Factors associated with knowledge of diagnosis, prognosis & distress in cancer patients receiving palliative care – A retrospective cohort analysis

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Background & objectives: Demographic attributes of cancer patients are associated with the awareness of diagnosis, the prognosis of cancer and their associated psychological distress. This study was aimed to assess the knowledge of diagnosis, prognosis and psychological distress among patients reporting to the pain and palliative care department in a tertiary cancer hospital, south India.

Methods: Data of all patients visiting the palliative care outpatient department of a tertiary cancer centre in south India between January and June 2018 were included in the study (n=754). A structured pro forma was used to collect information on the sociodemographic details and clinical aspects and a distress thermometer was used to assess the level of distress. Information, thus collected, were analysed using descriptive statistics and logistic regression.

Results: Around 16.2 per cent of the patients were unaware of their diagnosis while two third (68%) were unaware of the prognosis. More than half of the patients reported significant distress (54.1%). Gender, education, not working and being diagnosed with head-and-neck cancers were associated with knowledge of diagnosis, while educational level predicted the knowledge of prognosis. Younger age group, head-and-neck cancer, haematology cancer, state of being unaware of diagnosis and prognosis were found to be associated with distress.

Interpretation & conclusions: Higher educational levels and better socio-economic status increase the likelihood of patients being aware of their diagnosis and prognosis. Being unaware of the prognosis remains associated with the higher level of distress.

Key words Advanced cancer - demographics - diagnosis - distress - palliative care - prognosis

According to the World Health Organization (WHO) report, cancer is the second leading cause of death globally and was responsible for an estimated 10 million deaths in 2020[1]. An estimated number of cancer cases in India for the year 2022 was found to be 14,61,427[2]. In Tamil Nadu (a southern State in India), about 93,536 new cases were registered and 50,841 deaths occurred in 2022[3,4]. The higher cancer incidence and poor prognosis in lower- and middle-income countries like India are attributable to lack of education,

late diagnosis, inequitable access to affordable curative services leading to financial burden, insufficient policies of the government and lack of awareness about treatment options[5]. There is also substantial variability in the type of treatment available across various states in India[6].

Distress in a cancer patient is attributable to numerous factors. Studies have shown that distress due to cancer is greater among women and those with low levels of education[7,8]. People with low levels of education reported advanced stage cancer at presentation[9]. Chronic diseases such as cancer require continued follow up, which in the scenario of pre-existing financial problems makes it difficult for patients and their families to cope[8]. In India, financial constraints were reported to be one of the main reasons for the delay in seeking help despite suspicion of cancer[9]. The place of stay also causes the difference in the level of distress and the awareness of diagnosis and prognosis. Patients who live in remote/rural areas often report to hospitals at an advanced stage of disease[10].

The knowledge of the diagnosis and prognosis has been reported as a strong determinant of distress in the cancer settings. However, the opportunity of disclosing a diagnosis to patients or caregivers is not always feasible in a country like India, due to cultural factors and stigma attached to the diagnosis[11]. Caregivers in the Indian setting withhold information regarding the diagnosis and prognosis from the patients to buffer their distress. Caregivers believe that disclosing the diagnosis and prognosis may affect a patient's illness negatively resulting in stress, depression, loss of hope and confidence[12]. In addition, cultural factors also seem to play a role in the practice of disclosure of diagnosis and prognosis of cancer to the patient. Although there are extensive literatures on the factors contributing to distress among cancer patients, reliable data linking demographic factors with awareness on diagnosis and prognosis is limited[13,14]. This retrospective study was undertaken to analyse the relationship of demographic factors with the knowledge of diagnosis, prognosis and levels of distress among cancer patients.

Material & Methods

Design and sampling: This retrospective study was conducted at the outpatient department (OPD) of Pain and Palliative Care (PPC), Cancer Institute (WIA), Chennai, Tamil Nadu, India, a tertiary cancer centre in south India. Demographic data were obtained from the electronic medical records (Indian Cancer Registry (IcanR) - an online database of JivDaya foundation - an NGO that was funding palliative care at cancer institute) of patients with cancer, irrespective of diagnosis and stage of the disease. All consecutive patients, who attended the OPD during January through June 2018, were included.

