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An observational study of socioeconomic status and demographic profile of advanced cancer patients receiving palliative care in tertiary care institution of Bihar, India

Abstract

Introduction: Access to high-quality healthcare without financial constraints is necessary for inclusive universal health coverage. Low socioeconomic status (SES) individuals have less access to palliative care services. The study was conducted to evaluate the demographics and socioeconomic status of palliative care patients with advanced cancer.

Patients and methods: The prospective observational study included 118 patients with advanced cancer receiving palliative treatment. Their clinical, demographic, and socioeconomic data were collected in predesigned social assessment sheets and medical records. The socioeconomic status was evaluated using the modified Kuppuswamy scale. Descriptive statistics were performed. Student's t-test and Chi-square tests were performed to compare continuous and categorical variables respectively.

Results: Out of the total 118 patients, 71 (60.2%) were females and 47 (39.8%) were males. The mean age of the patients was 49.9 ± 13.9 years. Out of the total study participants, 54 (45.8%) were illiterate. Most of the participants had social insecurities like financial insecurity (n = 50, 42.4%), followed by insecurities regarding the future of the family members (n = 37, 31.4%). The frequency of lung cancer (n = = 30, 25.4%) was the highest among the participants, followed by breast (n = 20, 17%) and gall bladder cancer (n = 15, 12.7%). The mean family income of the patients was Indian Rupees (INR) 10,847.50 ± ± 8,026.30 ($130.61 ± 96.64). Most of the participants (38, 32.2%) belonged to lower middle SES. Type of cancer, social insecurities, and type of caregiver were significantly associated with gender ($p < 0.05$).

Conclusions: The majority of patients and their families were financially limited, and a significant portion of patients expressed financial insecurities and social stress about the future of their families. Gender was significantly associated with a type of cancer, social insecurities, and type of caregiver.

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Introduction

Worldwide, 18 million new cases of cancer were reported in 2018 and 9.5 million cancer patients lost their lives [1]. According to the recent World Health Organization estimates, cancer is the leading cause of death worldwide, accounting for nearly 10 million deaths in 2020. Over 35 million new cancer cases are predicted in 2050, a 77% increase from the estimated 20 million cases in 2022 [2]. In 2016, cancer claimed 813,000 lives in India, making up more than over 8% of all fatalities [3]. In 2020, there were 19.3 million incident cancer cases globally, according to projections from the Global Cancer Observatory (GLOBOCAN). GLOBOCAN projected that 2.08 million cancer cases will be diagnosed in India in 2040, representing a 57.5 percent increase from 2020. Low understanding of symptoms and risk factors, a significant stigma associated with cancer in the community, limited access to healthcare, and high out-of-pocket expenses are all factors that contribute to India's high cancer death rate. A cancer diagnosis has significant effects on households in low- and middle-income nations. In a recent study involving nearly 9,000 cancer patients in Southeast Asia, it was found that 75% of patients had either passed away or faced financial ruin 12 months after diagnosis [1].

With a focus on the patient's physical, psychological, social, and spiritual well-being, palliative care for people with advanced cancer strives to help patients and their families. The continuum of treatment that is required to address the significant burden of serious health-related suffering endured by individuals with chronic noncommunicable illnesses includes palliative care. Palliative care has been highlighted as a crucial aspect of universal health coverage in recent Lancet Commission reports and World Health Assembly resolutions [4]. Equal access to palliative care treatments at the end of life (EOL) for all patients with advanced cancer, regardless of their socioeconomic status (SES), is a key component of universal health coverage. Though many patients with advanced cancer in low- and middle-income countries, particularly those from low SES, suffer poor outcomes at the EOL and believe that their care is of low quality, this is not always the case [5].

