

# Assessment of Distress among Patients and Primary Caregivers: Findings from a Chemotherapy Outpatient Unit

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## Abstract

**Background:** Chemotherapy is one of the treatment modalities for cancer. The side effects of treatment, at times, can affect the emotional well-being of patients and their caregivers, thereby leading to distress. This paper aims at screening and identifying levels of distress among patients undergoing chemotherapy and their caregivers. **Subjects and Methods:** A cross-sectional study design was used. Patients ( $n = 102$ ) undergoing chemotherapy in the outpatient daycare unit and their caregivers ( $n = 101$ ) were screened for distress using the National Comprehensive Cancer Network distress thermometer and the problem checklist. Data were analyzed using descriptive and inferential statistics. **Results:** Patients (53.4%) and their caregivers (22.2%) reported experiencing moderate-to-severe levels of distress. Patients reported significant distress in the areas of physical ( $P = 0.000$ ) and emotional problems, whereas caregivers reported distress in the areas of family ( $P = 0.000$ ) and emotional problems. There was no significant difference in emotional problems ( $P \geq 0.05$ ) between the patients and their caregivers. There was a positive correlation between physical and emotional problems ( $r = 0.760$ ,  $P = 0.000$ ). Majority of patients (85.2%) and caregivers (80.1%) showed interest to avail psycho-oncology services. **Conclusions:** Distress is prevalent among patients with cancer undergoing chemotherapy and their caregivers. Clinical implications highlight the need to identify and address caregiver distress during routine distress screening for patients using specific psychosocial interventions. Future research warrants the use of administering specific assessments to identify severe psychological issues, such as depression and anxiety for patients reporting severe levels of distress on the screening tool.

**Keywords:** Caregivers, chemotherapy, distress, psycho-oncology

## INTRODUCTION

Distress is defined by the National Comprehensive Cancer Network (NCCN) as a “multi-factorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.” The NCCN in its distress management guidelines focuses on the need for screening of distress for patients diagnosed with cancer at every stage of the illness.<sup>[1]</sup>

An Indian study found that patients (23%) diagnosed with cancer (irrespective of type or stage of cancer) reported moderate-to-severe levels of anxiety and depression on the hospital anxiety and depression scale, leading to emotional distress.<sup>[2]</sup> Another study of breast cancer patients in Rome found

that patients undergoing neoadjuvant chemotherapy reported higher levels of distress, leading to anxiety and depression when compared to patients planned for primary surgery.<sup>[3]</sup>

Evidence also suggests that distress is commonly experienced by caregivers, as well. A study conducted with an aim of understanding caregiver distress in early phases of cancer while patients were still receiving chemotherapy revealed that caregivers had high levels of anxiety and depression, financial burden, and lesser time for recreational activities, leading to significant distress.<sup>[4,5]</sup> Cal *et al.* studied experiences of caregivers whose spouses were

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diagnosed with colorectal cancer receiving chemotherapy reported issues pertaining to facing the disease (encounter with cancer, hopelessness), difficulties encountered (care burden, burnout, changes in social life), continuing to live (social support, spiritual approach, tolerance), and provision of healthcare services (need for health care staff, need for home visits).<sup>[6]</sup>

Even though there are studies that highlight the psychological impact of chemotherapy on patients and caregivers, there are sparse data available from an Indian population. Therefore, we aimed to assess levels of distress experienced by patients receiving chemotherapy and their caregivers at the outpatient daycare unit of a tertiary cancer hospital.

## SUBJECTS AND METHODS

### Study design

A cross-sectional design with a purposive sampling method was used.

### Setting

The study was conducted at a tertiary cancer hospital located in Bengaluru, Karnataka, India. The outpatient daycare unit of the hospital is routinely involved in administering chemotherapy and other procedures (injections, hormone therapy) that do not require a patient to stay overnight. The entire chemotherapy process takes between 3 and 6 hours depending on the protocol that has been planned by the medical oncologist. While chemotherapy is being administered to the patient, the accompanying caregiver can either sit with the patient (bedside) or wait in the outpatient waiting area outside the daycare unit.

