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"A Study To Assess The Care Giving Burden Of Caregivers Of Patients With Cancer Availing Services In A Selected Tertiary Care Hospital In Kolkata."

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ABSTRACT

INTRODUCTION: Cancer has become a significant public health issue globally. Caregivers of cancer patients often handle medical responsibilities, provide emotional support, and assist with daily activities while managing their own work and personal lives. This demanding role can result in emotional distress, financial challenges, and physical exhaustion, potentially leading to burnout.

MATERIALS AND METHODS: A cross-sectional descriptive study was conducted in a selected tertiary care center at Kolkata. 100 caregivers of cancer patients were selected by using convenience sampling method. A standardized tool(Zarit Burden Interview) was used to assess the care givers burden.

RESULTS: Study findings revealed that majority (43%) of the caregivers reported no to mild burden whereas 40% of caregivers reported mild to moderate burden and only 10% of them reported severe burden, there is no association of any of the selected variables with the caregiving burden of care givers of cancer patients as the Fisher's exact p value calculated for the selected variables are more than the significant value p=0.05

CONCLUSION: Caregiver burden is a fact that affects multiple aspects of caregiver's life. The study findings emphasize the importance to implement the welfare services to support caregivers within the hospital.

Keywords: Cancer, Caregiver burden, Primary Care Givers.

INTRODUCTION:

In South Asian countries like India, cancer became one of the leading causes of mortality and morbidity among the non-communicable diseases. In the year 2022 there is an estimated 20 million cancer cases were there which aids in the prediction of over 35 million new cancer cases by 2050. As per latest data, about 1 in 5 people develop cancer in their lifetime and 1 in 9 men and 1 in 12 women die from this disease. According to Global cancer estimate, the cancer burden will increase by 64.7% from 2022 to 2040 in medium human development index. In 2023, West Bengal recorded approximately 1.13 lakh new cancer cases, positioning it as the state with the third-highest number of reported cases in the country. This marked a slight increase from the 1.1 lakh new cases reported in 2021.

Physical, psychosocial and financial support to people living with cancer is one of the important aspects of current scenario and is usually provided by the family members and friends. Caregiver is defined as 'Individuals (eg, adult children, spouse, parent, friend and neighbor) who provide care typically uncompensated, involve within psychosocial, medical, financial, relationship, information and daily activities aspects. The sudden and complex caregiving responsibilities can have negative impact on caregivers' own health and well-being. Zarit and colleagues defined caregiver burden as "The degree to which caregivers feel that caregiving has negatively impacted their emotional, social, financial, physical, and spiritual well-being."

Gupta et al.'s study highlights that a large proportion of caregivers faced anxiety, fear, and sleep disturbances. These issues should be addressed as part of cancer care, as they can have a long-term detrimental effect on the quality of patient care.⁴ Importantly, high levels of caregiver burden can negatively impact not only the caregiver's well-being but also the physical and mental health of the care recipient which is addressing caregiver burden as a critical priority.⁵

STATEMENT OF THE PROBLEM

"A study to assess the care giving burden of caregivers of patients with cancer availing services in a selected tertiary care hospital in Kolkata."

- To assess the caregiving burden among caregivers of patient with cancer.
- To determine the association of caregiving burden among caregivers with selected variables.

ASSUMPTION

- The Primary caregivers may have significant care giver burden while caring for cancer patients.
- The socio demographic variables may influence the caregiver burden.

METHODS AND MATERIALS

The present study adopted a quantitative research approach with cross sectional descriptive design. The study was conducted in the Oncology Day Care Centre, Oncology inpatient departments and outpatient departments of the selected tertiary care hospital in Kolkata. A sample size of 100 caregivers of cancer patients who were above 18yrs and being able to read and understand Bengali, Hindi or English was selected by using non-probability convenient sampling technique.

The tool used to collect the data consists of two sections:

Section I – A structured questionnaire to collect the sociodemographic and clinical data of cancer patients and sociodemographic data of caregivers of them.

Section II – A standardized tool - Zarit Burden Interview, to assess the caregiving burden.