Due to the disease and its associated side effects, patients with advanced cancer frequently have low health-related quality of life. It is well established that socioeconomic disadvantage affects cancer diagnosis, treatment, and access to resources, but less is known about how it affects the severity of symptoms in individuals with advanced disease [6]. Socioeconomically disadvantaged cancer patients are more likely to be diagnosed later in the course of the illness, to experience poorer health outcomes, and to succumb to the disease at a higher rate than those who are socioeconomically well off [7]. In the past, research on palliative care inequalities has placed a higher priority on demographics and access to treatment than symptom burden related to socioeconomic variables. When it comes to cost reductions at the home level, which are crucial for patients and families, current methodologies have mostly failed to collect pertinent data from low- and middle-income nations. This study sought to determine the SES, demographics, and frequency of social difficulties that patients with advanced cancer who were getting palliative care experience.

Patients and methods

This prospective observational quantitative research was conducted in the Department of Anesthesiology and Critical Care Medicine, Indira Gandhi Institute of Medical Sciences (IGIMS), Sheikhpura, Patna, Bihar, India.

Ethical approval

The study was initiated after approval from the Institutional Ethical Committee of IGIMS, Patna (672/IEC/IGIMS/2018). The study was conducted by the Declaration of Helsinki. All the participants provided signed informed consent before participating in the study. The informed consent form was explained both in English and in the local language (Hindi) to the participants before taking their signature on them.

Inclusion and exclusion criteria

Advanced cancer patients in palliative care who gave their agreement to take part in the study were included. All cancer types and age groups were included in the study. Patients who did not provide signed informed consent were excluded from the study.

Data collection

In outpatient clinics, a palliative care consultant evaluated the patients and recruited the patients willing to participate for evaluation and analysis. Only the patients who were taking palliative care were included in the study. Demographic and clinical data were collected from the medical records. Participants were evaluated using a self-designed social assessment sheet and a modified Kuppuswamy scale to determine SES. The participants were asked to fill in the assessment sheets. For the patients who did not read or write, the questions were explained in their local language and the responses were filled in the sheets by the first author. The modified Kuppuswamy scale was used to estimate the SES of the participants. The patients were graded into five distinct socioeconomic classes based on their separate scores using the modified Kuppuswamy scale, which uses education, occupation, and monthly family income to determine the socioeconomic scale [8]. The modified Kuppuswamy scale used in the present study applies to both urban and semi-urban populations. The patients were classified into different socioeconomic classes according to their scores on the modified Kuppuswamy scale: 26–29 (upper class), 16–25 (upper middle class), 11–15 (middle class), 5–10 (lower middle class), and < 5 (lower class).

Statistical analysis

Statistical analysis was carried out using STATA (Stata Corp., College Station, TX, USA, Version 17 for Windows). A descriptive analysis was performed. Mean and standard deviations were calculated for continuous variables, while frequencies were used for categorical data. Results were expressed as mean ± SD and percentages as required. Student's t-test was used to compare continuous variables and for categorical variables, Pearson's chi-square test was used. A p-value of < 0.05 was considered statistically significant.

Results

Of the 118 patients included, most of the subjects were females (n = 71, 60.2%). The mean age of the patients was 49.9 ± 13.9 years. Out of 118 participants, 42 (35.6%) were in the 51–60 age group, followed by 25 (21.2%) in the 61–70 group, and 24 (20.3%) in the 41–50 group. Fifty-four (45.8%) patients were illiterate and only 7 (5.9%) subjects were graduates. In most cases, the caregivers were either children (n = 64, 54.2%) or their spouses (n = 46, 39%). The patients enrolled in the study had social insecurities like financial insecurity (n = 50, 42.4%), insecurities regarding family members future (n = 37, 31.4%), progression of disease (n = 23,19.5%), and fear of death (n = 8, 6.8%) (Table 1). Thirty (25.4%) patients had lung cancer, followed by breast cancer (n = 20, 17%) and gall bladder cancers (n = 15, 12.7%) (Table 2).

