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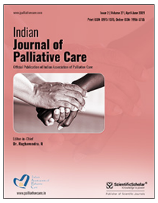

Original Article

Social Issues and Emotional Distress amongst Patients with Cancer Receiving Palliative Care in a Tertiary Cancer Centre

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ABSTRACT

Objectives: Cancer can lead to social isolation as patients and families may withdraw from social activities due to physical symptoms or the emotional distress of the disease. The purpose of the study was to assess the social issues and emotional distress amongst palliative care patients with cancer, to identify the correlation between social issues and emotional distress and to find the association between emotional distress and sociodemographic variables amongst palliative care patients with cancer attending the Department of Cancer Palliative Medicine, Tertiary Cancer Centre.

Materials and Methods: The study used a descriptive survey design with a consecutive sampling technique. Social issues were assessed using a five-point Likert scale that the researcher developed and validated, and emotional distress was measured using the standardised National Comprehensive Cancer Network Distress thermometer scale. The validity and reliability of the rating scale were assessed, and the content validity index is 0.8, and Cronbach's alpha is >0.07, respectively. Between October and December 2023, data were collected from 68 patients with cancer who satisfied the inclusion criteria after obtaining Institutional Ethical Clearance and informed consent from study participants. The data were analysed using descriptive and inferential statistics.

Results: Majority (54.4%) of them were under the age of 60–75 years, 60.3% were men, and 83.3% belonged to a low socioeconomic position. About 2.9% of them had distant metastases, and about 27.9% of them had a primary tumour site in the pulmonary region. Ninety-one percent of survey participants reported experiencing moderate-to-severe emotional distress due to cancer, and around 50% of them felt that cancer was a manageable social issue. On further subanalysis of moderate-to-severe emotional distress, the majority of them faced moderate emotional distress (69.1%), while 25% faced severe emotional distress. In addition, social difficulties and emotional distress amongst cancer patients were found to be significantly correlated ($P < 0.01$; $r = 0.47$).

Conclusion: The study reiterates the fact that social issues have a relationship with emotional distress amongst patients with cancer. Nurses and healthcare workers should take timely efforts to address the underlying issues which result in enhanced patient well-being.

Keywords: Cancer, Emotional distress, Palliative care, Social issues

INTRODUCTION

Palliative care is an interdisciplinary comprehensive approach to symptom management that involves the physical, psychological, social and spiritual care of patients and their families in an effort to maximise quality of life, according to the National Comprehensive Cancer Network (NCCN) Guidelines.[1,2] The above-mentioned guidelines also define cancer distress as a complex, unpleasant experience consisting of psychological, social, spiritual and physical dimensions that can hinder an individual's capacity to cope with the disease, its symptoms and treatment.[3] Emotional distress and social issues in cancer patients are interrelated yet distinct concepts; emotional distress typically refers to the psychological impact of the cancer diagnosis and treatment, such as anxiety, depression and fear, while social issues encompass challenges in interpersonal relationships, social support and societal perceptions that may arise during the illness. Emotional distress can exacerbate social issues by creating withdrawal or difficulty in communication, while social issues may heighten emotional distress by inducing feelings of isolation or stigma.[4] For cancer survivors, psychosocial distress is a pervasive and debilitating burden that not only erodes their quality of life but also has a profound impact on their oncologic outcomes.[3] Social

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and emotional distress in patients with cancer can often manifest in various forms, affecting their overall well-being and quality of life.[5,6] Emotional distress, including anxiety (17%) and depression (8–24%)[7,8] is highly prevalent amongst cancer survivors. As per the National Cancer Institute, mental or emotional distress affects one out of every three patients with cancer.[9] A study by Pandey *et al*. conducted in an Indian cancer hospital found that approximately 25% of cancer survivors experienced anxiety, while about 30% suffered from depression.[10] Studies have also shown that a substantial proportion of survivors also experience post-traumatic stress disorder (7–10%).[11] Socially, many cancer survivors (20–30%)[12] report feeling isolated and disconnected from their social networks. Apart from changes in social roles, the financial burden of cancer treatment can lead to significant stress and changes in lifestyle.[6,13]

The combined impact of social and emotional issues can significantly diminish the quality of life for cancer survivors.[11] These challenges often interrelate, creating a complex web of stressors that can be difficult to navigate. Survivors who experience high levels of emotional distress and social isolation are at greater risk for poorer health outcomes, including reduced adherence to follow-up care and increased risk of recurrence.[14] Comprehensive cancer care not only includes the physical but also the emotional and social needs of patients. The ultimate goal of cancer treatment is to improve the quality of life for patients. Research into these areas can help develop better support systems and interventions that contribute to holistic patient care to ensure that patients with cancer lead fulfilling lives despite their diagnosis. Therefore, this study was undertaken to assess the social issues and emotional distress amongst patients attending the palliative care unit with cancer

