

# Burden and Psychological distress among the caregiver of Cervical Cancer patients admitted in a Maternity tertiary care centre, Chennai

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## Abstract

**Background:** The incidence and frequency of cervical cancer have increased over the past few decades, especially in low-income regions. Burnout among primary care providers, which, if untreated, can have a severe effect on patient outcomes. The purpose of this study was to measure the burden and psychological distress experienced by caregivers of women with advanced cervical cancer.

**Materials and Methods:** The investigator used a descriptive, single-center approach. The duration of the study was three months. In this study, we randomly selected 50 caregivers of women with advanced cervical cancer. Participants in the study were caretakers ranging from 20 to 65 years of age. Professional caretakers were excluded. A caregivers self-assessment questionnaire, a sociodemographic scale, and the Zarit burden interview (ZBI-12) scale were used to gather the data. The obtained data were entered into a Microsoft Excel spreadsheet and analysed using SPSS version 26.

**Results:** The numbers show that 46% of caretakers have a high level of burden, 54% experience a moderate level of burden. 64 % of caretakers reported feeling some emotional distress, 26 % reported significant distress, and 10 % reported feeling very little.

**Conclusion:** In sum, the nurse educator plays a key role in reducing the mental and physical stress placed on caregivers by assisting them in identifying and responding to their loved ones' needs.

**Keywords:** Caregivers, Burden, Psychological Distress, Cancer Cervix

## INTRODUCTION

Cancer is the most commonly diagnosed disease and is a major killer all over the world. Cancer cervix is becoming a more common disease in low-income regions, and its incidence and prevalence have been rising over the past few decades. The World Health Organization ranks cancer as the second biggest cause of mortality worldwide. Both the person having the diagnosis and his or her loved ones who will be taking care of them will be profoundly affected <sup>(1)</sup>. The majority of cancer cases are detected at a late stage. The vast majority of people in need of care in India receive it from close relatives. In their efforts to care for those with severe cancer, caregivers often neglect their own health. Because of this, caretakers experience increased stress, burden, and mental anguish<sup>(2)</sup>.

Cancer caregiving may be a stressful and exhausting experience for both the caregiver and the patient. Caregiver burnout, which can have a negative impact on patient outcomes if not addressed with proper psychological support <sup>(3)</sup>. Few community or clinically based services exist, and the requirements of these crucial carers are chronically neglected, despite the urgent demand for quality and timely supportive care services for cancer care givers.

This course is intense and unpredictable, placing a heavy burden on the caretaker. Caretakers are frequently exposed to numerous sources of stress at once, which can have detrimental impacts on their health and well-being <sup>(4)</sup>. Cancer's effects on both patients and their loved ones who tend to them are intertwined. Unresolved issues and unfulfilled needs for the patient might place additional stress on the care provider. Furthermore, the health of both the carer and the patient may suffer if the caregiver's personal needs are not satisfied <sup>(5)</sup>.

Based on research from 2019, Karin Oechsle et al. conclude that family caretakers experience significant levels of discomfort and anxiety, and that the need for psychological assistance and care-related risk factors increase the mental burden of family carers. A similar study by E Goerge et al. in 2020 also suggests that public initiatives aimed at raising awareness of the psychological anguish experienced by carers might be beneficial.

In 2020, researchers Ine Decadt et al. discovered that 13% of carers experienced a high level of danger and 20% expressed severe anguish. They suggested that trained professionals play a crucial role in assisting caretakers and identifying those who pose a danger to those in their charge. The primary purpose of this research is to determine the extent to which cervical cancer caregivers experience burden and psychological distress.

## **MATERIALS AND METHODS:**

The research study was conducted after the approval of the institution's ethics board. The appropriate written permission was obtained from the concerned department. This study was a descriptive, single-center investigation. This research was carried out in the obstetrics oncology unit of a tertiary care hospital in Chennai. The fifty caregivers were selected using a simple random sampling method with a computer-generated random table. The information was gathered during a three-month period. Participants ranged in age from 20 to 65 and were all providing care to someone with advanced cervical cancer. Professional caregivers, who declined to participate were not included in the study. The information was compiled with the aid of a socioeconomic status scale, a Zarit burden interview (ZBI-12) scale, and a caregiver self-assessment questionnaire. Ten caregivers participated in the pilot trial, which confirmed the study's viability. The information was entered into an MS Excel spreadsheet and analysed with IBM SPSS version 26.

## **RESULTS:**

The study was conducted to assess the level of burden and psychological distress among caregivers of advanced cervical cancer.

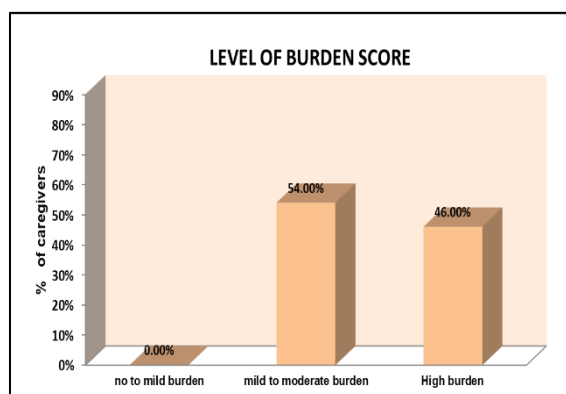
Table .1. Demographic data of the study participants

