**Original Research** 

## Role of distress thermometer as a screening tool for psychological distress in oncology- a cross- sectional observational study in a tertiary care hospital of punjab

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### ABSTRACT

Psychological distress in patients fighting with cancer is woefully an under diagnosed problem. Our study was a cross sectional observational study, carried out at SGRDIMSR, Punjab, India, between October 2022 to December 2022 to evaluate psychological and physical distress and symptom burden in Indian population with cancer using the National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT).

*Material and Methods*: We enrolled 300 oncology patients aged 20 to 75 years in different stages of treatment, reporting to Opd of SGRDIMSR after written informed consent. These patients were screened for distress using a questionnaire consisting of national comprehensive cancer network (NCCN) distress thermometer (DT) and problem list 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.

*Results:* Of the 300 patients, 51 % were women and 49% were men; maximum fell into age group of 40 to 50 years. Overall, majority of the females enrolled were having breast cancer, followed by cervical cancer while the males had bladder cancer followed by carcinoma prostate. It was noted that out of 300 patients screened (n=300), 88 patients were having distress score of more than 5 with 212 patients reported a distress score above 5. All the patients exhibited emotional problems like sadness, worry, fear. Amongst physical, family and practical problems leading to distress; sleep disturbance, dealing with partner and work related issues respectively were significantly reported as primary causes of distress.

*Conclusions*: The prevalence of distress is high in cancer patients. Female gender was significantly associated with distress. DT is a very simple yet quick-paced tool that is more easily accepted by patients and clinicians and can act as a medium to prematurely screen high risk patients who can develop serious psychological issues if not intertwined early.

# Key words: oncology, distress, DT INTRODUCTION

Cancer is one of the leading causes of mortality 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 lakhs by the year 2025 according to the facts presented by Indian council of medical research (ICMR).<sup>1</sup>

The scenario in Punjab is even more alarming, with 90 cancer patients per 100,000 people compared to the national average of eighty, with Malwa region dubbed"the cancer belt" because of particular high incidence of the disease<sup>2</sup>.

Cancer patients apart from suffering from the primary disease, the adverse effects of the treatment, also suffer from distress which is under-diagnosed, under-reported and under- managed, posing a hurdle in providing holistic patient care.

The National Comprehensive Cancer Network (NCCN) defines distress as a multifactorial unpleasant emotional experience of a psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress may also compromise the quality of life and, if not identified and managed early, has a negative effect on the treatment and treatment adherence, and in worst of scenario can account to suicidal tendencies in cancer patients.<sup>3</sup>

Distress has been recognised as the sixth vital sign to be frequently and regularly monitored in the cancer care course, so as to classify patients who are in need psychosocial intervention.<sup>4</sup> Routine distress screening was recommended by the National Comprehensive Cancer Network (NCCN) in 2007, with the development of a screening tool to assess distress in adult cancer patients; the NCCN distress thermometer (DT) and problem checklist (PL).<sup>5</sup>

There is a need for research to fully comprehend the presence of psychological distress (anxiety and depression) in cancer patients. Most of the data available is from developed countries, which is quite different from those in developing ones. There are published studies assessing anxiety and depression in cancer patients in various countries, <sup>6-8</sup>but very few Indian studies , with limitation of small sample size <sup>9,10</sup>.

Furthermore, while prevalence of psychological distress among people receiving treatment for cancer in out-patient setting has received attention by researchers, few studies have investigated the factors associated with it. Our study thus aimed to assess prevalence and pattern of distress in cancer patients presenting to the out-patient department of a tertiary care centre in Punjab. This will facilitate in prevention of development of serious psychological issues and aid in providing holistic care to the patient.

#### Method

This cross -sectional study enrolled 300 adult cancer patients coming to surgery outpatient department at different stages of active treatment (hospitalization, surgery treatment, chemotherapy, radiotherapy etc.) in SGRDIMSR over a period of 3months (October to December) 2022. Patients were assessed by the Distress Thermometer (NCCN DT) along with the problem list (PL). Participation was voluntary and inclusion criteria were minimum age 18; having given consent to participate in the study. Patients who were non-ambulatory, with poor general condition, not able to give consent, ones with already diagnosed psychiatry conditions and patients with cognitive impairment were excluded from the study. The research project was approved by the ethical committee of the institute involved.

#### Measures

The Distress Thermometer is a self-report, pencil and paper measure consisting of a line with a 0-10 scale anchored at the zero point with "No distress" and at scale point 10 with "Extreme distress". The patient was asked to indicate on a scale from 0 to 10 the level of distress experienced in the last

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week, so he/she can mark it on the scale. In addition, it included a supplemental problem list consisting of 39 potential causes which can contribute to distress in cancer patients. It is broadly categorised into five domains for selection by patients: (1) practical, (2) family, (3) emotional, (4) spiritual or religious, and (5) physical. The DT was chosen due to its ease and specificity. A score of  $\geq$  5 corresponds to clinically significant distress in cancer patients.

