate-severe burden among primary caregivers of breast cancer patients. No statistical association was found between caregiver burden score and various socio-demographic variables.

### *Recommendations*

Counselling centres can be setup in all cancer hospitals and to provide appropriate psychological intervention may alleviate the distress among caregivers. Support groups can be formed so as to help the caregivers to cope and deal with the wretched multifaceted "burden". Other family members also should share the responsibility of care giving in various possible ways so as to alleviate the distress among caregivers.

### *Limitations*

The findings of the study cannot be generalised as the present study was done on a limited population.

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