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Original Research Article

Assessment of distress in patients visiting pain and palliative out patient department of a tertiary care hospital in Assam

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ABSTRACT

Background: Distress is a multifactorial entity seen in patients battling with cancer. It is under-reported and under-managed posing a hurdle in providing holistic patient care. It has a negative effect on the treatment and treatment adherence in cancer patients.
Methods: A cross- sectional study was done in the pain and palliative outpatient clinic of State Cancer Institute, Guwahati, Assam. About 250 patients were screened for distress using a questionnaire consisting of national comprehensive cancer network (NCCN) distress thermometer (DT) and problem list over a span of 4 months after obtaining due consent. They were asked to mark their level of distress and the contributing factors for distress as enlisted in the NCCN DT problem list. Chi square test and Mann Whitney test were used to analyze statistical significance.
Results: The distress levels were assessed based on the effects of the disease, treatment and other demographic variables and possible causes contributing to distress were determined. It was noted that out of 250 patients screened (n=250), 88 (35.2%) reported a distress score of 4 while 79 (31.6%) reported with a score of 6. Nature of the disease and current treatment received by the patient was significantly associated with distress while age, marital status and sex was not. Amongst physical, emotional and practical problems leading to distress, pain (45.2%), worry (49.2%) and transportation issues (45.1%) respectively were significantly reported as primary causes of distress.
Conclusions: NCCN DT in an effective tool for assessment of distress in cancer patients of Assam. It helps in identification of probable causes of distress which aids in holistic patient care.

Keywords: Distress, DT, Palliative care, Cancer

INTRODUCTION

Cancer is one of the leading causes of mortality all across the globe. In India, about 13.9 lakh new cases are registered in a year with an alarming death of about 8.5 lakhs in 2020. It is estimated to rise to a whopping 15.7 lakh by the year 2025 according to the factsheet given by Indian council of medical research (ICMR-Bangalore).[1] The North Eastern region of India is also noted to have significantly contributed in this increase incidence of cancer. Assam marks its presence in the list with increase prevalence of head and neck cancer.[1] The probable reason for the rise in the cases is cited to be lack of proper awareness, late diagnosis, lack of access to timely cancer care and poor prognosis of the disease.[2]

Distress is a common terminology associated with cancer patients and their family members. It is a multifactorial entity which tends to affect the physical, psycho-social and spiritual well-being of the patient. If not identified and managed early, it can pose as a serious threat in itself and may interfere with the patient's ability to cope effectively with the disease, its physical symptoms and its treatment.[3] It has also shown to be associated with

psychological illness like anxiety and depression accounting for development of suicidal tendencies in cancer patients.

The aim of this study is to determine the level of distress and the factors contributing to distress in cancer patients visiting the pain and palliative unit of a tertiary care centre in assam. This will facilitate in prevention of development of serious psychological issues and aid in providing holistic care to the patient.

METHODS

This cross -sectional study was conducted on 250 patients visiting the pain and palliative outpatient unit of state cancer institute, Guwahati, Assam were screened for distress using the NCCN DT for over a period of 4 months (May-August) 2022.A self-assessment form was given consisting of the NCCN DT along with the problem list (PL). Informed consent was taken form the participants after explaining the purpose and the need of the study. The study was conducted after obtaining ethical clearance from the institutional ethical committee.

Inclusion criteria

All patients attending the pain and palliative OPD from the month of May-August 2022 were included in this study.

Exclusion criteria

Patients who are non-ambulatory, with poor general condition, those who were unable to give consent, ones with already diagnosed psychiatry conditions and patients with cognitive impairment were excluded from the study.

Tool

NCCN DT is one of the standard tools which is used for assessment of distress in cancer patients. It was designed by the NCCN, USA. It is a simple tool consisting of a 0-10 scale where 0 denotes no distress and 10 denotes severe distress. It also includes a supplemental problem list consisting of 39 potential causes which can contribute to distress in cancer patients. It is broadly categorised as practical problems, physical problems, emotional problems, family problems and spiritual problems. [4]

In this study the DT and its problem list was translated from English to Assamese language and then to English to ensure the linguistic validity of the problem list which was validated by three language scholars of the state.

Data collection procedure

A total of 250 patients including 153 males and 93 females visiting the OPD were handed over a questionnaire. They were First asked to circle a number in the DT which best described their level of distress which they have been facing from past one week including the day of visit.

They were then asked to browse through the list of problems and asked to tick any of the relevant problems which they are been facing in past one week including the day of visit from the Problem list. Demographic data were obtained and their medical charts were reviewed to obtain the diagnosis, time since diagnosis and details about their current treatment.

