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Research Article

Palliative Care on Oncology and Quality of Life of Family Caregivers in Tamilnadu

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ABSTRACT

This study explores the impact of palliative care on the quality of life of family caregivers of oncology patients in Tamil Nadu. As cancer prevalence increases, caregivers face physical, emotional, and financial challenges. This research investigates how palliative care services can alleviate these burdens and improve caregivers' well-being. Using a mixed-methods approach, we conducted surveys and interviews with caregivers across multiple palliative care centers. The results reveal that comprehensive palliative care significantly enhances caregivers' mental health, reduces stress, and improves overall life satisfaction. However, accessibility and awareness of these services remain limited. This study underscores the need for expanded palliative care programs and increased support for caregivers, advocating for policy changes to integrate these services into mainstream healthcare. By highlighting the critical role of palliative care, this research aims to contribute to better outcomes for both patients and their families in Tamil Nadu.

Keywords: Geo-Mapping, Unmet Needs, Advanced Cancer Patients, Caregivers, Healthcare Professionals, Palliative Care, Tamil Nadu.

Introduction

Cancer remains a major public health concern globally, significantly affecting patients and their families. In Tamil Nadu, the burden on family caregivers is profound, as they often provide essential support to oncology patients. Palliative care, aimed at improving quality of life for both patients and caregivers, plays a crucial role in addressing this challenge. Family caregivers face numerous stressors, including emotional strain, physical exhaustion, and financial pressures. These challenges can lead to decreased quality of life, making effective support systems vital. Palliative care offers holistic support that can alleviate these burdens by addressing physical symptoms, providing emotional support, and facilitating better communication between patients and healthcare providers.
Despite its benefits, access to palliative care in Tamil Nadu is limited, with many caregivers unaware of available resources. This study aims to examine the impact of palliative care on caregivers' quality of life, highlighting the need for increased accessibility and awareness of these services. By focusing on the intersection of oncology and caregiver support, this research seeks to contribute to the development of comprehensive care models that improve outcomes for families affected by cancer in Tamil Nadu.

Cancer

Cancer is a singular word that embraces a vast diversity of diseases that can occur in any organ system throughout the animal kingdom. Cancer is a generic term for a large group of diseases that can affect any part of the body. Other terms used are malignant tumours and neoplasms. Cancer has been derived from a Latin word meaning 'crab'.

The ancient association between crab and the disease of cancer developed from the physical resemblance between the legs of a crab and the radiating engorged veins surrounding cancerous tissue. The word itself derives from the two roots 'can' meaning to 'surround' and 'cer' meaning to 'hard'. Cancer arises from one single cell. The transformation from a normal cell into a tumour cell is a multistage process, typically a

progression from a pre-cancerous lesion to malignant tumours. A cancer cell does not obey the complex rules of architecture and function that govern the usual placement and behaviour of cells within a tissue. The body is made up of many types of cells. These cells grow and divide in a controlled way to produce more cells as they are needed to keep the body healthy. When cells become old or damaged, they die and are replaced with new cells. However, sometimes this orderly process goes wrong.

The genetic material (DNA) of a cell can become damaged or changed, producing mutations that affect normal cell growth and division. When this happens, cells do not die when they should and new cells form when the body does not need them. The extra cells may form a mass of tissue called a tumour. Not all tumours are cancerous; tumours can be benign or malignant. Benign tumours aren't cancerous. They can often be removed, and in most cases, they do not come back. Cells in benign tumours do not spread to other parts of the body. Malignant tumours are cancerous. Cells in these tumours can invade nearby tissues and spread to other parts of the body.

Review of Literature

Palliative Care: Palliative care is an approach that improve the Quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2002)

Depression: Depression is specific alteration in mood, whether sadness, apathy or loneliness, a negative self-image involving self-blame, desire for self-punishment, desire to escape, to hide or die, changes in the level of activity, whether there will be increased agitation or hyperactivity or withdrawal and inaction (Beck, 2009)

Anxiety: Anxiety is a multisystem response to a perceived threat or danger. Conditions such as anxiety disorder occur, as people's thinking shifts to themes of defeat, loss or danger. There are certain attitudes that predispose individuals to this negative bias in certain life situations (Beck, 2008)

Methodology

The present study explores the psychological factors affecting Quality of life of caregivers of different cancer patients in palliative care. Self-report measures in terms of Questionnaire and a semi-structured interview were utilized to obtain both quantitative and qualitative analysis. At the starting of the research, the review of literature did not reveal much on psycho-oncology in Indian situation, and very few reviews found on caregivers of cancer patients were on patients undergoing chemotherapy. Based on the review of literature in the field of psycho-oncology the following aim and objectives were framed for the study.

