

Original Research Article

Exploring Factors Influencing Cancer Patients' Understanding of Diagnosis, Prognosis, and Emotional Well-being under Palliative Care: A Cross-sectional Investigation

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Article History

Received: 03.02.2024

Accepted: 10.03.2024

Published: 15.03.2024

Journal homepage:

<https://www.easpublisher.com>

Quick Response Code

Abstract: Introduction: The demographic characteristics of cancer patients correlate with their awareness of diagnosis, prognosis, and the psychological distress associated with their condition. **Objectives:** The purpose of this study was to evaluate patients' knowledge of psychological distress, diagnosis, and prognosis who were presenting to the palliative medicine department of a tertiary hospital in Bangladesh. **Methodology:** This cross-sectional study was conducted among 377 patients living with cancer attending the Department of Palliative Medicine, Bangabandhu Sheikh Mujib Medical University, Bangladesh from November 2021 and March 2022. Information on the clinical and sociodemographic aspects was gathered through a structured questionnaire and in-person interview, and the degree of distress was measured using a distress thermometer. After information was gathered, descriptive statistics were used to analyze it. **Result:** Approximately 16.2% of patients were unaware of their diagnosis, with two-thirds (68%) lacking awareness of prognosis. Over half (54.1%) reported significant distress. Gender, education, employment status, and head-and-neck cancer diagnosis were linked to diagnosis awareness, while educational level predicted prognosis awareness. Younger age, head-and-neck or hematological cancer diagnosis and lack of awareness regarding diagnosis and prognosis were associated with distress. **Conclusions:** Higher education and socioeconomic status correlate with patients' awareness of diagnosis and prognosis. However, distress remains higher among those unaware of prognosis. **Keywords:** Cancer; sociodemographics; diagnosis; prognosis; distress; palliative care.

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INTRODUCTION

In 2008, cancer killed 7.6 million people, or 13% of all deaths worldwide. Low- and middle-income countries accounted for roughly 70% of all cancer deaths. Cancer deaths worldwide are expected to increase to more than 13.1 million by 2030 [1]. The American Cancer Society predicts that nearly 1,600 Americans will die from cancer each day. In the United States, cancer remains the second leading cause of death after cardiovascular disease, accounting for nearly one in every four deaths. The American Cancer Society

estimates that 1,638,910 new cases of invasive cancer will be diagnosed in the United States in 2032 [2]. Cancer is one of the third leading causes of death in developing countries, and these countries have experienced the greatest increase in cancer disease incidence rates. Cancer, once thought to be a 'rich world' disease, is now a growing public health threat in developing countries. People have limited access to information on how to detect early signs of various cancers. Those seeking treatment often have few options. Medication is expensive. There are only a few facilities, and they are

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overcrowded. The numerous stigmas associated with the disease make things even more difficult [3].

Distress in cancer patients can be caused by a variety of factors. According to studies, cancer-related distress is more prevalent among women and those with low levels of education [4,5]. People with limited education reported advanced-stage cancer at presentation [6]. Chronic diseases, such as cancer, necessitate ongoing monitoring, which can be difficult for patients and their families to manage when they already have financial difficulties [5]. Financial constraints were reported to be one of the primary reasons for the delay in seeking help despite cancer suspicions in Bangladesh [6]. The location of stay also influences the level of distress and awareness of diagnosis and prognosis. Patients from remote/rural areas frequently present to hospitals at advanced stages of disease [7]. Knowledge of the diagnosis and prognosis has been identified as a significant predictor of distress in cancer care settings. However, disclosing a diagnosis to patients or caregivers is not always possible in a country like Bangladesh due to cultural factors and the stigma associated with the diagnosis [8]. Caregivers in Bangladesh withhold information about the diagnosis and prognosis from patients in order to reduce their distress. Caregivers believe that disclosing a patient's diagnosis and prognosis may have a negative impact on their illness, causing stress, depression, and a loss of hope and confidence [9].

Furthermore, cultural factors appear to influence the practice of disclosing a cancer diagnosis and prognosis to the patient. Although there is a wealth of literature on the factors that contribute to cancer patients' distress, there is a scarcity of reliable data linking demographic factors to awareness of diagnosis and prognosis [10, 11]. This retrospective study examined the relationship between demographic factors and knowledge of diagnosis, prognosis, and levels of distress among cancer patients.