Statistical analysis

Statistical package for social sciences (SPSS) version no.16.0 was employed to analyse the data. Statistical significance was considered at $p<0.05$. Chi square test, Kruskal Wallis test and Mann Whitney test were employed to obtain descriptive and inferential statistics.

RESULTS

Amongst the cancer patient screened (n=250), 53 (61.2%) were males and 97 (38.8%) were females. About 88 patients (35.2%) exhibited a distress score of 4, 79 (31.6%) exhibited a score of 6 ,37 (14.8%) reported with a score of 8 and 7 (2.8%) with a score of 10. This data was statistically significant ($p<0.001$) (Table 1).

Table 1: Analysis of distress score distribution.

Distress score	Frequency	Percent (%)	P value*
2.00	26	10.4	<0.001, S
3.00	2	0.8	
4.00	88	35.2	
5.00	10	4.0	
6.00	79	31.6	
7.00	1	0.4	
8.00	37	14.8	
10.00	7	2.8	
Total	250	100	

*Chi square test at 0.05 significance level; S-Significant.

Distress scores assessed based on various demographic parameters like age group, sex, marital status, time since diagnosis, nature of the disease and current treatment received by the patient (Table 2). Considering 5 as the cut-off score due to its numerical placement in the middle of DT, the distress scores were divided into 2 groups i.e., score 5/ below and score greater than 5.[5]

Statistical significance was noted when distress scores were assessed based on the nature of disease and current treatment received by the patient while age, gender, marital status and time since diagnosis didn't show significance statistically.

Patients with metastatic cancer (76.8%) showed a mean distress score of 5.41 while patients with non-metastatic cancer (23.2%) reported a mean score of 4.64 (Figure 1).

Table 2: Distress score analysis based on various demographic factors.

Variables			Distress score category		Total	P value
			Scored 5 and below	Scored above 5		
Age (years)	Below 20 years	Count	2	1	3	0.121, NS
		%	66.7	33.3	100	
	20 to 30	Count	2	7	9	
		%	22.2	77.8	100	
	31 to 40	Count	19	7	26	
		%	73.1	26.9	100	
	41 to 50	Count	27	38	65	
		%	41.5	58.5	100	
	51 to 60	Count	39	34	73	
		%	53.4	46.6	100	
	61 to 70	Count	20	21	41	
		%	48.8	51.2	100	
	71 to 80	Count	15	14	29	
		%	51.7	48.3	100	
	Above 80	Count	2	2	4	
		%	50	50	100	
Gender	Male	Count	78	75	153	0.818, NS
		%	51	49	100	
	Female	Count	48	49	97	
		%	49.5	50.5	100.0%	
Marital status	Married	Count	101	93	194	0.493, NS
		%	52.1	47.9	100.0%	
	Unmarried	Count	6	10	16	
		%	37.5	62.5	100	
	Widower	Count	19	21	40	
		%	47.5	52.5	100	
Nature of disease	Metastatic	Count	89	103	192	0.020, S
		%	46.4	53.6	100	
	Non-metastatic	Count	37	21	58	
		%	63.8	36.2	100	
Time since diagnosis (Months)	Less than 3 months	Count	4	3	7	0.234, NS
		%	57.1	42.9	100	
	3 to 6	Count	55	67	122	
		%	45.1	54.9	100	
	7 to 9	Count	47	29	76	
		%	61.8	38.2	100	
	10 to 12	Count	14	20	34	
		%	41.2	58.8	100	
	13 to 18	Count	3	2	5	
		%	60	40	100	
	19 to 24	Count	3	3	6	
		%	50	50	100	
Current treatment	Chemotherapy	Count	45	9	54	<0.001, S
		%	83.3	16.7	100	
	Palliative	Count	35	95	130	
		%	26.9	73.1	100	
	Palliative chemotherapy	Count	21	13	34	
		%	61.8	38.2	100	
	Palliative radiotherapy	Count	3	2	5	
		%	60	40	100	
	Radiotherapy	Count	12	3	15	
		%	80	20	100	
	Surgery	Count	4	2	6	

Continued.

Variables			Distress score category		Total	P value
			Scored 5 and below	Scored above 5		
		%	66.7	33.3	100	
	Others	Count	6	0	6	
		%	100	0	100	

*Pearsons Chi Square test at 0.05 significance level; S-Significant.

Table 3: Mean distress score according to current treatment received by the patient.

Treatment	N	Percent (%)	Mean	Std. deviation	P value
Chemotherapy	54	21.6	3.87	1.60	
Palliative	130	52	6.19	1.74	
Palliative chemotherapy	34	13.6	4.82	1.27	
Palliative radiotherapy	5	2	4.80	1.10	<0.001, S
Radiotherapy	15	6	4.00	1.31	
Surgery	6	2.4	4.33	1.51	
Others	6	2.4	3.17	1.33	
Total	250	100	5.23	1.91	

*Kruskal Wallis test at 0.05 significance level.