#### **Data collection procedure**

A total of 300 patients including 147 males and 153 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 were facing in past one week including the day of visit from the Problem list. Demographic data was 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.

#### Results

In our study, we studied the prevalence and pattern of cancer-related distress in patients visiting the out-patient department of a tertiary cancer care hospital.

There were 153 females and 147 males. Gender was significantly related to distress wit females being more distressed than males.

Sex	Distress				Odd's ratio	95% CI		p-value	
	<u>&lt;</u> 5		>5			Lower	Upper		
	No.	%	No.	%					
F	30	34.09	123	58.02	.374	.223	.628	0.001	
М	58	65.91	89	41.98	-				
Total	88	100.00	212	100.00	]				

**TABLE 1** 

Breast cancer in females and genitourinary cancer in males was predominant. The different percentages of cancer is as follows.

#### TABLE 2

		Frequency	Percent	Valid Percent	Cumulative Percent
	Ascending colon	6	2.0	2.0	2.0
	Bladder	37	12.3	12.3	14.3
	Breast	80	26.7	26.7	41.0
	Buccal mucosa	6	2.0	2.0	43.0
	Cervix	24	8.0	8.0	51.0
	Colorectal	6	2.0	2.0	53.0
	Esophagus	6	2.0	2.0	55.0
	Gall bladder	6	2.0	2.0	57.0
	GB	6	2.0	2.0	59.0
	GCT	6	2.0	2.0	61.0
	HCC	6	2.0	2.0	63.0
	Kidney	6	2.0	2.0	65.0
Valid	Leukemia	6	2.0	2.0	67.0
	Lung	6	2.0	2.0	69.0
	NHL	12	4.0	4.0	73.0
	Ovary	6	2.0	2.0	75.0
	Ovary with mets	6	2.0	2.0	77.0
	Prostate	19	6.3	6.3	83.3
	Rectum	7	2.3	2.3	85.7
	Soft palate	6	2.0	2.0	87.7
	Stomach	6	2.0	2.0	89.7
	STS	6	2.0	2.0	91.7
	Tongue	18	6.0	6.0	97.7
	Tr. colon	7	2.3	2.3	100.0
	Total	300	100.0	100.0	

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In our study we aimed to identify the stressors from the problem list.All the patients were emotionally unstable. Amongst practical, family and physical factors the distribution is as follows.



Amongst practical factors, the patients were more distressed because of lack of insurance. Travelling and work were the other important stressors.

#### FIGURE 2



Among physical factors, nausea, fatigue, bathing, indigestion, appearance and disturbed sleep were predominant.

#### FIGURE 3



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Dealing with partner was the major factor amongst family problems.

We tried to find out the significance of various factors and distress. Insurance, Transportation and work related factors amongst practical problem; partner and dealing with children amongst family problem; appearance, urine problem, nausea, sexual, sleep disturbance and tingling in hands amongst physical problem are significantly related to distress.

Variables	Odds rat	io95% CI		p-value
		Lower	Upper	Î
PRACTICAL		ł		•
Child care	0.628	0.379	1.040	0.069
Housing	0.617	0.317	1.024	0.060
Insurance	0.181	0.075	0.437	0.001
Transportation work/school	0.334	0.170	0.656	0.001
Work school	0.486	0.259	0.911	0.024
Treatment decision	0.695	0.420	1.148	0.155
FAMILY PROBLEM	•			
Children deal	0.561	0.324	0.972	0.038
Partner deal	2.765	1.545	4.949	0.001
Ability to have child	0.883	0.467	1.670	0.702
Family health problem	0.433	0.259	0.725	0.142
PHYSICAL				
Appearance	1.995	1.668	3.411	0.010
Bathing	1.250	0.646	2.417	0.507
Breathing	0.912	0.483	1.721	0.776
Urine problem	2.634	1.450	4.786	0.001
Constipation	1.642	0.939	2.871	0.081
Eating	0.986	0.560	1.734	0.962
Fatigue	1.451	0.660	3.192	0.352
Swelling	1.607	0.885	2.919	0.117
Fever	0.809	0.385	1.699	0.574
Getting around	1.071	0.651	1.764	0.786
Idigetion	1.620	0.897	2.926	0.108
Memory	1.124	0.747	2.062	0.403
Nausea	74.662	9.891	563.573	0.001
Mouth sore	1.195	0.710	2.012	0.501
Dry nose	0.666	0.350	1.267	0.213
Pain	1.590	0.945	2.676	0.080
Sexual	2.035	1.228	3.373	0.005
Dry skin	1.232	0.710	2.138	0.458
Sleep	0.425	0.205	0.886	0.019
Substance abuse	0.600	0.236	1.579	0.278
Tingling in hand	2.357	1.309	4.242	0.004
Diarrhoea	0.622	0.330	1.173	0.140

# Discussion

With increasing number of oncology cases being detected annually, healthcare providers are inundated with patients in the out patient department as well as increased hospital admissions. In the multitudinous of disease assessment and cancer treatments, symptoms of distress may go undetected.