Demographic variables		Number of care givers	%
Age	< 20 years	0	0.00%
	21-35years	25	50.00%
	36-50years	10	20.00%
	50-65years	15	30.00%
Sex	Male	23	46.00%
	Female	27	54.00%
Education	No formal education	9	18.00%
	primary education	13	26.00%
	secondary education	20	40.00%
	Diploma/degree	8	16.00%
Occupation	unemployed/housewife	10	20.00%
	Daily wages	29	58.00%
	Self employed	3	6.00%
	Govt employee	0	0.00%
	private employee	8	16.00%
Income	<Rs.10,000	36	72.00%
	Rs.10,002-29,972	9	18.00%
	Rs.29,973- 49,961	5	10.00%
	>Rs. 49,962	0	0.00%
Residence	Rural	27	54.00%
	Urban	23	46.00%
Type of family	Nuclear family	34	68.00%
	Joint family	14	28.00%
	Extended family	0	0.00%
	Separated family	2	4.00%
Marital status	Yes	37	74.00%
	No	13	26.00%
Relationship with patient	Husband	15	30.00%
	Daughter/son	26	52.00%
	elder sister/younger sister	7	14.00%
	Others	2	4.00%
Treatment year	3 months	17	34.00%
	3-6months	16	32.00%
	6months-1years	12	24.00%
	>1years	5	10.00%
Personal habit	alcohol	4	8.00%
	smoking	5	10.00%
	alcoholic and smoking	4	8.00%
	Tobacco	8	16.00%
	Others	29	58.00%

Table no.1. shows that a little over half of the study population was comprised of young adults (aged 21-35), and over half (54%) of those individuals were female. 72% of the participants were earning less than Rs.10,000 per year; 58 % of participants earned daily wages; the majority lived in rural areas; 74% of participants were married; 52% of caregivers were daughters and sons; and 34% of participants had been caregivers for less than three months.

## LEVEL OF BURDEN:

The level of Burden among the caregiver was assess using Zarit burden interview (ZBI-12) scale.

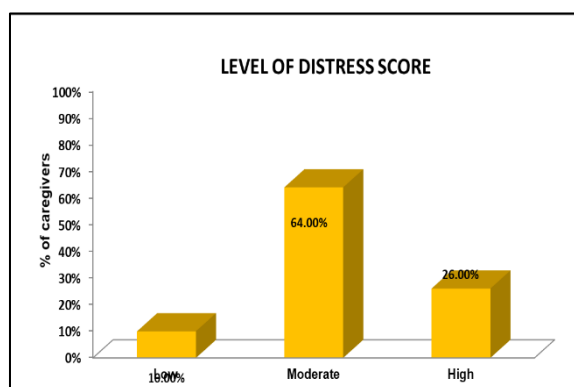


Level of score	No. of Caregivers	%
No to mild burden	0	0.00%
Mild to moderate burden	27	54.00%
High burden	23	46.00%
Total	50	100.00%

As can be seen from the above table, 46% of caregivers reported high burden, 54% reported moderate burden, and 0% reported no burden.

## LEVEL OF PSYCHOLOGICAL DISTRESS:

The psychological distress among the caregivers were assessed using Caregivers self assessment questionnaires.



Level of score	No. of caregivers	%
Low	5	10.00%
Moderate	32	64.00%
High	13	26.00%
Total	50	100.00%

According to the data shown above, around 64% of caretakers were experiencing some degree of psychological discomfort, 26% were experiencing moderate distress, and 10% were experiencing very little.

## ASSOCIATION BETWEEN LEVEL OF BURDEN AND CAREGIVERS DEMOGRAPHIC VARIABLES:

While associating with sociodemographic variables, caregivers between age group of 21-35 years, Male caregivers, and low-income caregivers were having high levels of burden when compared with others.

## ASSOCIATION BETWEEN LEVEL OF PSYCHOLOGICAL DISTRESS AND CAREGIVERS DEMOGRAPHIC VARIABLES:

In terms of the level of psychological distress, caregivers with age group 50-65 years and male caregivers were having high psychological distress than others.

## DISCUSSION:

Caretakers of patients with advanced cervical cancer were surveyed to determine their level of burden and distress. Paulina A. et al. (2020) found that 46.19% of caretakers experienced severe burden, 36.2 % of primary caregiver perceived moderate burden, and 17.62 % of caregivers experienced trivial or no burden, lending credence to the findings of the current study that about 54 % of caretakers were having mild to moderate level burden.

When evaluating the severity of psychological distress, A study by Onyechi, K. et al. (2016) found that 15% of caretakers experienced low distress, 59% experienced moderate distress, and 26% experienced severe psychological distress. This finding is consistent with the perception that 10% of carers are experiencing low distress, 64% are experiencing moderate distress, and 26% are experiencing severe distress.

## IMPLICATIONS:

Cancer ward, palliative care, hospital, and community centre nurses can all benefit from using the study's findings as a teaching tool. To better equip caretakers, the nursing administration should implement an in-service education programme as well as continuing nursing education on counselling.

## CONCLUSION:

According to the results, caretakers of cancer patients experience increased stress and strain. The nurse educator has a crucial role to play in easing the emotional and physical strain on caregivers by helping and understanding to meet their loved one's needs.

## ACKNOWLEDGEMENT:

We thank Dr. R. Shankar Shanmugam., PhD., Dsc for his tremendous help and encouragement to perform this study.

## CONFLICT OF INTEREST: Nil

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