Objectives

1. To assess the impact of palliative care on the quality of life of family caregivers of oncology patients in Tamil Nadu.
2. To identify the key challenges faced by caregivers in accessing palliative care services.
3. To analyze the effectiveness of current support systems and resources available to caregivers.
4. To explore strategies to increase awareness and accessibility of palliative care services among caregivers.
5. To develop policy recommendations to improve integration of palliative care into mainstream healthcare.
6. To investigate cultural factors influencing the acceptance and utilization of palliative care services.

Interview Schedule

A semi-structured interview schedule developed by the researcher to elicit extra information other than the questionnaires was used for the study. The dimensions were awareness about cancer, challenges of caregiving, decision making, experiences in palliative care ward and coping with current situation

Research Design

Between group design is used for the study. Purposive sampling technique was used as the sample was caregivers of different types of cancer patients.

The caregivers were caring for the patients who were in palliative care. The caregivers caring for 6 types of cancer patients namely, Lung cancer, Oesophageal cancer, Gastrointestinal cancer, Breast cancer, Lymphoma and Cervical cancer were taken for the study as the availability of caregivers of these types of cancers were more. The caregivers were with patients who were in palliative care ward throughout the period of hospitalization.

Sample Selection

The inclusion and exclusion criteria followed were as follows:

Inclusion criteria:

1. Primary caregivers caring for patients with cancer of Lung, Oesophageal, Gastrointestinal, Breast, Cervical cancer and Lymphoma
2. Primary caregivers of cancer patients in advanced and limited stage of cancer
3. Caregivers living with patients for past five years
4. Caregivers living in semi-urban and rural areas of Cuddalore district
5. Caregivers caring for patients in palliative ward for more than30 days
6. Caregivers caring for patients who are treated under the government head quarter's hospital in cuddalore, Tamilnadu, India.
7. Caregivers who are able to communicate and read either in Tamil or English language

Exclusion criteria:

1. Caregivers who get respite care
2. Caregivers who have undergone intervention
3. Caregivers of bone marrow transplant
4. Caregivers of Pediatric cancer

Sampling Technique

The sampling technique used in research was purposive sampling. Based on the types of cancer registered in oncology hospital, six types of cancer were taken for the study. The more common type of cancer patients registered as in-patient were patients with lung cancer, oesophageal cancer, gastrointestinal cancer, breast cancer, cervical cancer, and lymphoma. Most of cancer cases were in advanced or limited stage and admitted to palliative ward. As the patient's day to day activity was restricted the primary caregivers were with the patient in the hospital from the day of admission to the day of being discharged. The sample size was based on the availability of cases for a period of 24 months. In the palliative ward the patients of both advanced and limited stage with different types of cancer were admitted. The caregivers stayed with the patient throughout the period of hospital stay. The patients were in palliative ward for minimum period 30 days. Out of 253 caregivers (caring for the 6 types of cancer chosen for the study) approached 20 caregivers declined and 217 caregivers gave their consent to participate in the study. The reasons for declining were: the patient wanted to go back home, out of pocket cost for the caregiver to continue with treatment, the caregivers lost hope about survival of patient.

Analysis and Interpretation

Table: 1- List of Cancer wise Respondents in Tamilnadu

List of Cancer	Number of Respondents	Percentage
Lung Cancer	41	18.89
Esophageal Cancer	23	10.59
Breast Cancer	54	24.88
Cervical Cancer	70	32.25
Lymphoma Cancer	12	5.56
Gastrointestinal Cancer	17	7.83
Total	**217**	**100.00**

