

Burden and Quality of Life among Caregivers of Patients with Advanced Carcinoma

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Abstract:

Background: Cancer continues to be a major concern causing severe disability resulting in uncertainty about the future & deterioration in quality of life. Family caregivers (FCs), who are major but unpaid care partners, are affected most by meeting multi-dimensional needs of cancer patients

Materials and Methods: Quantitative approach with descriptive design was used to assess the quality of life and burden of caregivers of advanced cancer patients and the correlation between the quality of life and burden. The study was conducted in a tertiary setting in southern India. Participants were above the age of 18years, who could understand and write English, Tamil, Telugu, Hindi, Malayalam and Bengali. Instruments used for data collection were a family member profile which included the age, gender, marital status, religion education, occupation family income and relationship to patient, patient profile including information such as diagnosis, duration of illness, type of treatment, degree of physical dependence and preference to spend the end days of life, Quality of Life in Life-Threatening Illness – Family Carer Version 13, and the Zarit Burden Interview (ZBI-22) scale. Patients with advanced cancer were identified, their family member willing to participate in the study were asked to fill the self administered scales.

Results: Study findings reveal that 64% of the care givers of advanced cancer patients had poor quality of life and 59% of them had severe burden. Also, a statistically significant ($p < 0.001$) weak negative correlation ($r = -0.49$) is noted between Burden and Quality of Life.

Key Word: cancer, quality of life, care giver, burden

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I. Introduction

Cancer continues to be a major concern causing severe disability resulting in uncertainty about the future and deterioration in quality of life. Most of the cancer patients who are terminally ill demand more holistic approach to their treatment which accounts to their physical, mental, emotional and spiritual well-being¹. Diagnosis of cancer has a significant impact not only on the patients, but also on their family caregivers. Therefore cancer has a substantial impact on both patients and their families. Cancer can worsen the caregiver's health, impair social life, increase stress, and cause depression. Caregiver burden is relative to patient demands, and health is considered the overall outcome of the care giving process. The inability of a caregiver to meet a patient's need for practical assistance may compromise the patient's physical well-being and ability to comply with treatment.^{2,3,4} Though the treatment strategies for cancer have evolved over the past 20 years, majority of Indians seek treatment only at terminal illness. Research with families of individuals with life-limiting illnesses has identified that attending to the care needs of families is paramount.⁵ Care needs can be described not only in terms of the specific needs of families such as receiving timely information about the patient's condition but also in terms of patient care needs that are important to families such as physical comfort⁵. Family caregivers (FCs), who are major but unpaid care partners, are affected most by meeting multi-dimensional needs of cancer patients. They play a pivotal role in monitoring treatment, managing treatment-related symptoms, and providing emotional, social, and spiritual support to their patient.^{2,3,4} In recent years, the role of FCs has become more diverse and involved, as the duration of hospital stays of cancer patients has shortened while outpatient care services have expanded with improved anti-cancer drugs⁶. In addition, the homecare system in our country is not as well-established as it is in developed countries. As a result, informal care is more widespread than formal care. In general, the responsibility of caring for the cancer patient at home is down to the patient's spouse, children, relatives, or friends.⁷ The nurse can extend the service beyond the scope of hospital by involving the family members and friends in care by providing standard health education and compassionate counseling. Nurses need to promote the evidence-based practice by timely involvement of multidisciplinary team (Palliative nurse, physiotherapist, psychologist, counsellor, chaplain) in caring for the needful at their most

fragile moments of life. Home care services needs to be strengthened by giving appropriate training and education to the community health nurse and also the specialist nurse.

II. Material And Methods

Most of the cancer patients who are terminally ill demands more holistic approach to their treatment which accounts to their physical, mental, emotional and spiritual well-being. Diagnosis of cancer has a significant impact not only on patient, but also on their family caregivers. Family caregivers have become increasingly responsible for providing home care for cancer patients as the patients are dependent on them for their ADL, pain and wound management. Therefore cancer has a substantial impact on both patients and their families. Cancer can worsen the caregiver’s health, impair social life, increase stress, and cause depression. Caregiver burden is relative to patient demands, and health is considered the overall outcome of the care giving process. There are limited number of studies that address caregiver burden among advanced cancer patients, as they and their family members are systematically excluded from routine satisfaction surveys in Indian hospital settings. The present study aims to assess the burden and QOL among caregivers of patients with advanced carcinoma and to determine the relationship between burden and QOL of caregivers of patients with advanced carcinoma.