METHODOLOGY

In a Bangladeshi tertiary care hospital, a cross-sectional descriptive study was carried out with the goal of researching and treating cancer. For our study, we enrolled patients over the age of eighteen who had

received a cancer diagnosis but had not yet begun treatment. Prior to the interview, the participants gave their written consent. The research was done between November 2021 and March 2022.

A total of 377 patients were progressively selected from the hospital's out-patient department, regardless of their treatment plan, cancer stage, or treating physician. The study excluded patients who were too sick to participate or who could not understand the questionnaire. A semi-open-ended, self-prepared questionnaire was given to study participants in order to obtain their clinical and sociodemographic information. After three months, all of the individuals who were recruited were re-interviewed to gather information about their treatment regimen and any complications that may have arisen. The Statistical Package for the Social Sciences (SPSS) program (version 28.0, released 2011, IBM Corp., Armonk, New York, USA) was used to enter and analyze the data that were gathered. The clinical and sociodemographic variables were compiled using percentages and frequencies. To determine the relationship between sociodemographic factors and knowledge of diagnosis, prognosis, and DT score, a chi-square test was used. All analyses were conducted with a significance level of $P < 0.05$.

The Hospital's Institutional Ethics Committee granted permission to conduct the study.

RESULT

Sociodemographic characteristics: Of the 387 cancer patients who visited the OPD at BSMMU during the study period, 10 were excluded because they were minors (under the age of 18), leaving 377 for analysis. The sociodemographic characteristics are summarized in Table 1. More than half of the patients (53.4%) were male, with 69.5 percent aged 41 to 65 years. The patients' mean age was 53.78 years (standard deviation ± 12.79). Approximately 47.5% of patients had completed their secondary education, while 23% had received no formal education. Among the patients, 56.4 percent did not have a job, and 57.9 percent were from cities. In our cohort, head and neck cancer (21.4%), breast (19.4%), and gastrointestinal (17.5%) cancers were the most frequently reported diagnoses; for nearly 56.4% of patients, the monthly income was less than BDT 10,000.

Table 1: The demographic profile of patients (n=377)

Sociodemographic Factor	Categories	n=377	Percentage (%)
Age (in years)	18-40	55	14.6
	41-65	262	69.5
	60 and above	60	15.9
Gender	Male	201	53.6
	Female	176	46.6
Place of Residence	Inside Dhaka	217	57.4
	Outside Dhaka	160	42.6
Marital Status	Married	212	80.6
	Unmarried	146	5.8

Sociodemographic Factor	Categories	n=377	Percentage (%)
	Widowed	19	13.7
Education Status	No formal education	86	22.8
	Primary level	78	20.7
	Middle school	153	40.5
	High school	26	7
	Graduation	34	9
Occupation	Employed	165	43.6
	Unemployed	212	56.4
Monthly family income	Up to 10,000	212	56.4
	11,000-20,000	101	26.7
	21,000-30,000	37	9.7
	>30,000	27	7.3
Cancer types	Head and neck	81	21.4
	Breast	56	19.4
	Lung	35	9.4
	Gastrointestinal	66	17.5
	Gynaecology	37	9.7
	Haematology	12	3.2
	Unknown primary	19	5.3
	Others	71	18.7

Knowledge of diagnosis and prognosis, as well as the prevalence of distress: The DT scores had a median value of 5 (range 0 to 10). Of the patients, 54.1%

reported moderate-to-severe distress. 83.2% of patients said they aware of their diagnosis, but 57.9% unaware of their prognosis (Figure 1).