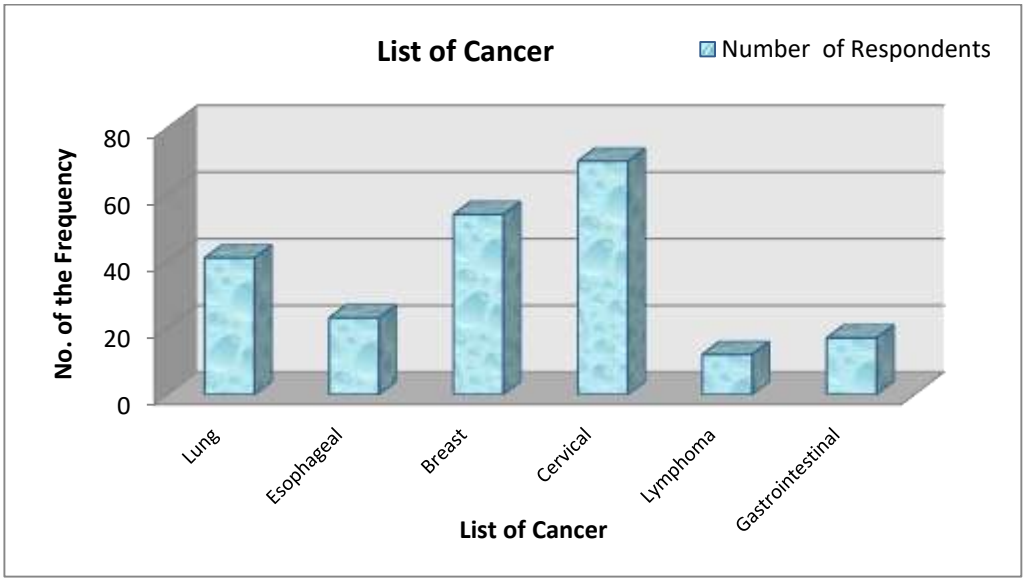

Table: 2- Demographic Characteristics of Caregivers

Demographical Variables	Particulars	Frequency	Percentage
Age (in years)	Below 35	31	14.28
	36 to 45	45	20.73
	46 to 55	103	47.46
	56 and above	38	17.51
Gender	Male	115	53.00
	Female	102	47.00
Educational Qualification	Upto primary	45	20.73
	Secondary	56	25.80
	Higher Secondary	76	35.02
	Graduation and Above	40	18.43
Occupation	Salaried	82	37.78
	Self Employed/Retired	30	13.82
	Home Maker/Unemployed	105	48.38
Religion	Hindu	167	76.95
	Muslim	31	14.28
	Christian	19	8.75
Types of Family	Nuclear	159	73.27
	Joint	58	26.73
Domicile	Urban	147	67.76
	Rural	70	32.25

Table No: 2-shows the demographic characteristics of the caregivers. It indicates that a highest of 47.46 percentages of them belongs to the age group of 46 to 55 years and 20.73 percentages of them belong to the age group of 36 to 45 years. The age group of 56 years and above as represented by 17.51 percentages of the respondents and 14.28 percentages of the caregivers were below 35 years of age of the respondents respectively. The majority of respondents belong to the age wise 47.46 percentages of them belong to the age group of 46 to 55 years. In this study the majority of 53 percent the caregivers were males and 47 percentages of them were females. With regard to the education of the caregivers 35.02 percentages of the caregivers were having education up to Higher Secondary, 25.80 percentage of having respondents are Secondary level,

20.73 percentage of having respondents are Upto primary level and 18.43 percentages of having respondents are Graduation and above level respectively.
The majority of respondents belong to the educational qualification wise 35.02 percentages of them belong to the Higher Secondary level. The caregivers of 48.38 percentages of belong to the Home Maker/Unemployed followed by 82.00 percentages of Salaried and 13.82 percentages of Self Employed/Retired respondents respectively. The majority of respondents belong to the occupations wise 48.38 percentages of belong to the Home Maker/Unemployed. In this study the majority of 76.95 percentages of the caregivers were Hindu religion followed by 14.28 percentages of Muslim and 8.75 percentages of them were Christian. The caregivers who were running nuclear family systems were 73.27 percentages and 26.73 percentages of them belong to joint family system. Majority of 67.76 percentages of the caregivers belong to urban area and 32.25 percentages of them belong to rural area.\