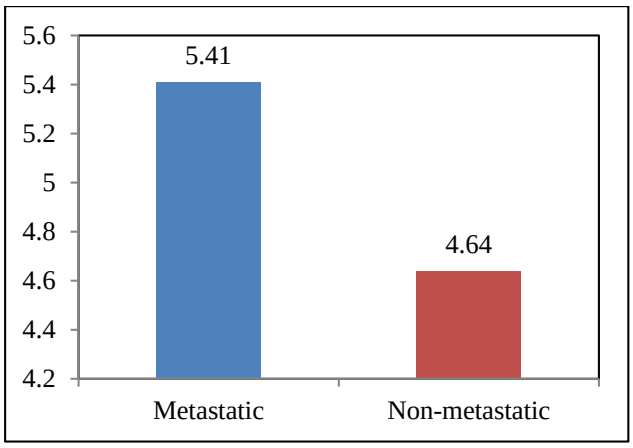

Figure 1: Mean distress score with nature of the disease.

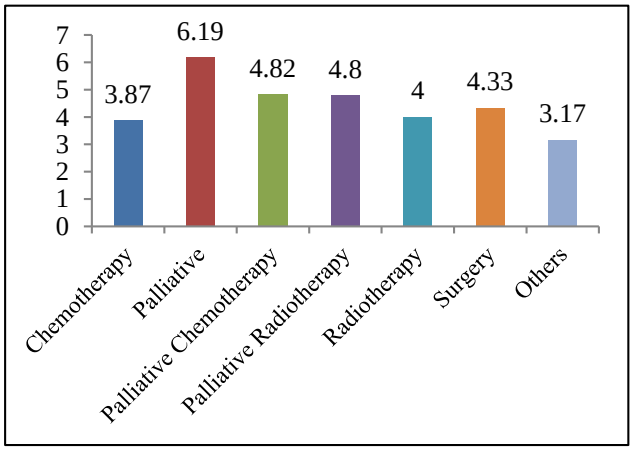

Figure 2: Mean distress scored with current treatment.

It was also observed that patients on palliative treatment alone reported with a mean distress score of 6.19 as compared to patients receiving chemotherapy (score of 3.8) and radiation therapy (score of 4). This signifies that patients who are receiving adjuvant treatment with curative intent tend to exhibit a lower distress score as compared patients receiving end of life care (Figure 2) (Table 3).

In this study, upon assessing the factors contributing to distress from the problem list given along with the DT, it was noted that physical, personal and emotional problems were significantly associated in attributing to distress. Spiritual issues were not reported by the screened sample hence was not analysed in the study.

Upon physical factor, pain (45.2%) was reported as the predominant cause followed by fatigue (18.4%) and constipation (15.6%) in the total study group of 250 patients. (Figure 3) (Table 4).

Table 4: Physical factors contributing to distress.

Physical causes	Frequency	Percent (%)	P value*
Constipation	39	15.6	
Fatigue	46	18.4	
Mobility	9	3.6	<0.001, S
Nausea	22	8.8	
Pain	113	45.2	
Sleep	21	8.4	
Total	250	100	

*Chi square test at 0.05 significance level; S - Significant

The 193 patients out of 250 patients presented with underlying emotional cause and cited as a contributing factor for their distress. The 95 patients (49.2%) reported worry as the main emotional problem contributing to distress followed by fear in 55 patients (28.5%) and loss of interest in 29 patients (15%) (Figure 4).

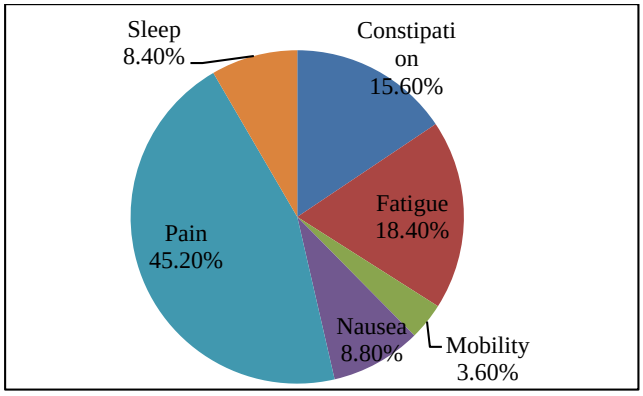

Figure 3: Physical problems contributing to distress.