MATERIALS AND METHODS

This descriptive cross-sectional study was conducted amongst 68 patients with cancer receiving palliative care in the outpatient department of cancer palliative medicine of a tertiary cancer centre in the State of Kerala, in South India, from October to November 2023. The study was approved by the Institutional Review Board and Institutional Ethics Committee (IEC No. 161/IEC- ERC/13/MCC/22-8-2023) of this Tertiary Cancer Centre. Samples were selected using consecutive sampling techniques, and the sample size was estimated using power analysis, based on the previous study findings[9] and pilot study, and the calculated sample size was 68 (confidence interval of 95). A pilot study was conducted amongst seven patients, and it was found to be feasible. To enhance uniformity in data collection in the interviewer administered structured questionnaire, prior training was given to the data collectors. All the data collectors were gathered together, an informal training was given, and they were instructed regarding the method of administering an interviewer administered questionnaire, to prevent bias. All patients diagnosed with any type of cancer receiving palliative care between 18 and 75 years of age, and those on palliative care treatment for more than 3 months in the cancer palliative unit of the tertiary cancer centre were included in the study. Patients with intellectual deficit or with psychiatric ailments were excluded from the study. A participant information sheet was distributed, and data were collected after obtaining informed consent from the study participants, and the duration was 30 min per participant. The researcher abides by all the ethical prerequisites needed in the collection of data through an anonymous survey. In case any participant experienced significant distress during data collection, remedial measures to handle the situation by a trained psychologist were also arranged. Privacy and confidentiality were ensured throughout the process by refraining from mentioning patients' identities.

Instruments

The demographic and clinical characteristics of the participants (age, gender, employment status, primary site of cancer, metastasis, type of treatment modality, time of diagnosis, etc.) were collected using a questionnaire.

Social issue rating scale

An extensive literature review and discussions with stakeholders were done before the development of the tool on social issues faced by patients with cancer receiving palliative care. Data on social issues were collected using the five-point rating scale, consisting of 16 items, which was developed by the researchers. This scale included four concepts, namely family role changes, financial crisis, social isolation and dependence. Responses to the items in the rating scale were marked as Always (5), Often (4), Sometimes (3), Rare (2) and Never (1) and reverse scoring was done for negative statements. The median score was considered as a cutoff point, and values above and below it were interpreted as an unmanageable social issue and a manageable social issue. Initially, the scale was given for validation to five subject experts, and the content validity index was measured as content validity index: 0.80. The scale was also checked for internal consistency, and reliability was good (Cronbach's alpha: >0.07).

NCCN distress thermometer (DT)

This standardised tool available in the public domain is a one-item, 11-point Likert scale represented on a visual graphic of a thermometer that ranges from 0 (no distress) to 10 (extreme distress) with sensitivity and specificity[15,16] of 98% and 73%. Therefore, this study was undertaken to assess the social issues and emotional distress amongst patients attending the palliative care unit with cancer. The level of distress identifies parameters such as fear of death, hopelessness and disappointment. The individual score value was taken, and overall scores were interpreted based on the standardised cut-off value as mild distress (0–3) and moderate-to-severe distress (4–10).

Statistical analysis

All data were collected and analysed using the Statistical Package for the Social Sciences 21.0. Outliers were removed, and the collected data were cleaned before analysis. Descriptive and inferential statistics were used. Results were presented as frequencies and percentages for categorical variables and as median (minimum and maximum) for continuous variables. Pearson's correlation was used to find the relationship between social issues and emotional distress. The chi-square test was used to find the association of emotional distress with sociodemographic variables.

RESULTS

Demographics of palliative care patients with cancer (*n* = 68)

There was a response rate of 94.4%. Four participants exited the study early on the grounds of apprehension while filling out the questionnaire. In total, 68 patients with cancer participated in this study. The majority of the study participants were between 60 and 75 years of age (54.4%), males (60.3%), unemployed (39.7%) and belonged to below poverty line status (83.8%). Most of them had the primary site of cancer in the pulmonary region (27.9%), had been diagnosed with cancer <5 years (85.3%) and were receiving radiation therapy as their type of treatment [Table 1].

Social issues experienced by palliative care patients with cancer (*n* = 68)

Half of the participants (50%) stated that cancer was a manageable social issue, while the other half (50%) felt that it was an unmanageable social issue [Table 2]. The majority of the participants considered social isolation (62.06%), followed by family roles (57.35%), financial crisis (54.81%) and dependency (54.41%) as manageable social issues [Table 3].

Emotional distress experienced by palliative care patients with cancer (*n* = 68)

The majority of the participants claimed to experience moderate-to-severe emotional distress (94.1%), and only 5.9% of them experienced mild emotional distress [Figure 1]. On subanalysis on moderate-to-severe emotional distress, the majority of them faced moderate emotional distress (69.1%), while (25%) faced severe emotional distress.