Data variables, sources of data and data collection: Data were collected from the patients (older than 18 yr) visiting PPC OPD during the study period, using a structured case record form (CRF) of IcanR, which was developed and validated with the help of subject experts. All the assessments were conducted directly with the patients during their first visit to the PPC OPD by a trained social worker who was part of the PPC and were documented. Although the data were collected on the first visit to the PPC clinic, the patients were under prior hospital care for other modalities of treatment. The IcanR is a private database developed exclusively by Jiv Daya for tracking and documenting the patients from hospitals collaborating with the foundation. The CRF of the IcanR contains information on the sociodemographics, disease-related information, knowledge of diagnosis, prognosis and distress. The distress was assessed using the National Comprehensive Cancer Network distress thermometer (DT)[15]. The DT is a self-assessing one-item 11-point Likert scale displayed as a visual graphic of a thermometer that ranges from 0 (no distress) to 10 (extreme distress), wherein patients rate their level of distress, the week before assessment. A score of ≥4 on DT indicates moderate-to-severe distress. The distress assessment was carried out in the local language (Tamil) which is a translated version, face validated with experts for routine clinical assessment within the institute. With respect to the awareness of diagnosis and prognosis, all the patients were asked the following questions during their first visit. 'Can you tell the name of the diagnosis?' for assessing the knowledge of diagnosis and 'Are you aware of the likely disease course (prognosis)?' to assess the knowledge of prognosis. The responses were categorized as aware and unaware. Those patients, who were able to state the name of the diagnosis correctly, were considered as aware of diagnosis and patients, who were able to state the current outcome of the disease were considered as aware of prognosis. As these assessments are part of routine clinical care, all the data are collected mandatorily and documented robustly without any missing information.

Statistical analysis: The data collected were entered and analysed using the Statistical Package for the Social

Sciences (SPSS) software (version 20.0, released 2011, IBM Corp., Armonk, New York, USA). The socio-demographic and clinical variables were summarized using frequencies and percentages. Chi-square test was performed to find the association of socio-demographic variables with knowledge of diagnosis, prognosis and DT score. Binary logistic regression was used to examine the association between socio-demographic variables (age, gender and level of education) and distress (no distress <4; significant distress ≥4), knowledge of diagnosis and prognosis (aware and unaware). The significance level for all analyses was set at $P<0.05$, two tailed.

Results

Sociodemographic characteristics: Of the 764 cancer patients visiting the OPD of PPC during the study period, 10 were excluded as they were minors (below 18 yr) and 754 were included for analysis. The sociodemographic characteristics are summarized in Table I. More than half of the patients (53.4%) were male with 69.5 per cent were between 41 and 65 yr. The patients' mean age was 53.78 yr (standard deviation ± 12.79). Around 47.5 per cent patients had completed their secondary level of education, while 23 per cent had not received any formal education. More than half of the patients (56.4%) were unemployed; 57.4 per cent hailed from urban settings. The monthly income was below ₹ 5000 for nearly 56.4 per cent of patients; head-and-neck cancer (21.4%), breast (19.4%) and gastrointestinal (17.5%) cancers were the most commonly reported diagnosis in our cohort.

Prevalence of distress, knowledge of diagnosis and prognosis: The DT scores had a median value of 5 (range 0 to 10). Over half of the patients reported moderate-to-severe distress (54.1%). Most patients reported being aware of diagnosis (75%), but 68 per cent were unaware of their prognosis (Figure).

Association between knowledge of diagnosis, prognosis and level of distress with demographic characteristics: Knowledge of diagnosis was significantly associated with sociodemographic variables including gender (χ^2 (1)=9.59, $P<0.01$), education (χ^2 (4)=36.82, $P<0.001$), type of disease (χ^2 (7)=30.10, $P<0.001$) and knowledge of prognosis (χ^2 (1)=65.27, $P<0.001$). Knowledge of prognosis was significantly associated with socio-demographic variables including education (χ^2 (4)=32.16, $P<0.001$), occupation (χ^2 (1)=4.44, $P<0.05$) and income (χ^2 (3)=15.10, $P<0.01$). Distress