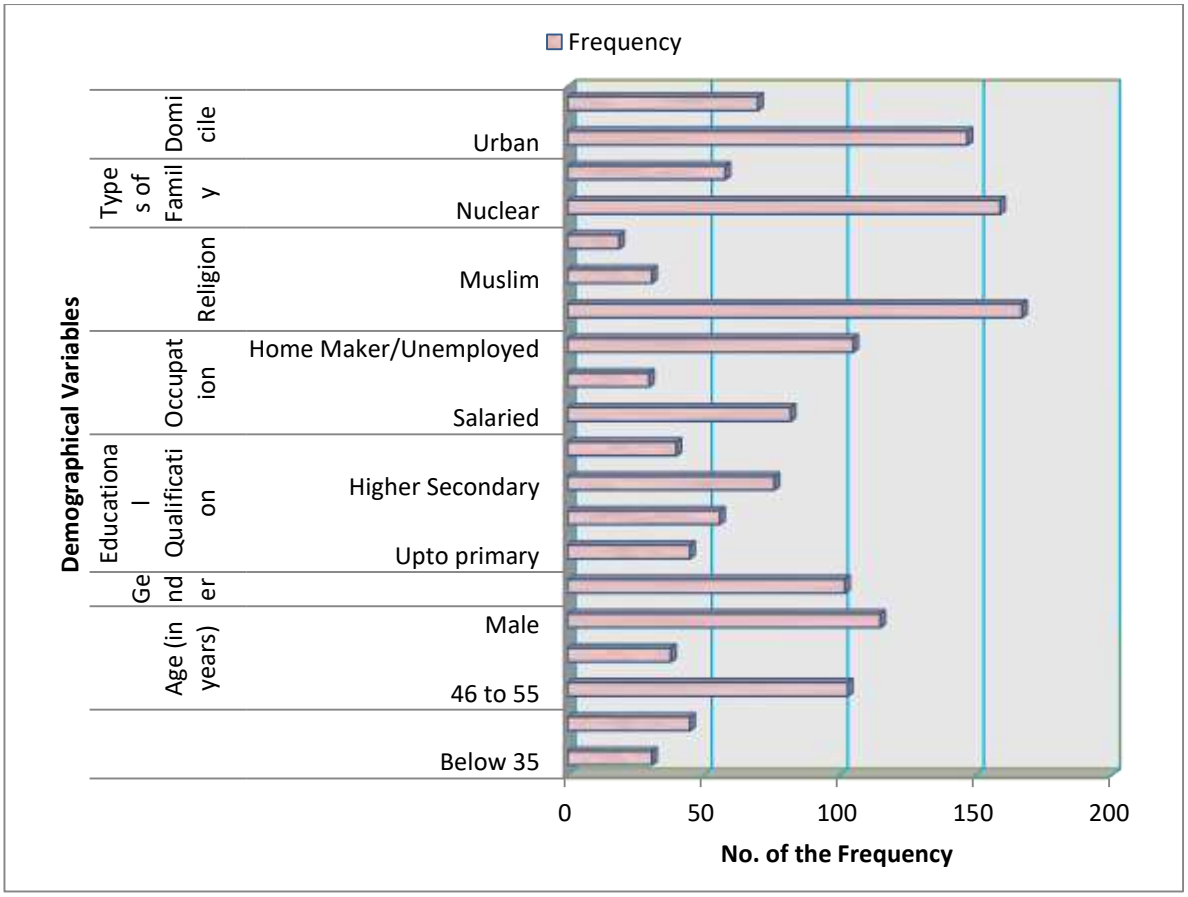

Table: 3 - Caregiver burden among the caregivers

Level of burden	Frequency	Percentage
Mild to Moderate burden	3	1.38
Moderate to Severe burden	112	51.62
Severe burden	102	47.00
Total	217	100.00

Burden among the caregivers is shown in table 3. The burden is measured in terms of quantity and quality by the Zarit burden interview. According to the scores of the each item, overall score has been sorted in to three levels of burden namely “mild to moderate”, “moderate to severe”, and “severe” burden. In the present study it is noted that 51.62 percentages of the respondents reported Moderate to Severe burden and 47.00 percentages of the caregivers felt severe burden in caregiving. Only 1.38 percentages of the caregivers reported mild to moderate burden.

Table: 4 - Distress among the caregivers

Distress	Level	Frequency	Percentage
Level of depression experienced	Normal	45	20.73
	Mild	40	18.43
	Moderate	71	32.71
	Severe	40	18.43

	Extremely severe	21	9.67
Level of anxiety experienced	Normal	51	23.50
	Mild	32	14.74
	Moderate	76	35.02
	Severe	33	15.20
	Extremely severe	25	11.52
Level of stress experienced	Normal	39	17.97
	Mild	42	19.35
	Moderate	67	30.87
	Severe	32	14.74
	Extremely severe	37	17.05

The table 4. Depicts the frequency distribution of caregivers based on their level of depression, anxiety and stress collectively addressed as caregiver distress. Scores for depression, anxiety and stress is calculated by summing the scores for the relevant items in the scale. In the present study it is found that 32.71 percentages of the caregivers experience Moderate depression and 20.73 percentages of them experience normal depression, 18.43 percentages are experiencing Mild and severe level of depression and 9.67 percentages of them have extremely severe level of depression.