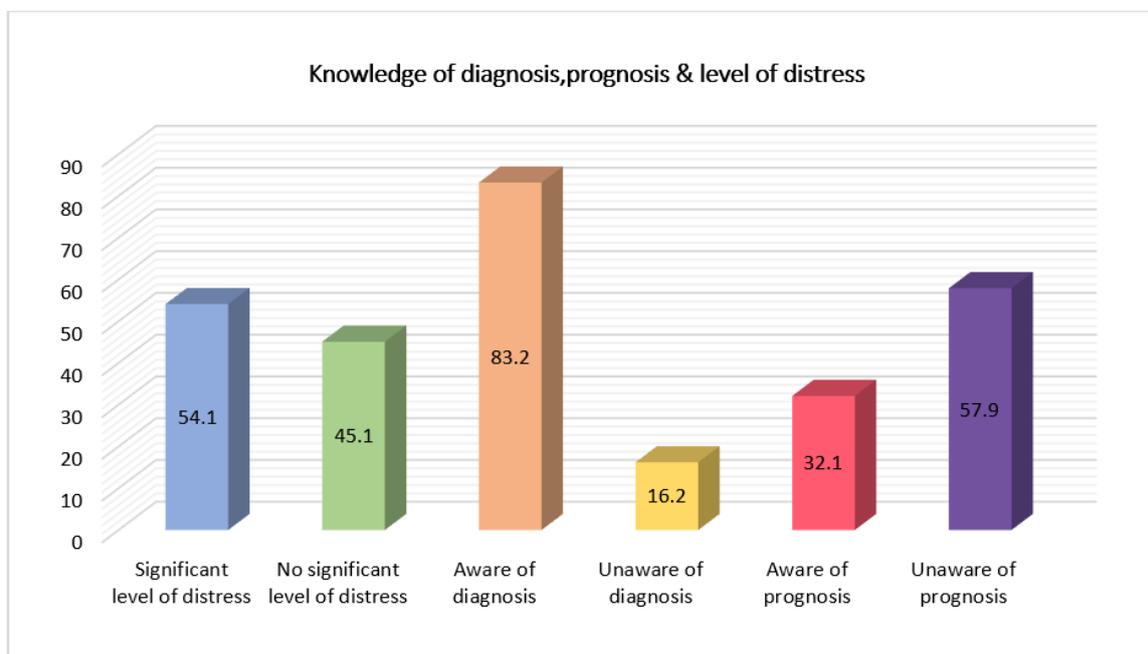


Figure 1: Prevalence of distress and knowledge of diagnosis and prognosis

Relationship between demographic traits and awareness of the diagnosis, prognosis, and degree of distress:

Sociodemographic variables such as gender (χ^2 (1) = 9.59, $P < 0.01$), education (χ^2 (4) = 36.82, $P < 0.001$), disease type (χ^2 (7) = 30.10, $P < 0.001$), and prognosis knowledge (χ^2 (1) = 65.27, $P < 0.001$) were significantly correlated with diagnosis knowledge. Prognosis knowledge was substantially correlated with sociodemographic factors such as income (χ^2 (3) =

15.10, $P < 0.01$), occupation (χ^2 (1) = 4.44, $P < 0.05$), and education (χ^2 (4) = 32.16, $P < 0.001$). Age (χ^2 (2) = 6.24, $P < 0.05$), disease types (χ^2 (7) = 14.31, $P < 0.05$), diagnosis knowledge (χ^2 (1) = 3.28, $P < 0.05$), and prognosis (χ^2 (1) = 11.91, $P < 0.001$) were the sociodemographic variables that were significantly correlated with distress. Table 2 shows that there was no significant correlation ($P > 0.05$) between distress and other sociodemographic variables.

Table 2: Exploring the Relationship Between Demographic Characteristics and Understanding of Diagnosis, Prognosis, and Distress Levels