Table I. Demographic characteristics of patients (n=754)	
Characteristics	Frequency, n (%)
Age (mean±SD)	53.98±12.79
Age (yr)	
18-40	110 (14.6)
41-65	524 (69.5)
65+	120 (15.9)
Gender	
Male	403 (53.4)
Female	351 (46.6)
Education	
No formal education	172 (22.8)
Primary school	156 (20.7)
Middle school	305 (40.5)
High school	53 (7)
Graduate	68 (9)
Occupation	
Unemployed	425 (56.40)
Employed	329 (43.6)
Income (₹)	
Below 5000	425 (56.4)
5001-10,000	201 (26.7)
10,001-20,000	73 (9.7)
Above 20,000	55 (7.3)
Residence	
Rural	321 (42.6)
Urban	433 (57.4)
Cancer types	
Head and neck	161 (21.4)
Breast	112 (19.4)
Lung	71 (9.4)
Gastrointestinal	132 (17.5)
Gynaecology	73 (9.7)
Haematology	24 (3.2)
Unknown primary	40 (5.3)
Others	141 (18.7)
SD, standard deviation	

was significantly associated with sociodemographic variables, namely age (χ^2 (2)=6.24, $P<0.05$), types of diseases (χ^2 (7)=14.31, $P<0.05$), knowledge of diagnosis (χ^2 (1)=3.28, $P<0.05$) and prognosis (χ^2 (1)=11.91, $P<0.001$). Other sociodemographic variables were not significantly associated with distress ($P>0.05$) (Table II).
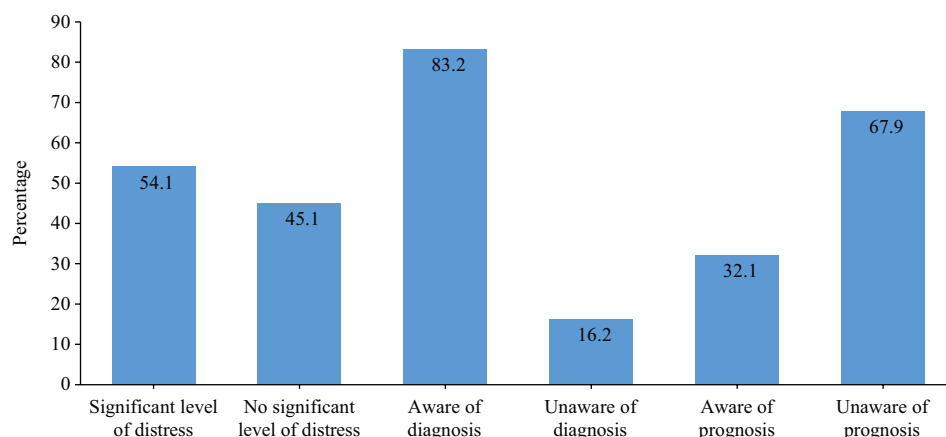
Figure. Prevalence of distress and knowledge of diagnosis and prognosis.

Univariate and multivariate logistic regression: The simple logistic regression analysis showed that distress was significantly associated with age and type of cancer, knowledge of diagnosis with gender, age, education and type of cancer and knowledge of prognosis with age, education, occupation and income ($P<0.05$). The variables that were associated with distress, knowledge of diagnosis and prognosis in simple logistic regression analyses, were included in multivariate logistic regression for a final model predicting distress, knowledge of diagnosis and prognosis (Table III). In the multivariate logistic analysis, patients between 18-40 yr, with head and neck and haematology cancers, who were unaware of diagnosis and prognosis had an increased adjusted odds of distress. Males with no formal or only primary education, with head and neck cancer and unknown primary was associated with a low level of knowledge of the diagnosis. No formal education or primary and middle level of education were associated with low levels of knowledge of prognosis (Table IV).

Discussion

This study focused on awareness about cancer diagnosis, prognosis and distress and identified sociodemographic and other factors associated with them using a retrospective descriptive study design. The major strength of this study rests with its large sample size and robust data. More than half of the cancer patients had reported moderate-to-severe distress and were unaware of their prognosis. Gender, education, type of cancer and knowledge of diagnosis were significantly associated with distress. Knowledge of diagnosis was significantly associated with gender, education and type of disease. However, knowledge of prognosis was significantly associated with sociodemographic variables including education, occupation and income. Younger age group, head-and-neck cancer, haematology cancer, the state of being unaware of diagnosis and prognosis were identified as factors associated with distress.

Our study revealed that more than half of the patients were experiencing moderate-to-severe distress and had poor knowledge of prognosis. A study conducted on cancer patients at Bangalore by Bandiwadeker *et al*[16] revealed that 22-50 per cent of the patients reported a significant level of distress. This study reported that the patients between 18 and 40 yr, with head and neck and haematology cancers, who were unaware of diagnosis and prognosis had an increased adjusted odds of distress. This finding related to age and lung cancer is consistent with the result generated through an earlier cross-sectional study[17].

