

ORIGINAL RESEARCH

Burden Faced by Caregivers of Cancer Patients: A Cross Sectional Study Conducted in Southern India

¹Punithavathi D, ^{*2}Bhuvaneshwaran D, ³Murali S

¹Senior Resident, Department of Psychiatry, Government Villupuram Medical College, India.

^{*2}Senior Resident, Department of Psychiatry, Government Nagapattinam Medical college and Hospital, India.

³Assistant Professor, Department of Psychiatry, Government Vellore Medical College, India.

Corresponding Author

Bhuvaneshwaran D

Senior Resident, Department of Psychiatry, Government Nagapattinam Medical college and Hospital, India.

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ABSTRACT

Background: Globally, cancer continues to be one of the major contributors for the morbidity and mortality. Family members of patients who are diagnosed with cancer and undergo treatment feel obligated to care for their loved ones. Care giving leads to disturbances in the physical, financial and psychological wellbeing of family members. The present study was undertaken to assess the burden faced by caregivers of cancer patients. **Methods:** The present study was conducted in Department of Neuroscience, Government Stanley medical college. In the present study 40 caregivers of cancer patients were included in the study. Assessment of Caregivers' burden was assessed using the Zarit Burden Interview (ZBI). **Result:** In cancer caregivers, depression is high among 40- 60 years. The chronic illness among the caregivers were found to be 67.5%. Majority of the caregivers were female, middle age groups, Married, Nuclear family, urban population and illiterate in educational status. Most of them were employed, supporting their family and cancer patients. Most of the caregivers were their spouses itself. The major group of caregivers were care giving for less than one year because of the high mortality in the cancer patients. According to Zarit Burden Interview, 33.5% had little burden, 20% had mild burden, 27.5% had moderate burden and 20% had severe burden. **Conclusion:** Caregiver burden has negative effects on quality of life of caregivers and also patients. Caregiver burden on long term may cause psychiatric comorbidities. Cancer care hospitals should be equipped with interventions like counselling services and support groups to deal with miserable multifaceted burdens encountered by the caregivers of the cancer patients.

Key words: Caregivers Burden, Cancer, Zarit Burden Interview, Malignancy.

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INTRODUCTION

Globally, cancer continues to be one of the major contributors for the morbidity and mortality. Global Burden of Cancer study carried out by the World Health Organization's International Agency for Research on Cancer has reported that almost 18 million new cases were diagnosed in 2018. By 2025, it has been predicted to be over 20 million cases of cancer worldwide. They have also reported that majority of the cases would be from the low and middle-income nations.¹⁻²

Among men, the most common sites of cancer are lung, prostate, colorectal, stomach and liver. Among women, the most common sites of cancer are breast, colorectal, lung, cervix and stomach cancer.³ Cancer is a chronic illness that causes patients' requirements

and issues to be significant, ongoing, and variable. Thanks to developments in cancer care and the current trend towards outpatient cancer treatment, family members can now play significant roles as carers and receive care in the home. Giving care is usually not something that individuals plan for. Family members of patients who are diagnosed with cancer and undergo treatment feel obligated to care for their loved one and vow to give unrestricted care.⁴⁻⁸ Advancements in palliative care treatment which relieve, rather than cure, symptoms caused by cancer it poses a burden to care givers by providing long term care for patients' activities of daily living. In care givers it is producing definite disturbances in the physical as well as psychological wellbeing and thereby affects the emotional and financial needs of

family members and their caregivers.⁹ Progression of cancer, physical issues associated with severity of the disease, time spent providing care, the patients' dependence on care givers, financial problems (especially if the patient is the sole bread winner), and a lack of social support contribute to increased distress and decline in quality of life of primary care givers of the patients.⁹ The present study was undertaken to assess the burden faced by caregivers of cancer patients.

MATERIALS AND METHODS

The present study was conducted in Department of Neuroscience, Government Stanley medical college. It is a tertiary care institute where patients come northern part of Chennai, Thiruvallur District and southern districts of Andhra Pradesh. The present study included 40 Caregivers of cancer patients. The present study was carried out for a period of 6 months. The study included consenting care givers aged between 20 to 85 yrs. Caregivers with the family history of psychiatric illness, history of Substance abuse and history of suicide attempt were excluded from the study.

Study Procedure: After obtaining informed consent from patients and their caregivers, socio-demographic details, family history details and a semi structured clinical profile of Caregivers were collected using a semi structured questionnaire. Assessment of Caregivers' burden by Zarit Burden Interview (ZBI). The Zarit Burden Interview, is a caregiver self-report tool employed for assessment of caregiver burden. The original version has 29 items of questions which was evolved by Zarit in 1980. The revised version by Bedard contains 22 items. Each item on the interview is an expression in which the caregiver is asked to endorse using a 5 point scale.¹⁰⁻¹²

RESULT

Socio-Demographic profile

In the present study majority of the caregivers were female (95%), while male constituted only 2 (5%) study participants. Majority of the caregivers were in the 4th and 5th decade of their life, 35% of the study participants were aged less than 40 years of age. In the present study, participants aged above 60 years of age constituted 10% of the study population. Majority of the study participants were married (82.5%) while single and widowed participants constituted 10% and 7.5% respectively. Among the caregivers, 70% belonged to nuclear families, while those from joint family constituted 30% of the study participants. In this study, the caregivers from urban areas were 60% of the study population while 40% were from rural background. The details of educational background of the caregivers showed that 45% of the study population were illiterate. Study participants educated up to Middle school (37.5%), High/Hr sec school (12.5%) and Graduates (5%) were also in the study.