Variables	Knowledge of diagnosis			Knowledge of prognosis			Distress score		
	Aware, n (%)	Unaware, n (%)	P	Aware, n (%)	Unaware, n (%)	P	<4, n (%)	≥4, n (%)	P
Age									
18-40	48 (15.2)	7(11.1)	0.097	22(18.2)	33 (12.9)	0.090	20(11.3)	36(17.4)	0.0444
41-65	220 (70.2)	42(66.1)		83(68.6)	179(69.9)		123(71.1)	139(68.1)	
60 and above	46 (76.6)	14 (22)		16(13.2)	44 (17.2)		30(17.6)	29(14.5)	
Gender									
Male	176 (56)	25 (40.9)	0.001	69 (57)	132(51.6)	0.101	94(54.3)	107(52.5)	0.301
Female	138 (44)	38 (59.1)		52 (43)	124(48.4)		78(45.4)	98(48)	
Location									
Inside Dhaka	182 (57.9)	34 (55.1)	0.315	68(56.6)	148(57.8)	0.408	94(54.3)	123(60)	0.006
Outside Dhaka	133 (42.1)	28 (44.9)		53(43.4)	108(42.2)		79(45.7)	81(40)	
Education									
No formal education	63 (16.5)	23(36.2)	<0.001	20 (5.1)	67 (26)	<0.001	44(25.4)	42(20.6)	0.428
Primary level	58 (15.2)	20(31.5)		21 (5.6)	56 (22.1)		36(20.5)	42(20.6)	
Middle school	138 (36.1)	15 (24.4)		50(13.1)	103(40.2)		65(37.6)	88(42.9)	
High school	24 (6.4)	2 (3.9)		10 (2.7)	16 (6.2)		12(6.6)	15(7.4)	
Graduation	31 (8.2)	3 (3.9)		20 (5.2)	14 (5.5)		17(9.8)	16(7.9)	
Occupation									
Unemployed	176 (56.1)	36 (57.5)	0.43	62(50.8)	151(59)	0.021	100(57.5)	113(55.4)	0.304
Employed	138 (43.9)	27 (42.5)		59(49.2)	105(41)		73(42.5)	91(44.6)	
Income									
Up to 10,000	177(56.3)	36(56.7)	0.552	64(52.9)	149(58)	0.002	94(54)	119(58.3)	0.647
11,000-20,000	84 (26.6)	17 (26.8)		28(23.1)	72(28.3)		49(28.6)	51(25)	
21,000-30,000	29 (9.3)	7 (11.8)		15(12.2)	22(8.6)		18(10.1)	19(9.3)	
>30,000	24 (7.8)	3 (4.7)		14(11.8)	13(5.1)		12(7.2)	15(7.4)	
Types of cancer									
Head and neck	74 (23.6)	6 (10.2)	0.001	26(21.5)	55(21.3)	0.336	40(19.6)	41(23.4)	0.046
Breast	48 (15.2)	9 (13.4)		20(16.9)	35(13.9)		30(15)	25(14.7)	
Lung	29 (9.3)	6 (10.2)		11(8.9)	26(10.5)		20(9.8)	16(9)	
Gastrointestinal	52 (16.6)	14 (22)		20(16.1)	46(18.2)		34(16.9)	31(18.2)	
Gynaecology	30 (9.7)	6 (9.4)		12(10.3)	24(9.4)		19(9.1)	18(10.4)	
Haematology	11 (3.4)	2 (2.4)		3(2.5)	9(3.5)		3(1.7)	9(5)	
Unknown	11 (3.4)	8 (12.6)		5(3.7)	15(6.1)		12(5.6)	9(5.17)	
Others	59 (18.7)	12 (18.9)		26(21.9)	44(17.2)		45(22.3)	25(14.5)	
Knowledge of diagnosis									
Unaware	-	-		1(0.8)	63(24.4)	<0.001	25(14.2)	39(19.1)	0.043
Aware	-	-		120(99.2)	193(75.6)		148(85.8)	165(80.9)	
Knowledge of prognosis									
Unaware	-	-		-	-		129(74.3)	128(62.5)	<0.001
Aware	-	-		-	-		45(25.7)	75(36.9)	

DISCUSSION

This study used a cross-sectional study design to identify sociodemographic and other factors associated with awareness about cancer diagnosis, prognosis, and distress. More than half of the cancer patients said they were in moderate-to-severe distress and had no idea what their chances of recovery were. Distress was significantly correlated with gender, education, cancer type, and diagnosis knowledge. The type of disease, education level, and gender all had a substantial impact on diagnosis knowledge. However, there was a significant correlation found between prognosis knowledge and sociodemographic factors like

income, occupation, and education. Distress factors included being younger, having cancer of the head and neck, having hematological malignancy and not knowing the diagnosis or prognosis.