The Zarit Caregiver Burden Interview (ZBI) was initially developed by Zarit and his colleagues among US caregivers of dementia seniors. The original ZBI contains 29 items on a four-point Likert scale, which was later revised as 22 items on a five-point Likert scale and commonly referred to as ZBI-22. Each item of the ZBI-22 assess the respondent's subjective burden with optional answers scored from 0 to 4. The total score of ZBI-22 ranges from 0 to 88, with high scores indicating higher burden.

Informed Consent was taken from the subjects prior to the administration of the tool. A formal permission is being taken from the Ethical Committee of the tertiary care hospital to perform the research in the selected population.

A pilot study was conducted on 17th march 2025 among 10 participants at oncology OPD of the selected tertiary care centre in Kolkata in order to ensure the feasibility of the study which was followed by main study wef 17.03.25 to 30.03.25.

RESULTS

Demographic Data

Table 1: Distribution of socio-demographic characteristics of cancer patients

Characteristics	Category	Frequency	Percentage (%)		
Age in years	18-29	01	1.0		
	30-39	04	4.0		
	40-49	14	14.0		
	50-59	27	27.0		
	60 and above	54	54.0		
Gender	Male	34	34.0		
	Female	Female 66			
Place of treatment	Ward /IPD	14	14.0		
	Day care centre	59	59.0		
	OPD	27	27.0		
Stage of cancer	I	29	29.0		
	II	22	22.0		
	III	22	22.0		
	IV	27	27.0		
Current treatment	Chemotherapy	56	56.0		
	Radiation therapy	06	6.0		
	Surgery	15	15.0		
	Hormone therapy	03	3.0		
	Blood stem therapy	01	1.0		
	Conservative	06	6.0		
	others	13	13.0		

Table 2: Distribution of socio-demographic characteristics of caregivers of cancer patients

Sociodemographic data	category	Frequency	Percentage
Age of caregiver	18-29	24	24.0
	30-39	28	28.0
	40-49	20	20.0
	50-59	10	10.0
	60 and above	18	18.0
	Male	69	69.0
Gender	Female	31	31.0
Marital status	Single	22	22.0
	Married	70	70.0
	Widow/ divorcee	08	8.0
Educational classification	Primary	08	8.0
	Secondary	23	23.0
	Higher secondary	32	32.0
	Graduate and above	37	37.0
Occupation	Employer	35	35.0
	Self employed	16	16.0
	Retired	16	16.0
	Unemployed /housewife	32	32.0
	Pensioner	01	1.0
Relation with patients	Parents	21	21.0
	Children	28	28.0
	Spouse	38	38.0
	Siblings	06	6.0
	Others	07	7.0
Any chronic illness	Yes	19	19.0
	No	81	81.0
Any training received on care giving	Yes	04	4.0
P. 11112	No	96	96.0

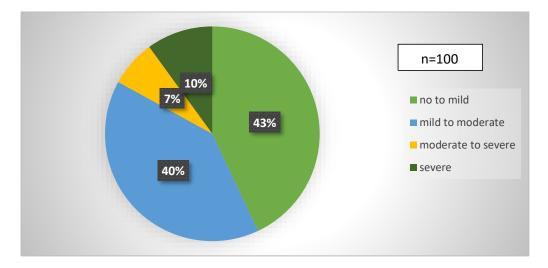


Fig1: Distribution of caregivers as per caregiving burden of cancer patients.

Figure 1 revealed that majority (43%) of the caregivers reported no to mild burden whereas 40% of caregivers reported mild to moderate burden and only 10% of them reported severe burden.

Table 3: Association of selected variables with care giver burden

n=100

Selected variable	Characteristics	No to mild	Mild to moderate	Moderate to severe	Severe	p value	Inference
Age of the caregiver	18-29	13	8	2	3	0.8416	No association
	30-39	14	11	3	4		
	40-49	10	8	2	3		
	50-59	2	7	1	0		
	60 and above	5	4	0	0		
Occupation	Employer	20	10	2	3	0.5344	No association
	Self employed	4	8	3	1		
	Retired	6	6	1	3		
	Unemployed/Housewife	14	13	2	3		
	Pensioner	0	1	0	0		
Relation	Parents	10	7	2	2	0.9316	No association
with patient	Children	14	9	3	2		
	Spouse	14	16	2	6		
	Siblings	3	2	1	0		
	Others	3	4	0	0		
Duration of	1-6 months	19	10	2	3	0.5393	No association
care	6-12 months	9	9	3	4		
	More than 12 months	16	19	3	3		
Type of care	Care of patient alone	20	12	3	4	0.6628	No association
given	Care of patient with others	24	26	5	6		
Current treatment	Chemotherapy	26	19	5	6	0.7237	No association
	Radiation therapy	4	1	0	1		
	Surgery	6	5	2	2		
	Hormone therapy	1	1	0	1		
	Blood stem therapy	0	1	0	0		
	Conservative	1	5	0	0		
	others	6	6	1	0		