Table 1: Distribution of study participants based on demographic and clinical variables (*n*=68).

S. No.	Variables	*n*	%
	Demographic variables		
1.	Age in years		
	18–40	4	5.9
	40–50	9	13.2
	50–60	18	26.5
	60–75	37	54.4
2.	Sex		
	Male	41	60.3
	Female	27	39.7
3.	Occupation		
	Employed	17	25.0
	Unemployed	27	39.7
	Housewife	24	35.3
4.	Socioeconomic status		
	APL	11	16.2
	BPL	57	83.8
	Clinical variables		
5.	Primary site		
	Pulmonary	19	27.9
	Reproductive	15	22.1
	Gastroenterology	15	22.1
	Haematology	4	5.9
	Head and neck	9	13.2
	Orthopaedic	2	2.9
	Nephrology	2	2.9
	Metastasis	2	2.9
6.	Year of diagnosis		
	<5 years	58	85.3
	>5 years	10	14.7
7.	Type of treatment		
	Palliative	56	82.4
	Combined	12	17.6
8.	Subtype of treatment		
	Surgery	8	11.8
	Chemotherapy	21	30.9
	Radiation therapy	37	54.4
	Hormonal therapy	2	2.9

APL: Above poverty line, BPL: Below poverty line

Correlation between social issues and emotional distress experienced by palliative care patients with cancer (*n* = 68)

Social issues were found to be positively correlated with emotional distress ($r = 0.47$; $P < 0.001$) amongst patients with cancer attending the outpatient department of cancer palliative medicine.

Association between emotional distress and sociodemographic variables amongst palliative care patients with cancer (*n* = 68)

There was a significant association found between emotional distress and gender at $P < 0.05$ [Table 4].

DISCUSSION

This study illustrates the complexity of social issues and emotional distress that patients with cancer experience. According to the present study, amongst 68 samples, the majority reported having moderate-to-severe emotional distress. This is congruent with the study findings on psychological distress amongst cancer patients undergoing radiation therapy treatment which showed that out of total of 454 patients, the likely presence of anxiety (hospital anxiety depression scale - anxiety [HADS - A] ≥11), depression (hospital anxiety depression scale - depression [HADS - D] ≥11) and overall psychological distress (hospital anxiety depression scale - psychological distress [HADS - T] ≥15) was 15, 5.7 and 22%, respectively. Another cross-sectional study was conducted amongst 102 cancer patients, and 53.4% of them reported experiencing moderate-to-severe levels of distress.[23] Further findings of the study are substantiated by the findings of a study by Meggiolaro *et al.*[17] that examined emotional distress in 302 patients with cancer and found that the prevalence of emotional distress was 60%. Of those, 26.1% experienced mild distress, 18.8% moderate distress and 14.9% severe distress. Clinically significant emotional distress was observed in the 2nd and 4th weeks of radiation therapy in another study by Lewis *et al.*[18] on distress screening in patients with head-and-neck cancer. Before and 4 weeks following the end of the therapy, lower distress scores were seen. These findings suggest that patients with cancer experience greater levels of emotional distress.

The current study's findings on social issues that patients with cancer experience reveal that most of the study participants (>50%) had faced financial crisis and social isolation, and felt that their family roles had changed severely. These results are consistent with a study by Mithrason *et al.*[19] investigating psychosocial issues in palliative care facilities, which indicated that loneliness was the most prevalent social issue amongst palliative care patients (93.3%). 73.2% perceived it as a severe problem. Fifty percent of the 156 cancer patients with uncontrolled disease status were shown

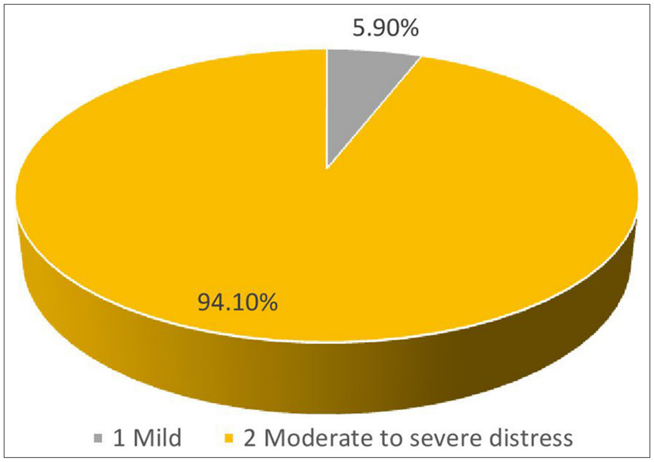

Figure 1: Distribution of study participants based on grading of emotional distress (*n* = 68).

Table 2: Distribution of study participants based on the overall severity of social issues (*n*=68).