According to our study, a majority of the patients had inadequate knowledge of their prognosis and were experiencing moderate-to-severe distress. Twenty-two to fifty percent of cancer patients in Bangalore reported experiencing a significant degree of distress, according to a study by Bandiwadaker *et al.*, [12]. This research found that patients with head and neck and hematological cancers, aged 18 to 40, who were

not informed about their diagnosis or prognosis, had higher adjusted odds of experiencing distress. The results of a previous cross-sectional study [13] are consistent with this age-related lung cancer finding.

Prognosis ignorance was common in our study, as it has been in previous research. Prognosis and treatment details are rarely shared in Bangladesh [14]. Although Applebaum *et al.*, [15] reported that patients in Bangladesh were frequently not given the details of their prognosis, Ghoshal *et al.*, [9] reported that patients actually preferred to know treatment details. This was thought to be because of the interdependence of family members and respect for elders.

Men were more cognizant of their diagnosis, according to our study. Frequently, a male member is informed about the diagnosis or prognosis first, particularly in India [16]. Some research indicates that women who have advanced cancer tend to understand their conditions better than men do. This is linked, in contrast to men, to the more in-depth conversations women have with their families about their diagnoses [17, 18]. Different cultural backgrounds could be the cause of the variation in results. Women are frequently discouraged by men in Bangladesh and India from talking to doctors and other healthcare providers about their health issues. In addition, because they are doubtful of women's emotional fortitude, they might withhold the information [19].

There is unquestionably a strong correlation between diagnosis knowledge and age. The younger age group was not aware of the diagnosis, according to this study. Similar results were obtained by Cartwright *et al.*, [20] in a focus group study, wherein they reported that patients frequently did not comprehend the prognostic information that was provided to them and would have preferred not to know, and that there was no agreement between the explanation provided by the healthcare provider and the patients' comprehension.

Consistent with previous research [9], our investigation revealed that patients lacking formal education or with low educational attainment (<8th standard) possessed inadequate or nonexistent understanding of diagnosis and prognosis. Even though they received their diagnosis and treatment in a cancer center, our patients didn't seem to comprehend what cancer meant or how serious it was. The majority of patients whose educational attainment was below middle school experienced severe distress. As other researchers have shown, inadequate diagnosis knowledge results in low life quality, anxiety, depression, and distress [5, 21]. According to a study by Engelman *et al.*, [22], the population's lack of knowledge and education contributed to uncertainty regarding the diagnosis, which in turn raised distress levels.

In our study, people from low-middle socioeconomic backgrounds knew very little about their prognosis and very little about their health. Similar findings were made by other researchers, who noted that because they were the only family provider and in poor financial standing, the poorer people did not report to hospitals even when their conditions were early [6]. This result was supported by a study by Fagundes *et al.*, [21], which also found a link between the severity of depression and low socioeconomic status. Compared to their male counterparts, female patients in our study experienced marginally less significant distress; however, Jacobsen *et al.*, [23] reported that women perceived more distress because of emotional, familial, and physical issues.

This research had certain restrictions. First off, patients with pediatric cancer—especially those in their teen years—were not included in our analysis. Secondly, the research did not explore the specification of distress, making a thorough analysis impossible.

CONCLUSION

This study demonstrates the relationship between sociodemographic characteristics and distress level as well as diagnosis and prognosis knowledge. Patients had a general understanding of the diagnosis, but they had little in-depth understanding of the prognosis. Patients were more likely to be aware of their diagnosis and prognosis if they were male, had greater educational attainment, and had a higher socioeconomic status. The higher degree of distress was linked to not knowing the prognosis. The results of this study highlight the importance of telling patients their prognosis; medical professionals should be required to complete professional training on cancer communication in order to ensure that patients and their families receive enough informational support. Additional research on the obstacles to telling patients the news and the specific source of their distress may shed more light on the required intervention.

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Cite This Article: Sabikun Naher Urmy, Shah Noor Sharmin, Rahat Noor, Md. Shaidur Rahman, Mossa. Nupur Aktar, Fahmida Sultana, Kazi Sanzida Haque, Rakiba Sultana (2024). Exploring Factors Influencing Cancer Patients' Understanding of Diagnosis, Prognosis, and Emotional Well-being under Palliative Care: A Cross-sectional Investigation. *East African Scholars J Med Surg*, 6(3), 99-104.