### Participants

A total of 207 (105 patients and 102 caregivers) individuals were screened for distress between February and April 2018. All patients and caregivers aged above 18 years were included; pediatric patients and patients admitted for other procedures except chemotherapy were excluded.

### Screening tool

We used the NCCN Distress Thermometer (DT) and problem checklist, a validated tool to assess the levels of distress and the problem categories affecting their distress. The screening tool has two parts. The first part comprises the DT, a graphical representation of thermometer marked from 0 to 10 representing the intensity of distress (0 = no distress and 10 = extreme/severe distress). The second part comprises the problem checklist, which consists of 39 items. It is divided into five different categories (practical problems, family problems, emotional problems, spiritual/religious problems, and physical problems). For the purpose of this study, the tool was translated, face validated, and back-translated to Kannada, Tamil, and Hindi (local South Indian languages) to ease in the process of comprehension.

### Study procedure

Before screening the participants for distress, consent was obtained, and demographic details were collected. The NCCN-DT and problem checklist were first given to the patients to complete after which it was given to their

caregivers. The tool was self-administered, and participants took approximately 3–5 min to complete the screening.

All participants who reported a score of 4 and higher, indicating moderate-to-severe distress, were encouraged to meet the psycho-oncology professional for individual sessions.

### Statistical analysis

Demographic characteristics of the participants were summarized using descriptive statistics that included frequencies, mean, percentages, and standard deviation. Levels of distress and its association with problem areas of participants were analyzed using inferential statistics (Chi-square, cross-tab analysis, and Pearson product-moment correlation). The data were analyzed using SPSS, Version 17. All  $P \leq 0.05$  was considered statistically significant.

### Ethical approval

Ethics approval for the study was obtained from the Clinical Research Business Review Team of the hospital.

## RESULTS

Of the 207 participants (105 patients and 102 caregivers) who were approached, 203 (102 patients and 101 caregivers) were included for the study. Three patients were excluded as they were admitted to the daycare for procedures other than chemotherapy. One caregiver was excluded due to prior commitments.

### Participant characteristics

Most of the patients (64.7%) were above the age of 50, female (63.7%), and married (93.1%). Majority (91.1%) of the patients had completed their formal education, of which 56.8% were unemployed. Breast cancer (41.2%) was the most common diagnosis. Majority of patients (72.5%) who received chemotherapy was treated with a curative intent. A significant number (85.2%) of patients reported preference to avail psycho-oncology services to manage their distress. Most of the caregivers (68.3%) were below the age of 50. Majority (95%) of the caregivers had completed a formal education, of which 72.2% were employed. Of the caregivers, majority were spouses (44.1%) and were male (51.4%) who were found to be involved in caregiving. Again, a significant number of caregivers (80.1%) reported preference for availing psycho-oncology services to manage distress [Table 1].

### Distress levels and problem categories

Patients (53.4%) and caregivers (22.2%) reported moderate-to-severe distress (score of >4) on the NCCN-DT [Figure 1].

Patients reported increased distress in the categories of physical problems (fatigue, pain, sleep, skin dry/itchy) and emotional problems (worry, sadness) [Figure 1].

Caregivers were found to report increased distress relating to family problems (family health issues), emotional problems (worry, sadness, fears), and physical problems (pain, sleep) [Figure 2].

### Association between problem categories of distress

There was a statistically significant association that was found between patients' and caregivers' overall distress levels and the

problem categories of the problem checklist. Among patients, it was found that physical problems had a statistically significant association with the overall distress ( $P = 0.000$ ). Fatigue (33%) was experienced by patients which had a significant impact on overall distress (Chi-square  $[\chi^2] = 29.37$ ). Similarly,

pain (30.2%) was another significant physical concern that influenced overall distress ( $\chi^2 = 13.49$ ).

Among caregivers, family problems had a statistically significant association with the overall distress ( $P = 0.000$ ). Family health issues (40.4%) were reported to influence overall distress ( $\chi^2 = 65.40$ ) [Figure 3].