Poor knowledge of prognosis was prevalent in our cohort as was in earlier literature indicating that divulging details of treatment and prognosis is seldom encouraged in India[18]. Ghoshal *et al*[12] reported that patients actually preferred to know treatment details, but according to Applebaum *et al*[19], patients were often not provided with the details of prognosis in India and this was perceived to be due to interdependence of family members and respect for elders.

Our study showed that men were more aware of their diagnosis. This is often the case, especially in India where a male member is first told about the diagnosis or prognosis[20]. A few studies have reported that women with advanced cancer develop more accurate understanding of their diseases than men do. This is attributed to in-depth discussions that women

	Table II. Association of knowledge of diagnosis, prognosis and level of distress with demographic characteristics								
Variables	Knowledge of diagnosis			Knowledge of prognosis			Distress score		
	Aware, n (%)	Unaware, n (%)	P	Aware, n (%)	Unaware, n (%)	P	<4, n (%)	≥4, n (%)	P
Gender									
Male	351 (56)	52 (40.9)	0.001	138 (57)	265 (51.8)	0.101	189 (54.6)	214 (52.5)	0.301
Female	276 (44)	75 (59.1)		104 (43)	247 (48.2)		157 (45.4)	194 (47.5)	
Age (yr)									
18-40	95 (15.2)	15 (11.8)	0.097	44 (18.2)	66 (12.9)	0.090	39 (11.3)	71 (17.4)	0.044
41-65	440 (70.2)	84 (66.1)		166 (68.6)	358 (69.9)		246 (71.1)	278 (68.1)	
65+	92 (14.7)	28 (22)		32 (13.2)	88 (17.2)		61 (17.6)	59 (14.5)	
Education									
No formal school	126 (16.5)	46 (36.2)	<0.001	39 (5.1)	133 (26)	<0.001	88 (25.4)	84 (20.6)	0.428
Primary school	116 (15.2)	40 (31.5)		43 (5.6)	113 (22.1)		71 (20.5)	85 (20.8)	
Middle school	276 (36.1)	31 (24.4)		100 (13.1)	206 (40.2)		130 (37.6)	175 (42.9)	
High school	49 (6.4)	5 (3.9)		21 (2.7)	32 (6.2)		23 (6.6)	30 (7.4)	
Graduate	63 (8.2)	5 (3.9)		40 (5.2)	28 (5.5)		34 (9.8)	34 (8.3)	
Occupation									
Unemployed	352 (56.1)	73 (57.5)	0.43	123 (50.8)	302 (59)	0.021	199 (57.5)	226 (55.4)	0.304
Employed	275 (43.9)	54 (42.5)		119 (49.2)	210 (41)		147 (42.5)	182 (44.6)	
Income (₹)									
Below 5000	353 (56.3)	72 (56.7)	0.552	128 (52.9)	297 (58)	0.002	187 (54)	238 (58.3)	0.647
5001-10,000	167 (26.6)	34 (26.8)		56 (23.1)	145 (28.3)		99 (28.6)	102 (25)	
10,001-20,000	58 (9.3)	15 (11.8)		29 (12)	44 (8.6)		35 (10.1)	38 (9.3)	
Above 20,000	49 (7.8)	6 (4.7)		29 (12)	26 (5.1)		25 (7.2)	30 (7.4)	
Residence									
Rural	264 (42.1)	57 (44.9)	0.315	105 (43.4)	216 (42.2)	0.408	158 (45.7)	163 (40)	0.066
Urban	363 (57.9)	70 (55.1)		137 (56.6)	296 (57.8)		188 (54.3)	245 (60)	
Types of cancer									
Head and neck	148 (23.6)	13 (10.2)	0.001	52 (21.5)	109 (21.3)	0.336	80 (19.6)	81 (23.4)	0.046
Breast	95 (15.2)	17 (13.4)		41 (16.9)	71 (13.9)		61 (15)	51 (14.7)	
Lung	58 (9.3)	13 (10.2)		17 (7)	51 (10.5)		40 (9.8)	31 (9)	
Gastrointestinal	104 (16.6)	28 (22)		39 (16.1)	93 (18.2)		69 (16.9)	63 (18.2)	
Gynaecology	61 (9.7)	12 (9.4)		25 (10.3)	48 (9.4)		37 (9.1)	36 (10.4)	
Haematology	21 (3.3)	3 (2.4)		6 (2.5)	18 (3.5)		7 (1.7)	17 (4.9)	
Unknown	23 (3.7)	3 (13.4)		9 (3.7)	31 (6.1)		23 (5.6)	17 (4.9)	
Primary Others	117 (18.7)	24 (18.9)		53 (21.9)	88 (17.2)		91 (22.3)	50 (14.5)	
Knowledge of diagnosis									
Unaware	-	-		2 (0.8)	125 (24.4)	<0.001	49 (14.2)	78 (19.1)	0.043
Aware	-	-		240 (99.2)	387 (75.6)		297 (85.8)	330 (80.9)	

Contd...