In terms of moderate level of anxiety is experienced by majority of 35.02 percentages caregivers and normal level of anxiety is experienced by 23.50 percentages of caregivers. Severe anxiety is found among 15.20 percentages of the caregivers and then 14.74 percentages of caregivers report with mild level of anxiety.

The level of stress among the caregivers show that moderate level of stress is among 30.87 percentages of caregivers and 19.35 percentages of caregivers have mild level of stress. Normal level of stress is among 17.97 percentages caregivers, 17.05 percentages caregivers report with extremely severe level of stress and 14.74 percentages of caregivers in severe level stress.

Table: 5 - Perceived Social Support (PSS) among the caregivers

Domains of PSS	Minimum	Maximum	Mean	SD
Family	4.00	28.00	56.16	9.58
Friends	4.00	28.00	54.45	8.01
Significant Others	4.00	28.00	49.01	8.42

Perceived Social Support among the caregivers was analysed in the table 5 Perceived social support is represented from three sources namely family, friends and significant others. All the three domains of perceived social support-family, friends and significant others found to be at moderate level among the caregivers.

Table: 6 - Coping patterns among the caregivers for positively

Coping patterns	Minimum	Maximum	Mean	SD
Self-distraction	2.00	7.00	6.89	1.92
Active coping	2.00	7.00	6.30	1.63
Denial	2.00	8.00	7.96	1.75
Substance use	2.00	8.00	7.70	1.72
Use of Emotional support	2.00	8.00	7.55	1.29
Use of Instrumental Support	2.00	8.00	6.90	1.96
Behaviour Disengagement	2.00	6.00	5.94	0.76
Venting	2.00	8.00	6.36	0.99
Positive reframing	2.00	8.00	6.95	1.58
Planning	2.00	8.00	6.64	0.98
Humor	2.00	7.00	5.89	1.32
Acceptance	2.00	7.00	5.42	1.02
Religion	2.00	8.00	6.97	1.58
Self-blame	2.00	8.00	6.20	1.07

Coping patterns among the caregivers in the table 6 shows the subscales of coping patterns. The coping patterns are either positive or negative coping methods. The subscales give us an idea of how far the

caregivers have adopted positive and negative coping patterns. In the present study it is found that the positive coping patterns of Self-distraction (M=6.89 ± 1.92), Active coping (M=6.30 ±1.63), Denial (M=7.96 ±1.75), Substance use (M=7.70 ±1.72), Use of Emotional support (M=7.55 ±1.29), Use of Instrumental Support (M=6.90 ±1.96), Behaviour Disengagement (M=5.94 ±0.76), Venting (M=6.36 ± 0.99), Positive reframing (M=6.95 ± 1.58), Planning (M=6.64 ± 0.98), Humor (M=5.89 ± 1.32), Acceptance (M=5.42 ±1.025), Religion (M=6.97 ±1.58), and Self-blame (M=6.20 ±1.07), are found to be moderately used by the caregivers for positively.

It is inferred from the above table that positive coping patterns are adopted quality by the caregivers. Even the copings used minimally also a mixture of positive copings only. This implies that caregivers in the present study are quality vulnerable to positive coping patterns.

Table: 7- Quality of life (QOL) among the caregivers

Coping patterns	Minimum	Maximum	Mean	SD
Physical	2.00	8.00	7.70	1.72
Psychological	2.00	8.00	6.98	1.36
Social	2.00	7.00	5.89	1.32
Environmental	2.00	7.00	5.64	1.06

Quality of life is represented in four domains namely physical, psychological, social and environmental. Table 4 reveal that the Quality of life of the caregivers in the present study. It indicates that quality of life is moderate in Physical domain (M=7.70 ± 1.72), Psychological domain (M=6.98 ± 1.36), Social domain (M=5.89 ±1.32) and Environment domain (M=5.64 ± 1.06). This means that overall quality of life among the caregivers in the study found to be at moderate level only.

Conclusion

This study highlights the crucial role of palliative care in enhancing the quality of life for family caregivers of oncology patients in Tamil Nadu. The findings demonstrate that comprehensive palliative care services significantly alleviate caregiver stress and improve mental well-being. However, challenges such as limited access and awareness persist. To address these issues, it is essential to expand palliative care programs and integrate them into the healthcare system. Raising awareness and providing education about available resources can empower caregivers, ensuring they receive the support needed. By implementing these changes, we can improve the quality of life for caregivers and patients alike, fostering a more compassionate and effective healthcare environment in Tamil Nadu.

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