S. No.	Severity of social issues	*n*	%
1.	Manageable social issues	34	50
2.	Unmanageable social issues	34	50

Table 3: Distribution of study participants based on the social issues experienced under various domains (*n*=68).

S. No.	Domains	Manageable social issues		Unmanageable social issues	
		n	%	*n*	%
1.	Family role change	39	57.35	29	42.64
2.	Social isolation	36	62.06	32	47.05
3.	Financial crisis	38	55.88	30	44.11
4.	Dependency	37	54.41	31	45.58

Table 4: Distribution based on association between emotional distress with the sociodemographic variables (*n*=68).

S. No.	Variables	*n*	%	Chi-square value	*P*-value
1.	Age in years				
	18–40	4	5.9	1.443	0.695
	40–50	9	13.2		
	50–60	18	26.5		
	60–75	37	54.4		
2.	Sex				
	Male	41	60.3	3.732	0.05*
	Female	27	39.7		
3.	Occupation				
	Employed	17	25.0	2.634	0.858
	Unemployed	27	39.7		
	Housewife	24	35.3		
4.	Socioeconomic status				
	APL	11	16.2	0.032	0.268
	BPL	57	83.8		

*$P<0.01$. APL: Above poverty line, BPL: Below poverty line

to be socially distressed in another study.[6] A similar cross-sectional study by Chino *et al.*[20] showed that 47% of the 174 participants had a significant financial burden. A comparable cross-sectional survey by Delgado-Guay *et al.*[21] revealed that a significant number of patients with advanced cancer reported experiencing severe financial difficulties. These data demonstrate that social issues are highly prevalent amongst patients with cancer and that financial strain and social isolation are more common amongst them. The range and depth of social issues demonstrate that these issues are common, important and need attention.

The current study indicated that amongst cancer patients getting palliative care, social issues had a significant association with emotional distress ($P < 0.001$). These results are consistent with another study by Ebob-Anya and Bassah[22] on the psychosocial distress of cancer patients, which found a significant positive relationship ($P < 0.0001$) between psychosocial and emotional distress.

Gender differences in emotional distress amongst patients with cancer may be very considerable and have indicated, for instance, that women tend to report higher levels of anxiety and depression than men as a result of differences in coping mechanisms, social networks and expectations in society.[23] Cultural factors in Kerala might aggravate these differences; traditional gender roles always provide a lot of responsibilities for women in terms of caregiving and family cohesion, which adds to an emotional burden when facing any health-related crisis, such as cancer.[24] Moreover, societal stigma associated with illness may also affect males' desire to reveal emotional distress, thus under-reporting their struggles.[25] However, in the present study, even though gender and emotional discomfort were found to be significantly associated (P - 0.05), emotional distress was seen more in males. Further study findings are contraindicated by another study in which out of 593 adult patients with cancer, the overall prevalence of psychosocial distress was 63.74% but in this study, being a female cancer patient was statistically associated with psychosocial distress Moreover, in the same study, other factors which were having significant positive association with psychological distress included patients living in rural areas, patients with comorbidity and patients with symptom burden of severe fatigue and nausea which was not evaluated in the current study.

Strengths and limitations of the study

This study, due to its descriptive nature, provided a comprehensive and accurate picture of social issues and emotional distress experienced by palliative care patients with cancer and how it affects their overall well-being was identified. It has also enabled us to get an understanding of the relationship and association between the variables within the data. The present study is also limited in terms of research design and sample size. Due to the cross-sectional design of this study, causality amongst the variables could not be established. The generalisability of the results would have been improved with a longitudinal and qualitative design. This study's subjects were all chosen from a single hospital. It is essential to use more varied sampling techniques to recruit people from a variety of sources to increase the external validity of future research.

Clinical implications

The findings suggest the need to do routine psychological screening in clinical settings for patients with cancer at their pivotal points, which will enable to identify distress and provide counselling interventions that will mitigate emotional distress and enable them to cope effectively during treatment process.

CONCLUSION

The current study has demonstrated the emotional distress and social issues experienced by patients with cancer who attend the palliative care unit of a tertiary cancer care centre in Kerala, India. The study's findings support the frequency of social problems and emotional distress and offer recommendations for improving the psychological and social needs of cancer patients. More interventional studies can be carried out to investigate potential remedies for social issues and emotional distress amongst patients with cancer. There is a need for healthcare providers to routinely assess emotional distress, including anxiety, depression and fear of death, amongst cancer patients. Implementing standardized tools for emotional distress screening by suitable training of health care staff will enable to recognize signs of distress and initiate timely referrals which provide counseling services and other interventions. Coordinated efforts should be made to understand the hidden arena on underlying social issues contributing to emotional distress amongst cancer patients, which will eventually narrow the existing gaps in care amongst cancer patients receiving palliative care.

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