Table 3 reveals that there is no association of any of the selected variables with the caregiving burden of care givers of cancer patients as the Fisher's exact p value calculated for the selected variables are more than the significant value p=0.05.

DISCUSSION

A study conducted by Ikechi et al (2021) to assess the caregiver burden and its associated factors amongst family caregivers of women with advanced breast cancer on 157 caregivers revealed that over half (53%) of the respondents were males which is consistent with the present study.

Nandini Menon et.al (2022) conducted a similar study on 127 caregivers to assess the care giving burden in older Indian patients utilizing Zarith Burden Interview tool revealed that caregiving burden was 'little/none' in 97(76.4%), 'mild to moderate' in 25(19.7%), 'moderate to severe' in 4(3.1%) and 'severe' in one (0.8%) of caregiver assessed which is in congruent with the present study.

An identical study conducted by Kaur SP et.al to assess the caregiving burden of cancer patients concluded that 41.6% experienced mild to moderate burden and 11.2% faced moderate to severe burden.

RECOMMENDATIONS

- Implement welfare services to support caregivers within the hospital.
- A comparative study can be conducted among Govt and private hospitals.
- Conduct a similar study with a larger population and including other medical conditions.
- Undertake qualitative research to explore the psychological experiences of caregivers of cancer patients.

CONCLUSION

This study utilized a descriptive survey approach to evaluate the caregiving burden of caregivers of cancer patients undergoing treatment at a tertiary hospital in Kolkata. The study revealed that about 40% of care givers experienced mild to moderate caregiving burden.

CONFLICT OF INTEREST: Nil

REFERENCES:

- Bray F, Laversanne M, Sung H, Ferlay J, Siegel RL, Soerjomataram I, Jemal A. Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin. 2024 May-Jun;74(3):229-263.
- Jena, D., Padhi, B.K., Zahiruddin, Q.S. et al. Estimation of burden of cancer incidence and mortality in India: based on global burden of disease study 1990–2021. BMC Cancer 24, 1278 (2024). https://doi.org/10.1186/s12885-024-13035-6
- 3. . Gupta S, Rohilla K, Bachheti Y, Kalyani CV, Gupta A, Sundriyal D, et al Challenges faced by caregivers of patients with cancer in Sub-Himalayan region: An exploratory survey Cancer Res Stat Treat. 2022 In this issue.
- 4. Muralidharan S, Sikalgar FR, B D, Nikalje MR, Subramaniam T, Kumar M. Exploring the Unmet Needs of Cancer Caregivers in India: A Cross-Sectional Survey. Cureus. 2024 Jun 11;16(6):e62159. doi: 10.7759/cureus.62159. PMID: 38868547; PMCID: PMC11167582.
- 5. Ferlay J, Ervik M, Lam F, Colombet M, Mery L, Piñeros M, et al. Global Cancer Observatory: Cancer Today. Lyon: International Agency for Research on Cancer; 2020 (https://gco.iarc.fr/today, accessed February 2021).
- Menon N, Patil VM, Ramaswamy A, Gattani S, Castelino R, Dhekale R, Gota V, Sekar A, Deodhar J, Mahajan SG, Daptardar A, Prabhash K, Banavali SD, Badwe RA, Noronha V. Caregiver burden in older Indian patients with cancer-Experience from a tertiary care center. J Geriatr Oncol. 2022 Sep;13(7):970-977.
- 7. Menon N, Patil VM, Ramaswamy A, Gattani S, Castelino R, Dhekale R, Gota V, Sekar A, Deodhar J, Mahajan SG, Daptardar A, Prabhash K, Banavali SD, Badwe RA, Noronha V. Caregiver burden in older Indian patients with cancer- Experience from a tertiary care center. J Geriatr Oncol. 2022 Sep;13(7):970-977.