**Table 1: Sociodemographic characteristics of patients and caregivers screened for distress at the daycare unit of a tertiary cancer hospital in Bengaluru, India (February-April 2018)**

Demographic characteristics	Patients (n=102), n (%)	Caregivers (n=101), n (%)
Age (years)		
<50	36 (35.2)	69 (68.3)
>50	66 (64.7)	32 (31.6)
Gender		
Male	37 (36.2)	52 (51.4)
Female	65 (63.7)	49 (48.5)
Marital status		
Married	95 (93.1)	90 (89.1)
Unmarried	6 (5.88)	11 (10.8)
Widow	1 (0.98)	0 (0.0)
Education		
Formal education*	93 (91.1)	96 (95.0)
No formal education	9 (8.8)	5 (4.9)
Employment status		
Employed**	43 (42.1)	73 (72.2)
Not employed***	58 (56.8)	28 (27.7)
Preference toward psycho-oncology services		
Yes	87 (85.2)	81 (80.1)
No	15 (14.7)	20 (19.8)
Diagnosis		
Breast cancers	42 (41.2)	
Gastrointestinal cancers <sup>a</sup>	18 (17.6)	
Hematological malignancies <sup>b</sup>	12 (11.8)	
Gynecological cancers <sup>c</sup>	11 (10.8)	
Head and neck cancers	7 (6.9)	
Lung cancer	5 (4.9)	
Genitourinary cancers <sup>d</sup>	4 (3.9)	
Sarcoma	3 (2.9)	
Intent of treatment (chemotherapy)		
Curative	74 (72.5)	
Palliative	28 (27.5)	
Caregiver relationship to patient		
Spouse		45 (44.1)
Children		37 (36.3)
Sibling		7 (6.9)
Parent		7 (6.9)
Friends/extended family		6 (5.8)

\*Formal education includes: School education, graduation, postgraduation, \*\*Employed includes: Agricultural farmer/laborers, students, private sector employees, \*\*\*Not employed includes: Housewife, on sabbatical, retired persons. <sup>a</sup>Stomach, pancreas, gall bladder, colon, rectum, cholangiocarcinoma, <sup>b</sup>Leukemia, lymphoms, myeloma, <sup>c</sup>Ovary, cervix, endometrium, <sup>d</sup>Prostate, urinary bladder