Variables	Knowledge of diagnosis			Knowledge of prognosis			Distress score		
	Aware, n (%)	Unaware, n (%)	*P*	Aware, n (%)	Unaware, n (%)	*P*	<4, n (%)	≥4, n (%)	*P*
Knowledge of prognosis									
Unaware	-	-		-	-		257 (74.3)	255 (62.5)	<0.001
Aware	-	-		-	-		89 (25.7)	153 (37.5)	
<4 score, non-significant distress; ≥4 score, significant distress									

tend to have with their families, regarding their diagnosis than men, unlike in India[21,22]. This difference in the result could be attributed to the cultural context, where men in India often do not allow women to discuss about their diseases with physicians and other health care professionals and also try to hide the truth from women as they are uncertain of their emotional resilience[23].

It is evident that there is a significant association between age and knowledge of the diagnosis. This study revealed that younger age group was unaware of the diagnosis. In a focus group study, Cartwright *et al*[24] generated similar findings and stated that the patients often did not understand the prognostic information given to them and preferred not to know about the prognosis and that there was no concordance between healthcare provider's explanation and patients' understanding.

In line with the existing literature[12], our study found that the patients with no formal education or low levels of education (<8th std) had poor or no knowledge of diagnosis and prognosis. Despite being diagnosed and treated in a cancer centre, our patients seemed to lack understanding of the term 'cancer' and its impact. Majority of the patients with below middle school education level had significant distress. As indicated by other researchers, having poor knowledge of diagnosis leads to poor quality of life, anxiety, depression and distress[8,25]. A study by Engelman *et al*[26] stated that lack of awareness and education among the population caused uncertainty about the diagnosis, thereby leading to high distress.

People from low-middle socio-economic status in our cohort, were ignorant about their health condition with poor knowledge on their prognosis. Other researchers reported similarly that the poorer people did not report to hospitals, even though they were at early stages, due to poor financial condition and as they were the only breadwinner of the family[9]. A study by Fagundes *et al*[25] was in line with this finding and also identified that poor socio-economic status was associated with depression severity.

Female patients in our cohort had a slightly lower level of significant distress compared to their male counterparts; however, Jacobsen *et al*[27] claimed increased perception of distress in women due to emotional, family and physical concerns.

This study had a few limitations. Firstly, we did not include paediatric cancer patients, particularly the teenage population. Second, the study did not delve into the details of distress precluding in-depth analysis.

Overall, this study highlights the association of sociodemographic factors with knowledge of diagnosis, prognosis and the level of distress. Although patients were widely aware of the diagnosis, detailed knowledge on prognosis was limited. Male gender, higher educational level and better socio-economic status increased the likelihood of patients being aware of their diagnosis and prognosis. Being unaware of prognosis was associated with the increased level of distress.The findings of this study emphasize the need for disclosure of prognosis to patients; professional training on cancer communication for medical professionals should be mandated so that adequate informational support for patients and families could be assured. Further, studies focusing on barriers to disclosing news to the patients and the detailed cause of distress may through more light on necessary intervention.

Table III. Univariate logistic regression analysis of sociodemographic characteristics with knowledge of diagnosis, prognosis and distress

