Perceived Social Support and Burden among Caregivers of Cancer Patients in a Tertiary Care Hospital: A Cross-Sectional Study

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Abstract
Despite the critical role of caregivers of cancer patients in the care continuum, their needs and experiences are often overlooked or under-addressed in clinical practice and research. While numerous studies have investigated the psycho social impact of cancer on patients, relatively few have focused specifically on the experiences of caregivers. Hospital based cross sectional study was conducted among 130 caregivers of cancer patients admitted in the cancer wards of a tertiary care hospital. pre-structured, pre-tested questionnaire was used to collect the data from the selected caregivers of cancer patients who met the inclusion criteria. The assessment of caregivers' burden was using the Zarit Burden Interview (ZBI) and perceived social support using Multidimensional Scale of Perceived Social Support. On analysis pearson's correlation was done between Zarit burden score and perceived social support score. Ordinal logistic regression analysis was done to determine the factors associated with caregiver burden and perceived social support. 62% of the caregivers of cancer patients had mild to medium perceived social support and 63% had moderate to severe burden. Age of caregiver, stage of cancer, duration of treatment, type of treatment and type of family was significantly associated with perceived social support. Stage of cancer, type of treatment and type of family was significantly associated with burden of caregivers. The perceived social support and burden of caregivers were negatively correlated (r=0.73). By identifying predictors of burden and social support, healthcare providers can develop tailored interventions to support caregivers effectively, ultimately improving the quality of care for cancer patients.

INTRODUCTION

Cancer, a formidable health challenge worldwide, not only affects individuals diagnosed but also extends its impact to their families and caregivers. In the Indian context, where the burden of cancer is significant and growing, the role of caregivers in providing support to cancer patients is indispensable[1]. Caregivers play a multifaceted role, offering emotional solace, physical assistance and logistical support throughout the challenging journey of cancer diagnosis, treatment, and recovery[2]. However, this responsibility often comes at a cost, with caregivers experiencing substantial physical, emotional and financial burdens[3].

In the Indian healthcare landscape, characterized by diverse cultural norms, socioeconomic disparities, and limited resources, the experiences of caregivers of cancer patients may be particularly nuanced[4].

The dynamics of care giving 5 in the Indian context are influenced by cultural values, familial structures, and societal expectations, which may shape caregivers' perceptions of social support and burden[6]. Social support, defined as the provision of assistance, empathy and understanding from one's social network, plays a crucial role in buffering the impact of stress and improving coping mechanisms[7]. Perceived social support, which refers to an individual's subjective appraisal of the availability and adequacy of support received, has been shown to significantly influence caregivers' well-being and care giving experiences[8]. While numerous studies have investigated the psycho social impact of cancer on patients, relatively few have focused specifically on the experiences of caregivers, particularly in the Indian context[9]. Therefore, there is a compelling need for research to explore the perceived social support and burden among caregivers of cancer patients in Indian tertiary care hospital settings[10].

In this study, we aim to investigate the perceived social support and burden among caregivers of cancer patients in a tertiary care hospital in India through a cross-sectional study design. By examining the predictors of burden and social support and correlating the relationship between these two factors, we seek to contribute to the growing body of literature on caregiver experiences in the context of cancer care in India.

Objectives:

- To study the perceived social support and assess burden among caregivers of cancer patients
- To determine the predictors of burden and social support among caregivers of cancer patients
- To correlate the relationship between burden and perceived social support of caregivers of cancer patients

MATERIAL AND METHODS

Study Design: Cross-sectional study

Study Location: This was a tertiary care hospital-based study done in Department of Preventive Oncology, at State Cancer Hospital, Aurangabad, Maharashtra.

Study Duration: August 2023 to October 2023.

Sample Size: 130 Caregivers of cancer patients.

Sample Size Calculation: Considering prevalence, p= 38% (12) allowable error=9%According to Cochrane's formula, sample size, n=116. Considering 10% non-responders, total sample size = 128 rounding to 130.

Study Population: The study population was drawn from the caregivers of cancer patients admitted in the cancer wards.