Quantitative approach with descriptive design was used for the study. The study was conducted among cancer patients in two general and two private oncology wards of a Tertiary hospital in South India. Family member above the age 18 years, who provide care to the patients of advanced cancer (stage), who can understand and write languages such as Tamil, Malayalam , English, Hindi, Bengali, and Telugu were included in the study.

Instruments used for data collection were a family member profile which included the age, gender, marital status, religion education, occupation family income and relationship to patient, patient profile including information such as diagnosis, duration of illness, type of treatment, degree of physical dependence and preference to spend the end days of life. QOL was assessed using QOLLTI-F (Quality of Life in Life-Threatening Illness – Family Carer Version 13) developed by Dr. Robin Cohen of the Division of Palliative Care, Departments of Oncology and Medicine, McGill University. QOLLTI-F has a test retest reliability score of 0.77-0.80 measuring seven domains such as carer’s own state, environment, carer’s outlook, quality of care, relationship, patient condition and financial. QOLLTI-F has a total score of 10, ‘0’ to always indicate the worst situation and ‘10’ the best situation. The was translated into Tamil, Malayalam ,English, Hindi, Bengali, and Telegu languages and the accuracy was checked by experts. The Zarit Burden Interview (ZBI-22) scale was used to assess the care giver burden. It consists of 22 items with five ordered frequency-related response categories scored 0 (never) to 4 (nearly always), except for the final item, which has five ordered intensity-related response categories (0 = not at all; 4 = extremely).

Data collection procedure

Patients with advanced cancer were identified, their family member who fulfills inclusion criteria were explained about the study and the informed consent was obtained in their vernacular language. Their socio demographic and patient’s clinical variables were obtained. After three –five days of hospitalization QOLLTI-F and Zarit care giver Burden Questionnaire were handed over to the family member in a self-addressed standardized cover letter and where asked complete and return the forms.

Statistical analysis

Data was analyzed using SPSS version 17 (SPSS Inc., Chicago, IL). Pearson’s correlation co-efficient was used to assess the relationship between variables. The level of p value was <.05.

III. Result

The demographic profile of the care givers reveal that 59% were females, 39% had primary education, 79% were married, 51% lived in nuclear family, 41% of them were either spouse or children, and 36% of them were employed. Among the patients only 11% had medical insurance (see Table 1).

Table 1
Demographic profile of the care givers

Variables	n	Variables	n
<i>Sex</i>		<i>Relationship to patient</i>	
Male	41	Spouse	41
Female	59	Child	41
		Sibling	4
<i>Education</i>	39	Parent	9
Primary	25	Relative	5

Higher secondary	25	<i>Family Income (Annual)</i>		
Graduate	11		<5000	19
Post graduate			5000 – 10,000	26
<i>Marital Status</i>	20	>10,000 – 25,000	29	
Single	79	>25,000	26	
Married	1	<i>Occupation</i>	36	
Widow		Employed	22	
<i>Family Type</i>	51	Unemployed	6	
Nuclear	49	Student	26	
Joint		Home maker	4	
<i>Duration of illness of patient</i>	54	Business	6	
0 – 6months	10	Others		
6months – 1 year	36	<i>Insured patients</i>	11	
>1 year		Yes	80	
		No		

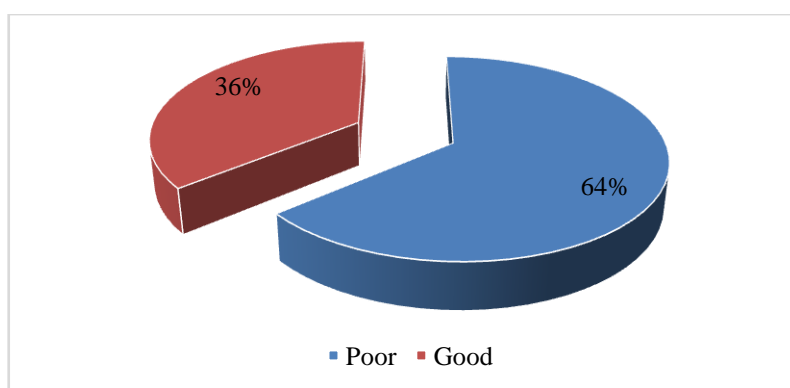


Figure 1. Quality of life of care givers of advanced cancer patients.