Care givers characteristics

Relationship of the caregivers was recorded in the present study. We observed that majority (70%) of the study participants were spouses of the cancer patients. Children of the cancer patients constituted 15% of the caregivers in the present study. Siblings and either daughter-in-law or son-in-law each constituted 2.5% of the study participants.

Degree of care giver burden

In the present study we used the Zarit Burden Interview to assess the caregiver burden. We observed that Majority of the study participants had some sort of burden in the process of care giving. Mild burden was experienced by 20% of the study participants. Moderate burden was observed in 27.5% of the caregivers of cancer patients. Severe burden was experienced by 20% of the study population. We had observed that 32.5% of the study participants reported to have experienced little or no burden.

Table 1: Socio-Demographic Characteristics of the study participants (n=40)

	Frequency (n=40)	Percentage
Gender		
Male	2	5
Female	38	95
Age of the caregiver		
≤ 40 Yrs	14	35
41-60 Yrs	22	55
Above 60 Yrs	4	10
Marital status of care givers		
Unmarried	4	10
Married	33	82.5
Divorced	0	0
Widowed	3	7.5
Type of family		
Nuclear family	28	70
Joint family	12	30

Locality		
Rural	16	40
Urban	24	60
Educational status of caregivers		
Illiterate	18	45
Middle school	15	37.5
High/Hr sec school	5	12.5
Graduates	2	5

Table 2: Care givers characteristics of the study participants (n=40)

	Frequency (n=40)	Percentage
Relationship to the patients		
Siblings	1	2.5
Spouse	28	70
Daughter/Son	6	15
Daughter/son -in-law	1	2.5
Others	4	10
Duration of caregiver given		
5-10 years	2	5
1-5 years	14	35
less than 1 year	24	60

Table 3: Degree of burden in ZBI scale of care givers of Cancer patients

	Frequency (n=40)	Percentage
Zarit Burden Interview Scale		
Little/No burden	13	32.5
Mild burden	8	20
Moderate burden	11	27.5
Severe burden	8	20

DISCUSSION

Adverse effects of treatment, disease progression and the morbidity linked to the disease leads to increased difficulties encountered by the caregivers. This adversely affects the emotional, psychological, and physical health of the caregiver.¹³ The present study was undertaken among 40 caregivers to assess the burden of caregiving. In the present study the burden encountered by the caregivers was assessed using the Zarit Burden Interview.

Majority of the caregivers of cancer patients in the present study were aged between 41-60 years. McMillan et al¹⁴ in their study has also reported the mean age of caregiver in cancer patient was between 45 to 54 years. Vrettos et al¹⁵ in their study had reported that the mean age of the caregivers of cancer patients was 48.9±14.3 years. Likhmana et al¹⁶ had also reported that majority of the care givers were aged between 40 to 60 years of age. Our findings are similar to the fore mentioned studies, this can be attributed to the age of diagnosis of the cancers, the type of cancer and the socio-cultural dynamics.¹⁷⁻¹⁹

In the present study 95% of the caregivers were female while 82.5% of the caregivers were married. Unnikrishnan et al²⁰ had reported that half of the caregivers were male, similar findings were also reported by various international studies.²³⁻²⁵ Kong et al, with 14% with moderate to severe levels of burden.²⁶ Various studies have reported that most of

the caregivers were married. It has been observed that the burden encountered by the caregivers who were married was lesser than the burden encountered by their unmarried, widowed, or divorced counterparts.²⁷⁻²⁸

In the present study we observed that a higher proportion (62.5%) of caregivers were employed. Similar observations were made by Likhmana et al,¹⁵ Garlo et al, and Liu et al.²⁹ They have also observed that when the caregivers are unemployed there is an increased financial burden as well.

Likhmana et al¹⁵ using a validated Hindi version of ZBI in northern parts of India, had reported caregiver burden rate reported to be 43.5%. Kong et al²⁶ had also reported a similar level of burden among the caregivers. Unnikrishnan et al²⁰ had reported that half of the caregivers had psychosocial burden, with 14% with moderate to severe levels of burden. The level of burden encountered by the caregivers varies greatly among different studies. Other studies elsewhere had varied levels of burden among the caregivers. International studies have reported increased number of caregivers with mild to moderate degree of burden.²¹⁻²² Bahrami et al²³ and Garlo et al²⁴ in their studies among caregivers of breast cancer patients had observed that there was a high degree of psychosocial burden, among the caregivers. The variations in levels of burden encountered by the caregivers can be attributed to the availability of health care services,

health care seeking behavior, and family structure and socio-cultural differences. These factors emphasize the need for tailored interventions to suit the needs of the caregivers based on their needs.

CONCLUSION

Increasing incidence of cancer has in turn increased the need for caregiving. It is necessary to identify the needs of the primary caregivers, this is essential in ensuring that neither the quality of care provided nor the quality of life of the caregiver is affected. Periodic screening, counselling and the creation of self-help groups would be instrumental in easing the burden encountered by the caregivers.

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