Inclusion Criteria: Caregivers of cancer patients admitted in cancer wards of tertiary care hospital and willing to give consent.

Exclusion Criteria: Those who are not willing to give consent.

Sampling Method: Study Population was randomly selected from the 4 cancer wards using table of random numbers.

Procedure Methodology: After written informed consent was obtained, a well-designed pretested and validated questionnaire was used to collect the data from the selected caregivers of cancer patients who met the inclusion criteria. The part A of the questionnaire included socio-demographic characteristics such as age, gender, address religion, relation to patient, marital status, socioeconomic status. Part B consists of type of cancer, stage of cancer, type of cancer treatment the patient is on and
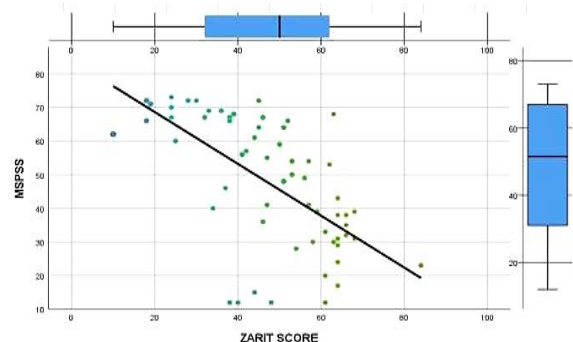
Graph 1: Showing correlation between zarit burden interview score with Multidimensional Scale of Perceived Social Support

Table 1: Distribution of the Sociodemographic profile of study participants

Characteristics		N (%)
Age of the care giver (years)	≤40	80(61.5)
	≥40	50(38.5)
Gender	Male	58(44.6)
	Female	72(55.4)
Relation with Patient	Spouse	28(21.5)
	Blood relatives	86(66.2)
	Non blood relatives*	16(12.3)
Type of family	Nuclear	52(40)
	Joint	44(33.8)
	Three Generation Family	34(26.2)
Religion	Hindu	91(70)
	Muslim	32(24.6)
	Buddhist	7(5.4)
Residence	Rural	91(70)
	Urban	29(30)
Education	Ille rate	29(22.3)
	Literate	101(77.7)
Socioeconimic status	Class 1	Nil
	Class 2	23(17.7)
	Class 3	24(18.5)
	Class 4	65(50)
	Class 5	18(13.8)

*In-Laws
**B.G. Prasad SES Classification for the year 2023.

Table 2: Shows the details of the cancer disease

Disease details		N(%)
Type of cancer	Breast cancer	41(31.5)
	Childhood cancer*	17(13.1)
	GIT cancer	26(20)
	Head and neck cancer	19(14.6)
	Lung cancer	14(10.8)
	Gynecological cancer	08(6.2)
	Others**	05(3.8)
Stage of Cancer	Stage 1 and 2	46(35.4)
	Stage 3 and 4	84(64.6)
Type of Treatment	Non-surgical	45(34.6)
	Surgical	85(65.4)
Duration of treatment	≤6months	78(60)
	>6months	52(40)

*All cancers that are diagnosed in Children less than 14 years.
**Bone cancer, bladder cancer.

Table 3: Distribution of care givers having mild, moderate and high perceived social support

Low perceived social support	Medium perceived social support	High perceived social support
(12-35)	(36-60)	(61-84)
40(30.8%)	42(32.3%)	48(36.9%)

Care-giver Burden
Mean Zarit Burden Score 47(88) with standard deviation +/- 18.

Table 4: Distribution of care givers having No, mild, moderate and severe burden

No/mild Burden	Mild-moderate Burden	Moderate-severe Burden	Severe Burden
(0-21)	(22-40)	(41-60)	(>61)
15 (11.5%)	32(24.6%)	41(31.5%)	42 (32.3%)