Study findings reveal that 64% of the care givers of advanced cancer patients had poor quality of life and 59% of them had severe burden (see Figure 1 & 2).

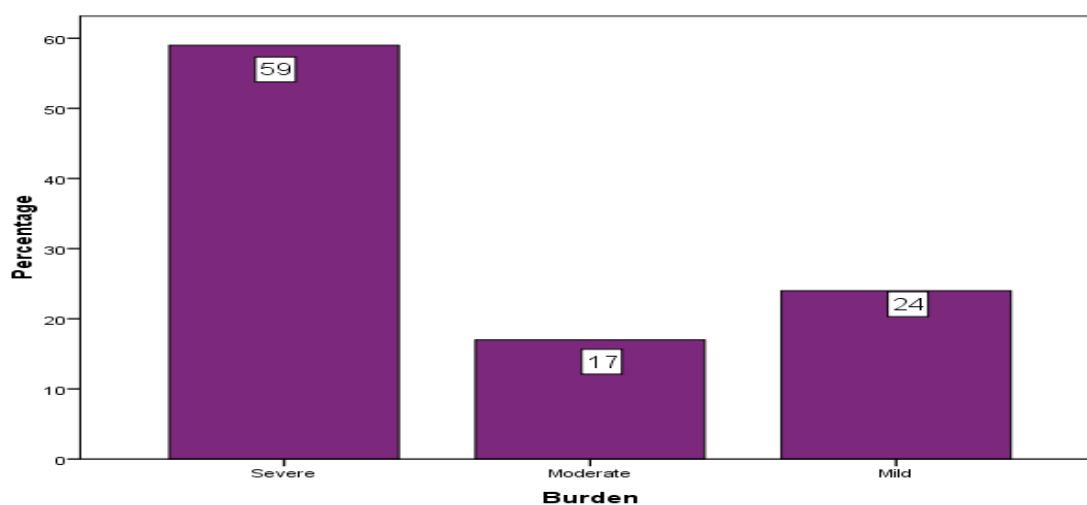


Figure 2. Level of burden among caregivers of advanced cancer patients

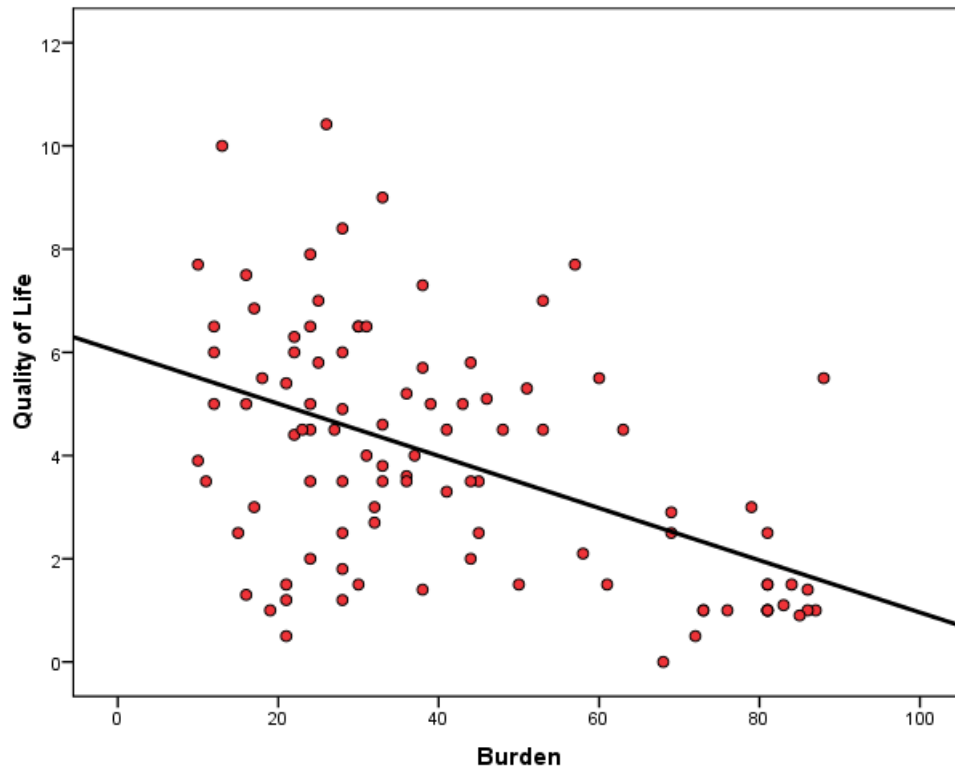


Figure3. Correlation between quality of life and burden among caregivers of advanced cancer patients

Figure 3 depicts that there is a statistically significant ($p < 0.001$) weak negative correlation ($r = -0.49$) is noted between Burden and Quality of Life. Thus it infers that the burden is reduced as quality of life improves and vice versa

IV. Discussion

The second major cause of death in the world is cancer, which incurs psychosocial and emotional impact on the family members. Most of the cancer patients who are terminally ill demands more holistic approach to their treatment which accounts to their physical, mental, emotional and spiritual well-being. The vast majority (80%) of care provided to patients is given by informal and unpaid caregivers, who are often family members. They may be responsible for everything from management of the household and finances to medical and personal care. Hard times often bring people closer and helps in strengthening their bonds. (Bicak et al., 2017). Family caregivers are essential partners in the delivery of complex health care services. Further people in an advanced stage of cancer commonly experience decreased functioning, increased symptom burden and dependency, consequently increasing the role of family caregivers. This experience is commonly perceived as a chronic stressor, and caregivers often experience negative psychological, behavioral, and physiological effects on their daily lives and health.

In the current study majority (59%) of the care givers were found to be female, apparently the children or the spouse (41%) of the patient. However more number of the caregivers had acquired only primary education (39%), with a minimal subjects employed (36%), earning between Rs.10,000/- to 25,000/-. Further 79% of the care givers were married living in nuclear family (51%). On the other hand patients suffering with advanced cancer either lived for less than 6 months (54%) or for more than a year (36%) with no financial support (80%).