The mean and median monthly family income of the patients was INR 10,847.50 ± 8,026.30 ($130.61 ± 96.64) and INR 8,000 (range 2,000–30,000), $96.33 (range $24.08–361.23) respectively. Following the administration of the modified Kuppuswamy scale, it was found that 38 (32.2%) of individuals had scores between 11 and 15, indicating that they were from the lower middle SES, 33 (27.9%) were from the upper middle class, and 21 (17.8%) were from the upper class. Twenty-six (22.1%) participants were from a lower class and had scores below 15 (Table 3).

Table 1. Demographic characteristics of the patients (n = 118)

Patient characteristics	Frequency	Percent [%]
Age category		
10–20	7	5.9
21–30	5	4.2
31–40	14	11.9
41–50	24	20.3
51–60	42	35.6
61–70	25	21.2
71–80	1	0.8
Gender		
Male	47	39.8
Female	71	60.2
Qualification		
Illiterate	54	45.8
High school	36	30.5
Intermediate	21	17.8
Graduate	7	5.9
Caregivers of the patients		
Spouse	46	39.0
Children	64	54.2
Parents	8	6.8
Social insecurities of the patients		
Insecurities regarding family members' future	37	31.4
Financial insecurity	50	42.4
Progression of disease	23	19.5
Fear of death	8	6.8

Data were presented as N, %

Association of different demographic and clinical parameters and SES with gender

All the studied parameters were evaluated for their association with gender. Gender is significantly associated with type of caregiver (p = 0.005) (Table 4). Gender is associated significantly with type of cancer (p < 0.001) (Table 5). There was a significant association between gender and social insecurities (p = 0.04) (Table 6). No other studied demographic or clinical parameters were significantly associated

Table 2. Diagnosis of the patients (type of cancer)

Type of cancer	Frequency	Percent [%]
Gall bladder	15	12.7
Breast	20	17
Pancreas	4	3.4
Liver	10	8.5
Ewing	7	5.9
Tongue	10	8.5
Ovary	3	2.5
Lungs	30	25.4
Genitourinary	10	8.5
GIST	4	3.4
Multiple myeloma	2	1.7
Chondrosarcoma	1	0.8
Parotid	2	1.7

GIST — gastrointestinal stromal tumour; data were presented as N, %

Table 3. Socio-economic status of the patients

Kuppuswamy score	SES	Frequency	Percent [%]
26–29	Upper class	21	17.8
16–25	Upper middle	33	27.9
11–15	Lower middle	38	32.2
5–10	Upper lower	12	10.2
< 5	Lower	14	11.9

SES — socioeconomic status; data were presented as N, %

Table 4. Association of gender with type of caregiver

Gender	Caregiver	Frequency	Percent [%]	p-value
Males	Spouse	25	53.2	0.005
	Children	17	36.2	
	Parents	5	10.6	
	Total	47	100.0	
Females	Spouse	21	29.6	
	Children	47	66.2	
	Parents	3	4.2	
	Total	71	100.0	

Data were presented as N, %; Chi-square test was performed to evaluate the association of gender with type of caregiver; p-values less than 0.05 were considered significant

with gender. There was no significant (p = 0.46) difference in the mean monthly income of males (INR 10,170.21 ± 6,907.21) ($122.46 ± 83.17) and females (INR 11,295.77 ± 8,706.98) ($136.01 ± 104.84).

Table 5. Association of gender with type of cancer

Gender	Type of cancer	Frequency	Percent [%]	p-value
Males	Gall bladder	2	4.3	< 0.001
	Breast	1	2.1	
	Pancreas	3	6.4	
	Liver	4	8.5	
	Ewing	5	10.6	
	Tongue	6	12.8	
	Lungs	13	27.7	
	Genitourinary	8	17.0	
	GIST	4	8.5	
	Chondrosarcoma	1	2.1	
	Total	47	100.0	
Females	Gall bladder	13	18.3	
	Breast	19	26.8	
	Pancreas	1	1.4	
	Liver	6	8.5	
	Ewing	2	2.8	
	Tongue	4	5.6	
	Ovary	3	4.2	
	Lungs	17	23.9	
	Genitourinary	2	2.8	
	Multiple myeloma	2	2.8	
	Parotid	2	2.8	
	Total	71	100.0	