Table 5: On Applying ordinal logistic regression on factors affecting burden on cancer-care givers

characteristic		Estimate	Standard Error	p-Value
Age of the Care-giver	Male	0.009(-0.061-0.079)	0.036	0.804
Gender	Female	-0.091(-1.076-0.894)	0.503	0.856
		0a		
Religion	Hindu	-1.155(-3.115-0.805)	1.000	0.248
	Muslim	-1.413(-3.462-0.636)	1.045	0.177
	Buddhist	0a		
Marital Status	Currently Married	-0.472(-2.378-1.433)	0.972	0.627
	Widowed	-2.629(-4.923- -0.336)	1.170	0.25
	Never married	0a		
Type of Family	Nuclear	0.568(-1.027-2.164)	0.814	0.485
	Joint	-1.450(-3.035-0.135)	0.809	0.043*
	Three generation	0a		
Residence	Rural	0.991(-0.311-2.293)	0.664	0.485
	Urban	0a		
Socio-economic Status	Class 1 and 2	-0.407 (-2.180-1.367)	0.905	0.653
	Class 3	-1.116 (-2.882-0.650)	0.901	0.216
	Class 4	-1.116 (-2.882-0.650)	0.706	0.672
	Class 5	-0.299 (-1.684-1.085)		
		0a		
Relation with Patient	Spouse	1.204(-0.757-3.165)	1.001	0.229
	Blood relatives	0.239(-1.119-1.598)	0.693	0.730
	Non. Blood relatives	0a		
Diagnosis	Breast Cancer	-1.597(-4948-1.754)	1.710	0.350
	Childhood Cancer	0.321(-2.285-2.926)	1.329	0.809
	Git Cancer	0.548(-2.189-3.286)	1.397	0.695
	Head and Neck Cancer	-0.436(-3.345-2.474)	1.484	0.769
	Lung Cancer	-0.472(-3.102-2.157)	1.342	0.725
	Gynecological Cancer	-0.794(-3.474-1.886)	1.367	0.562
	Others	0as		
Type of Treatment	Non-surgical	1.377(0.182-2.571)	0.609	0.024*
	Surgical	0a		
Duration of Treatment	≤6 Months	-0.621(-1.562-0.320)	0.480	0.196
	≥6 Months	0a		
Stage of Cancer	Stage 1 and 2	-1.949(-3.148- -750)	0.612	0.001*
	Stage 3 and 4	0a		

0a-This parameter is set to zero.

Table 6: On Applying ordinal logistic regression on factors affecting perceived social support on cancer-caregivers

Characteristic		Estimate	Standard error	P-Value
Age of the Care-giver		-0.053(-0.143-0.037)	0.046	0.247
Gender	Male	-0.570(-1.838-0.698)	0.647	0.378
	Female	0a		
Religion	Hindu	-0.504(-3.092-2.084)	1.320	0.703
	Muslim	-1.202(-4.168-1.765)	1.514	0.427
	Buddhist	0a		
Marital Status	Currently Married	-1.261(-3.943- -1.422)	1.369	0.357
	Widowed	1.972(-0.742- 4.687)	1.385	0.154
	Never married	0a		
Type of Family	Nuclear	-2.981(-5.385- -0.578)	1.226	0.015*
	Joint	2.248(0.111- -4.385)	1.090	0.039*
	Three generation	0a		
Residence	Rural	-0.736(-2.601-1.129)	0.952	0.439
	Urban	0a		
Socio-economic Status	Class 1&2	3.559(1.013-6.104)	1.299	0.006*
	Class 3	3.802(1.2-0.650)	1.228	0.002*
	Class 4	2.800(0.941-4.660)	0.949	0.003*
	Class 5	0a		
Relation with Patient	Spouse	-3.584(-6.319-0.848)	1.396	0.010*
	Blood relatives	-0.520(-2.252-1.212)	0.884	0.556
	Non blood relatives	0a		
Diagnosis	Breast Cancer	3.007(-1.964-7.978)	2.536	0.236
	Childhood Cancer	1.495(-2.004-4.994)	1.785	0.402
	Git Cancer	1.362(-2.296-5.020)	1.866	0.465
	Head and Neck Cancer	3.251(-1.237-5.906)	2.206	0.141
	Lung Cancer	0.358(-2.905-.3.622)	1.665	0.830
	Gynecological Cancer	2.335(-1.237-5.906)	1.822	0.200
	Others	0a		
Type of Treatment	Non-surgical	-1.952(-3.799-0.106)	0.942	0.038*
	Surgical	0a		
Duration of Treatment	≤6 Months	2.694(1.353-4.034)	0.684	0.001*
	>6 Months	0a		
Stage of Cancer	Stage 1 and 2	2.094(0.514-3.675)	0.807	0.009*
	Stage 3 and 4	0a		

0a-This parameter is set to zero.

the duration of treatment. Part C had the assessment of caregivers' burden was using the Zarit Burden Interview (ZBI) and perceived social support using Multidimensional Scale of Perceived Social Support.