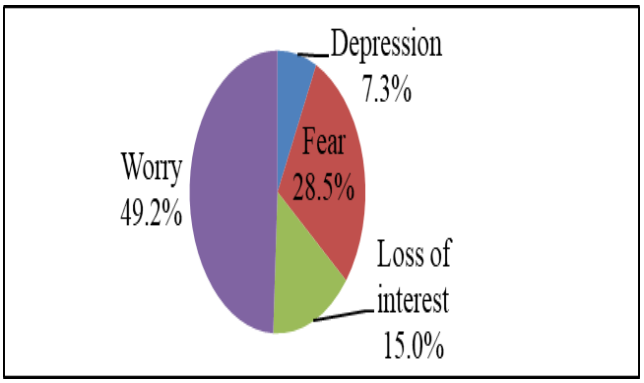

Figure 4: Emotional problems contributing to distress.

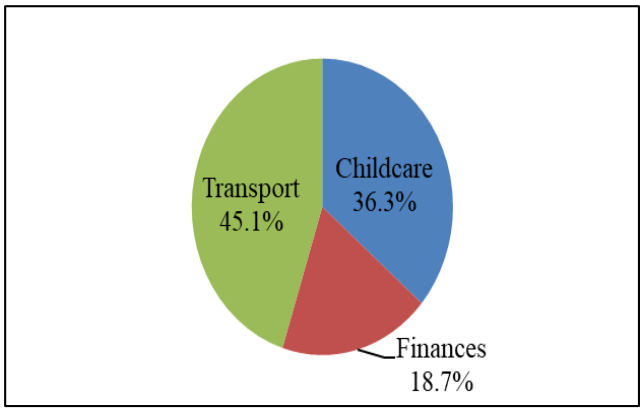

Figure 5: Practical problems contributing to distress.

Practical problems were reported by 91 patients out of 250 patients studied where causes cited were Transportation in 41 patients (45.1%), child care in 33 patients (36.3%) and finance in 17 patients (18.7%) (Figure 5).

DISCUSSION

NCCN DT and its problem list is the standard tool which is used in this study. Out of the 250 screened patients visiting the pain and palliative OPD of state cancer institute, Assam, it was noted that a majority presented with a distress score of 4. This score was significantly higher in a corresponding study by Bandiwadekar et al in 2020 which reported a mean distress score of 7.[6] Few other studies reported a mean score of 2 and 5 respectively.[7,8]

The cut off score of ≥5 is adapted in this study which was considered optimal for screening distress, anxiety and depression.[9] A few other studies have adapted a cut off score of ≥6 and≥4.[12,13] However, a cut off score of ≥5 reflects better sensitivity and is line with the existing research in the field of palliative care.[10]

Patients battling with metastatic disease and receiving Palliative treatment alone presented with score above the cut-off margin i.e., 103 and 95 patients respectively out of 250 studied. This data was significant statistically and is also in accordance with various other studies.[11] This signifies that such patients require more specialised care and attention and presents with an increase symptom burden thus increased distress.

Analysis of causes of distress as listed in the problem list shows that distress due to physical problems are comparatively higher followed by emotional, social and spiritual problems. This was in accordance with other studies.[6,8,10] However, few studies depicts that the incidences of distress due to emotional issues are higher than physical, social and spiritual issue.[12]

Patients who were screened in the palliative clinic exhibited psychological symptoms such as Worry (in 95 patients) and fear (in 55 patients). It is often noted that such patient if not intervened early may tend to display serious psychological issues like mood disorder, anxiety and depression.[13] The DT along with the problem list presented as a medium to prematurely screen high risk patients who can develop serious psychological issues if not intertwined early. Few literatures provide evidence that combining DT together with hospital anxiety depression scale (HADS) aids in better diagnosis and screening of such patients.[14]

Transportation issues, a major cause cited in this study casts a light on the importance of home care in cancer and palliative patients. Literatures have supported that home-care indeed serves beneficial for the patient and their family members in term of the over-all care.[15] Comparative study between home care and hospital care in palliative care patients of Assam presents with a scope for further research.

Limitations

Limited sample size and the time duration for the study was less. Few patients found the DT to be confusing. DT measures distress of a person at a given point of time. This score may vary at different stages and progression of the disease of the same person which may be difficult for the DT to pick up. Few patients were not willing to talk

about the emotional and personal problems and were only concerned about their physical symptoms.

CONCLUSION

From this study it is concluded that DT is a simple yet effective tool for distress assessment. It helps in detection and identification of stressors causing distress to both patients and the physicians enabling them to pay equal attention to distress in the same manner that they do to their physical health. Early identification and appropriate intervention in managing distress aids in providing holistic care, promote healing and improving the quality of life of the patient.

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Ethical approval: The study was approved by the Institutional Ethics Committee

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