Variables	Knowledge of diagnosis (unaware/aware)		Knowledge of diagnosis (unaware/aware)		Distress score (<4 score/≥4 score)	
	OR (CI 95%)	P	OR (CI 95%)	P	OR (CI 95%)	P
Gender						
Male	0.48 (0.30-0.78)	0.003	1.23 (0.90-1.68)	0.176	0.91 (0.68-1.22)	0.551
Female (reference)	1		1		1	
Age (yr)						
18-40	1.92 (0.96-3.84)	0.062	1.83 (1.05-3.19)	0.033	1.88 (1.10-3.19)	0.019
41-65	1.59 (0.98-2.58)	0.058	1.27 (0.81-1.98)	0.284	1.16 (0.78-1.73)	0.442
65+ (reference)	1		1		1	
Education						
No formal school	0.21 (0.82-0.57)	0.002	0.20 (0.11-0.37)	<0.001	0.95 (0.54-1.67)	0.871
Primary school	0.23 (0.86-0.61)	0.003	0.26 (0.14-0.48)	<0.001	1.19 (0.67-2.11)	0.536
Middle school	0.70 (0.26-1.87)	0.480	0.33 (0.19-0.57)	<0.001	1.34 (0.79-2.28)	0.269
High school	0.76 (0.20-2.78)	0.681	0.45 (0.22-0.95)	0.037	1.30 (0.63-2.68)	0.471
Graduate or above (reference)	1		1		1	
Occupation						
Unemployed	0.94 (0.64-1.39)	0.781	0.71 (0.52-0.97)	0.035	0.91 (0.68-1.22)	0.558
Employed (reference)	1		1		1	
Income (₹)						
Below 5000	0.60 (0.24-1.45)	0.258	0.38 (0.21-0.68)	0.001	1.06 (0.60-1.86)	0.838
5001-10,000	0.60 (0.23-1.51)	0.281	0.34 (0.18-0.63)	0.001	0.85 (0.47-1.56)	0.618
10,000-20,000	0.47 (0.17-1.31)	0.151	0.59 (0.29-1.19)	0.145	0.90 (0.44-1.82)	0.780
Above 20,000 (reference)	1		1		1	
Cancer type						
Head and neck	2.33 (1.14-4.78)	0.020	0.79 (0.49-1.27)	0.336	0.54 (0.34-0.86)	0.010
Breast	1.14 (0.58-2.25)	0.693	0.95 (0.57-1.60)	0.873	0.65 (0.39-1.09)	0.105
Lung	0.91 (0.43-1.92)	0.816	0.52 (0.27-0.99)	0.048	0.70 (0.39-1.26)	0.247
Gastro	0.76 (0.41-1.39)	0.379	0.69 (0.42-1.15)	0.161	0.60 (0.37-0.97)	0.040
Gynecology	1.04 (0.48-2.22)	0.914	0.86 (0.47-1.56)	0.630	0.56 (0.31-1.00)	0.051
Hematology	1.43 (0.39-5.20)	0.582	0.55 (0.20-1.48)	0.239	0.22 (0.08-0.58)	0.002
Unknown primary	0.27 (0.12-0.59)	0.001	0.48 (0.21-1.09)	0.080	0.74 (0.36-1.52)	0.417
Others (reference)	1		1		1	
Urban (reference)	1		1		1	
Knowledge of diagnosis						
Unaware	-	-	-	-	1.43 (0.97-2.11)	0.071
Aware	-	-	-	-	1	
Knowledge of prognosis						
Unaware	-	-	-	-	0.57 (0.42-0.79)	0.001
Aware	-	-	-	-	1	
OR, odds ratio; CI, confidence interval						

Table IV. Multivariate logistic regression analysis of sociodemographic characteristics with knowledge of diagnosis, prognosis and distress

Variables	Knowledge of diagnosis (unaware/aware)		Knowledge of diagnosis (unaware/aware)		Distress score (<4 score/≥4 score)	
	OR (95% CI)	P	OR (95% CI)	P	OR (95% CI)	P
Gender						
Male	2.16 (1.35-3.46)	0.001				
Female (reference)	1					
Age (yr)						
18-40					1.84 (1.06-3.18)	0.029
41-65					1.16	
65+ (reference)					1	
Education						
No formal school	0.15 (0.05-0.42)	<0.001	0.26 (0.13-0.52)	<0.001		
Primary school	0.17 (0.63-0.49)	0.001	0.33 (0.17-0.64)	<0.001		
Middle school			0.41 (0.23-0.75)	0.001		
High school						
Graduate (reference)	1		1			
Income (₹)						
Below 5000						
5001-10,000			0.50 (0.26-0.99)	0.048		
10,001-20,000						
Above 20,000 (reference)			1			
Types of cancer						
Head and neck	2.53 (1.20-5.33)	0.015			0.57 (0.36-0.92)	0.022
Breast						
Lung						
Gastrointestinal						
Gynaecology						
Haematology					0.22 (0.08-0.57)	0.002
Unknown primary	0.26 (0.11-0.59)	0.001				
Others (reference)	1				1	
Knowledge of prognosis						
Unaware					0.59 (0.43-0.82)	0.001
Aware					1	
OR, odds ratio; CI, confidence interval						

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