Zarit burden interview had 22 questions each question has a minimum score of 0 and maximum score of 4. Multidimensional Scale of Perceived Social Support has 12 questions each question with a minimum score of 1 and maximum score of 7.

Statistical Analysis: Data analysis was done using SPSS trial version. Pearson's correlation was done between Zarit burden score and perceived social support score. Ordinal logistic regression analysis was done to determine the factors associated with caregiver burden and perceived social support

The level $p<0.05$ was considered as the cutoff value or significance.

RESULTS AND DISCUSSIONS

Sociodemographic Profile: The mean age of the caregivers was 37.2 years (SD=1.58). The majority of the study participants was female by gender (55.4%), Hindu by religion (70%), blood relatives of the patient (66.2%), having nuclear family (40%) residing in rural area (70%), literate (77.7%) and belonging to socio-economic class 4(50%). (Table no 1)

Details of Cancer Disease: The majority of the cancer patients had Breast Cancer (31.5%) followed by GIT cancer (20%). 64.6% of patients belonged stage 3 and 4 and 65.4% of the cancer patients had surgical management of disease and 60% of patients had a duration of treatment <6 months. (Table no 2)

Perceived Social Support: Mean MPSS score was 48 (84) with Standard deviation of +/-Perceived Social Support vs Burden

Pearson's correlation was done between Zarit burden score and perceived social support score. The Pearson correlation r=-0.73. (Graph 1)

On Applying Ordinal Regression: Stage of cancer, type of treatment, type of family was significantly associated with burden of the caregivers (Table 6).

Socioeconomic status, stage of cancer, duration of treatment, type of treatment and type of family was significantly associated with perceived social support. (Table 7)

In this study, mean zarit burden score was 48(+/-18) and mean social support score was 47(+/-19), while in the study conducted by Maheshwari PS *et al*. in Punjab 66(+/-13) and 49(+/-12) respectively[11].
In the study conducted by Maheshwari PS *et al*. in Punjab Pearsons correlation between burden and perceived social support was negatively correlated (r=-0.68) similar results were seen in the present study r=-0.73[12].

In a study by Mishra S *et al*. in New Delhi minimal burden experienced was 9% and severe burden was 22% but in the present study its 11.5% and 33% respectively[13].

In the study conducted by Casado B et Sacco P in Baltimore, United States Being female and the care recipient's spouse were associated with higher burden[16].

In the present study age, sex, religion was not associated neither caregiver burden nor perceived

social support similarly study conducted by Maheshwari PS *et al*. in Punjab and Okamoto K et in Japan[19].

In this study, duration of treatment was not associated with the level of burden while in the study conducted by Maheshwari PS *et al*. in Punjab[14] and Ferrell *et al*.[17] has reported that as the duration of care giving increased, the burden among caregivers decreased. While in the study conducted by Milbury K *et al*. in USA, reported that level of burden increased significantly (P=< 0.001) with the duration of care[18].

Stage of cancer and type of treatment 15 was significantly associated with burden of the caregivers in the present study while in the study conducted by Maheshwari PS *et al*. in Punjab, stage and type of treatment had no relationship with burden[11].

CONCLUSION

62% of Caregivers of Cancer patients had mild-medium perceived support 63% and moderate to severe burden.

Socioeconomic status, stage of cancer, duration of treatment, type of treatment and type of family was significantly associated with perceived social support. Stage of cancer, type of treatment, type of family was significantly associated with burden of the caregivers. Perceived social support and burden of the caregivers were negatively correlated (r=-0.73).

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