Among the causes of under- estimation of distress in cancer patients, there is medical attention focused on physical symptoms and the belief of patients that a depressed mood or anxiety are an appropriate cancer response as well as their fear of being stigmatized by the emotional difficulty of being carriers. This situation has important consequences for the quality of life, leading to a low degree of adherence to the treatments, therefore pain and, in extreme cases, suicide.<sup>11</sup>

Infact, less than 33% of them are recognised and treated, despite the fact that this condition has a strong impact on the quality of life of patients and their families.<sup>12</sup>

The NCCN has developed guidelines for psychosocial screening based on the demonstration that clinical judgment alone is not sufficient and is not valid as a specific screening tool.<sup>13</sup>

Recommended tools include the Distress Thermometer (DT) and the Problem List (PL). In recent years, DT has been one of the most used tools for the screening of psychological distress in cancer patients.<sup>12,13</sup>

A very important aspect is that it allows the physician to identify possible causes of stress (physical, family, spiritual, emotional, related to practical issues.<sup>11</sup> NCCN practice guidelines for the management of distress recommends that a DT score of 4 or higher indicates moderate-to-severe distress.<sup>14</sup>

However, from the validation study of the Italian version conducted by Grassi in 2013, it emerged that the cut-off score > 5 of the DT had optimal sensitivity and specificity relative to both Hospital Anxiety and Depression Scales (HADS) and Brief Symptoms Inventory-18 (BSI-18) cut-off scores for general caseness and higher psychological distress, respectively.<sup>12</sup>

In our study, we evaluated the prevelance of distress in 300 patients battling with cancer and analyzed the possible correlation between the Distress Thermometer values and the Problem List. We also aimed to identify risk classes for the development of psycho- social distress.

Assessing the baseline data of patients, our study had higher proportion of female patients presenting with distress, which matches with the study by Rajpal et al.<sup>15</sup>

Breast and genito-urinary were the top two malignancies, similar to studies done by (16) and (17). Despite a higher cut-off value, the prevalence of clinically significant distress was higher in our study. This could be related to stress of disease itself or due to other factors, such as worry of job, family or economic stability. These patients tend to be worried about missed working days due to treatment and its side effects.<sup>18</sup>

Cancer, due to the costs involved in evaluation and treatment of the disease, causes a huge financial burden on patient and their family. This often causes patients to default from treatment in India. Emotional distress in such patients may progress to larger degree. This can have grave consequences; like poorer quality of life<sup>19,20</sup>,

lesser satisfaction with care and even greater non- compliance to treatment.<sup>21</sup>

Uncertainity about the future is commonly present throughout the cancer trajectory.

Financial problems are generally due to low family income, lack of financial support and lack of health insurance. This is consistent with other studies.<sup>22</sup>

Poor availability of transport services posed a difficulty in reaching hospital for treatment from rural areas. 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.<sup>23</sup>

More emotional distress in certain cancers found in this study could be related to symptoms associated with them, such as constant tiredness, pain, loss of weight, cosmetic disfigurement (especially in breast cancer patients underegoing mastectomies ) even while treatment is going on.

Those undergoing chemotherapy often feel nauseous, lose their appetite, and become tired easily. Radiation therapy has its own set of problems.

Analysis of causes of distress as listed in the problem list shows that distress due to physical problems are comparatively higher followed by practical and spiritual problems. This was in accordance with other studies.<sup>24,25,26</sup> However, few studies depicts that the incidences of distress due to emotional issues are higher than physical, social and spiritual issue.<sup>27</sup>

In the present study, the emotional problem was found in all the patients. At the time of diagnosis, almost all patients reported being worried, nervous, depressed, sad, and showed loss of interest in daily activity. Timely recognition, assessment, and management of distress symptoms in cancer patients are essential part of the holistic care and improve patient experience and quality of life. The study by(28) emphasized the importance of psychosocial screening for distress symptoms. If this is done while they are still in the hospital, more patients are likely to be identified. These patients can then be referred for further testing or psychological treatment.<sup>29</sup>

#### Conclusion

From this study it is concluded that DT is a simple yet effective tool for distress assessment. It promotes dialogue between doctor and patient and therefore helps in detection and identification of stressors causing distress to patients and enable physicians to pay equal attention to distress in the same manner that they do to 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.

#### 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.

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