India being a developing country more than 800 million people are considered poor, most of them live in the countryside and keep afloat with odd jobs. Hence in the current study the caregivers were females having close relationship with the patient with primary education and minimal economic backup. This leads to a catastrophic implication on the care givers when a family member suffers with advanced cancer.

Further the current study established that the care givers of patients with advanced cancer had poor quality of life (64%) experiencing severe burden (59%). Emotional and financial crisis are the major contributing factors for poor quality of life imposing a severe burden among the care givers. Further India being a developing country with poor socioeconomic background and very little exposure to such crisis the burden and quality of life is overwhelming. Hence greater attention is required towards the caregivers to support them

emotionally, spiritually, physical outlook and guidance for financial support, this would further encourage them in providing better care for the advanced cancer patients as well improve their quality of life.

In this study, there was a negative relationship between the care burden of caregivers and their quality of life (Figure 3). Thus it infers that the burden is reduced as quality of life improves and vice versa. Yun et al. (2005) reported that burden of caregivers had an adverse effect on their quality of life⁸. Another study reported that variables such as bad health conditions, lack of family support, and financial difficulties increased the burden of caregivers and decreased their quality of life scores.⁹

V. Conclusion

In this study, demographics of caregivers and the care burden had an effect on the quality of life of caregivers. It is recommended that caregivers are given support by being offered training about providing care. Nurses need to promote the evidence-based practice by timely involvement of multidisciplinary team (Palliative nurse, physiotherapist, psychologist, counsellor, chaplain) in caring for the needful at their most fragile moments of life. Home care services need to be strengthened by giving appropriate training and education to the community health nurse and also the specialist nurse.

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