GIST — gastrointestinal stromal tumor; data were presented as N, %; Chi-square test was performed to evaluate the association of gender with type of cancer; p-values less than 0.05 were considered to be significant

Discussion

The current study evaluated the SES and demographic profiles of advanced cancer patients receiving palliative care. A considerable number of patients showed social insecurities for their families' future, and most patients and their families were poor socioeconomically. According to the *Global Atlas of Palliative Care*, just 12% of the 57 million people and children who require palliative care are now receiving it [1]. In comparison to their more affluent neighbors, persons who experience socioeconomic hardship spend a greater proportion of their shorter lives

Table 6. Association of gender with social insecurities*

Gender	Social insecurities	Frequency	Percent [%]	p-value
Males	Insecurities regarding family members' future	21	44.7	0.04
	Financial insecurity	16	34.0	
	Progression of disease	9	19.1	
	Fear of death	1	2.1	
	Total	47	100.0	
Females	Insecurities regarding family members' future	16	22.5	
	Financial insecurity	34	47.9	
	Progression of disease	14	19.7	
	Fear of death	7	9.9	
	Total	71	100.0	

*Data were presented as N, %; a Chi-square test was performed to evaluate the association between gender and social insecurities; p-values less than 0.05 were considered to be significant

in poor health and carry a heavier load of chronic diseases, multi-morbidity, and symptom burden. Socioeconomic disadvantage is a risk factor on its own for greater mortality in populations with and without cancer and is linked to higher healthcare utilization and expenditures in the last year of life [9].

Cancer presentation and diagnostic delays can be influenced by socioeconomic circumstances, and patients in more socioeconomically deprived locations are less likely to be referred to hospice care services [10]. It has been discovered in the past that low-SES individuals experience greater delays in upper gastrointestinal tumor symptom recognition and primary care visitation. According to a study by Bus et al. [11], low-SES individuals had more comorbid conditions and were diagnosed at older ages and with more advanced tumor stages. Even with comorbidities, tumor stage, and age adjustments, high-SES individuals still had a greater chance of receiving curative therapy. After age, tumor stage, histology, and location were taken into consideration, high SES also had a favorable impact on life expectancy in the palliative group [11]. According to a comprehensive analysis, cancer patients in lower socioeconomic categories had a much lower likelihood of passing away at home and faced greater obstacles to receiving palliative care [12, 13]. According to some data, using specialized palliative care may change how socioeconomic status affects the site of dying [14]. Low SES is a risk factor for hospital deaths in high-income nations, according to another systematic study, as well as other signs of possibly subpar end-of-life care [6].

Socioeconomic status significantly affects the treatment rates and survival in cancer patients [11]. Studies by Dreyer et al. [15] and Guadamuz et al. [16] have highlighted that cancer patients belonging to low SES were less likely to receive treatments and showed reduced survival. Low SES individuals with pancreatic cancer were shown to be less likely to receive surgical therapy. Esophagectomy was observed to be performed more frequently on high-SES patients with esophageal cancer than on low-SES individuals. In contrast to cancer patients from higher SES groups, low SES cancer patients are more likely to experience higher mortality, depression, and other comorbidities, as well as a greater burden of symptoms [5]. Low SES cancer patients are also less likely to obtain palliative care and die at home [17]. According to a meta-analysis, patients with advanced cancer had the largest unmet requirements in the areas of information, patient care and support, and physical, psychological, and daily living activities [6]. In general, cancer patients with low SES are more likely than their better-off peers to report unmet requirements. Socioeconomic factors can affect how a patient is treated. According to a Canadian study of 34,022 patients with advanced gastrointestinal cancer, those who lived in the most disadvantaged areas were significantly less likely to receive radiotherapy and/or chemotherapy after receiving a diagnosis [10]. In contrast to two studies that indicated low SES cancer patients were more likely to use home-based hospice care services, another research revealed that low SES cancer patients were less likely to obtain hospice care during EOL therapy [12, 13, 18]. According to Kumar et al. [17], the majority of patients and their families had financial resource limitations, and a sizable portion of patients experienced social uneasiness over the welfare of future generations.

Financial insecurity (42%), family member future insecurity (31%), sickness progression (19.5%), and dread of death (7%) were the main social issues in the research scenario [19]. Most of the worries raised by Wright et al.'s [20] investigation were supported by these observations. Palliative treatment was more frequently preferred by women than by males. In the following analysis, female representation was greater than male representation, which is consistent with the reports of Wright et al. [20] and Saeed et al. [21]. Saeed et al [21] found that elderly persons had a lower tendency than younger adults to favor palliative care. In the following study, most participants were in the older age groups, with more than 50% being over 50, while adolescents and young children were scarcely represented.

Patients with higher financial hardship ratings had worse functional well-being, lower emotional well-being, higher anxiety, and higher depression scores, according to Jacob and colleagues [3]. Socioeconomic status was shown by few studies as an independent risk factor for death in cancer patients [22]. According to research by Hapuarachchi et al. [5], patients with low SES reported lower physical, emotional, spiritual, and social EOL outcomes than those with high SES [5]. Following a diagnosis of advanced cancer, poor households in low-income countries are exposed to catastrophic health-related expenses, according to a prospective cohort research by Bates et al. [1]. According to a systematic review conducted by Parajuli et al. [23], cancer patients with low SES are less likely to use palliative services.

It is widely recognized that the characteristics and experiences of individuals accessing palliative care services can vary significantly due to diverse factors, including geographic location, SES, and the organization of healthcare systems. Notably, patients receiving palliative care in developed countries may manifest distinct demographic profiles, disease trajectories, and care needs compared to those in less developed regions [24, 25]. In developed nations, where there tends to be better SES and more structured healthcare infrastructure, patients seeking palliative care may present with unique features. These differences may stem from factors such as enhanced healthcare accessibility, increased awareness and acceptance of palliative care services, and elevated overall standards of living. Acknowledging these potential disparities is crucial when interpreting research findings or devising interventions aimed at enhancing palliative care provision. Tailoring approaches to accommodate the specific requirements and contexts of patients within varying socioeconomic and healthcare settings is essential for promoting equitable access to and quality of care.

Since the study was focused only on the patients of Bihar which is an Eastern Indian state, the findings cannot be generalized to the whole country. Therefore, large multi-centric studies including patients from all the geographical regions of India should be conducted to understand the overall scenario of the country. Another limitation of the study is the small sample size. Further studies with larger sample sizes should be conducted to substantiate the findings of the present study.

Conclusions

Most patients and their families had financial difficulties, and many patients were socially insecure about what would happen to their loved ones following their death. In addition, it was observed that type of cancer, social insecurities, and type of caregiver were significantly associated with gender. The authors advocate for equal access to palliative care treatments for all advanced cancer patients, regardless of their SES.

Article information and declarations

Data availability statement

None.

Acknowledgments

None.

Ethics statement

The study was initiated after approval from the Institutional Ethical Committee of IGIMS, Patna (672/IEC/IGIMS/2018). The study was conducted by the Declaration of Helsinki. All the participants provided signed informed consent before participating in the study. The informed consent form was explained both in English and in the local language (Hindi) to the participants before taking their signature on them.

Author contributions

Patient recruitment, conceptualization, data collection, and analysis — MH; data analysis and drafting of the manuscript — PK, VKV, NA.

Conflict of interest

The authors declare no potential conflicts of interest concerning the research, authorship, and/or publication of this article.

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Supplementary material

None.

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