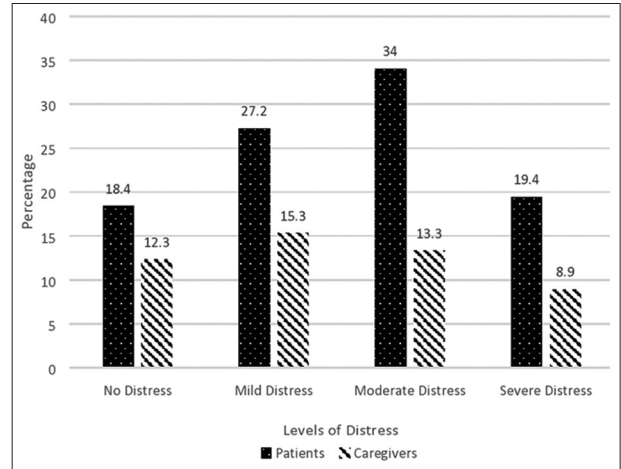


Figure 1: Levels of distress experienced among patients and caregivers

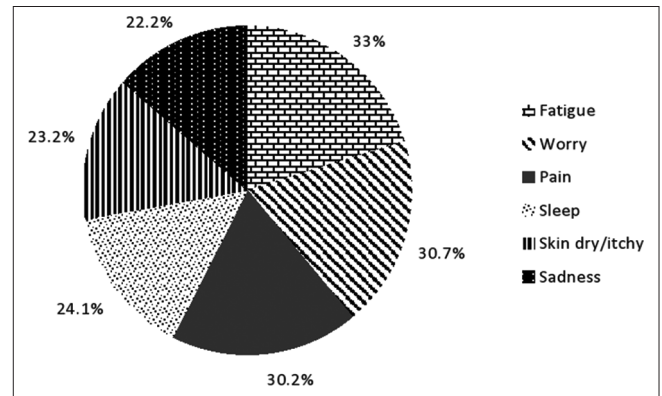


Figure 2: Areas of distress among patients

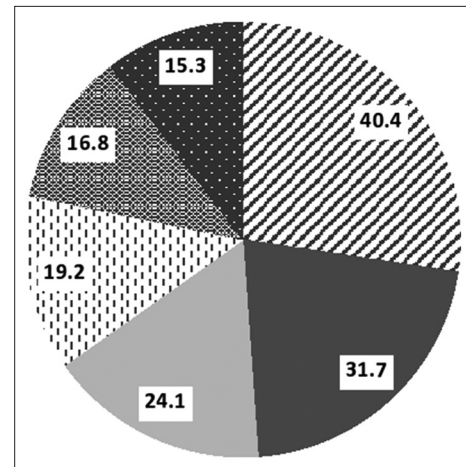


Figure 3: Areas of distress among caregivers

There was no statistical difference between the patients and caregivers in the category of emotional problems ( $P=0.000$ ). Both patients and caregivers reported significant distress in the area of emotional problems. Worry was the most frequently reported problem by patients (30.7%) and caregivers (31.7%), which had an influence on their overall distress ( $\chi^2 = 0.084$ ) [Table 2].

**Relationship between problem categories and intent of chemotherapy (curative or palliative)**

The association between the problem categories of distress and intent of chemotherapy was analyzed using Pearson product-moment correlation. Irrespective of the intent of chemotherapy received, the problem areas of distress that affected the patients and their caregivers remained the same. There was a positive correlation between physical areas of distress such as fatigue ( $r = 0.735, P = 0.004$ ), pain ( $r = 0.682, P = 0.000$ ), and intent of chemotherapy (curative or palliative) ( $r = 0.737, P = 0.000$ ) among patients. Similarly, for caregivers, a significant correlation was observed between emotional areas of distress such as worry ( $r = 0.684, P = 0.000$ ), sadness ( $r = 0.576, P = 0.002$ ), and intent of chemotherapy ( $r = 0.760, P = 0.000$ ) [Table 3].

**DISCUSSION**

Our study aimed to assess distress using the NCCN-DT and problem checklist among patients receiving chemotherapy and

their caregivers from an outpatient daycare unit of a tertiary cancer hospital. Both patients and caregivers were found to report moderate-to-severe levels of distress on the screening tool. However, patients reported distress in the categories of physical and emotional problems, which is consistent with studies that reported significant distress during chemotherapy in relation to patient’s physical and emotional well-being.<sup>[7-15]</sup>

Caregivers, on the other hand, reported significant issues in the categories of family and emotional problems. Santre *et al.* affirmed through their study findings that more than half of caregivers (53%) reported high emotional distress on the hospital anxiety and depression scale.<sup>[16]</sup> Other studies found low self-efficacy being reported by patients and caregivers which led to higher levels of anxiety, poorer quality of life, caregiver strain, and psychological distress. There were also significant correlations between cancer patient’s depression, anxiety, distress, somatization and caregiver’s depression, anxiety, distress, somatization.<sup>[17,18]</sup> Our findings are in line with literature, which suggests that caregivers face challenges such as processing emotions surrounding the patient’s initial diagnosis or recurrence and addressing the patient’s practical and emotional needs.<sup>[19]</sup>

Spouses and children were more commonly involved in caregiving in our study and reported higher levels of distress. Further, spouses (husbands of breast cancer patients) and adult

**Table 2: Association between problem categories among patients and caregivers at the daycare unit of a tertiary cancer hospital in Bengaluru, India (February-April 2018)**

Problem categories	Patients				Caregivers			
	Observed distress (%)	$\chi^2$	Df	P	Observed distress (%)	$\chi^2$	Df	P
Family problems								
Dealing with partner	4.4	3.56	1	0.046*	8.9	3.56	1	0.046*
Family health issues	12.3	65.40	1	0.000**	40.4	65.40	1	0.000**
Emotional problems								
Worry	30.7	0.084	1	0.77	31.7	0.084	1	0.77
Sadness	22.2	0.395	1	0.53	24.1	0.395	1	0.53
Fears	19.7	0.008	1	0.93	19.2	0.008	1	0.93
Nervousness	12.8	2.87	1	0.09	7.9	2.87	1	0.09
Physical problems								
Fatigue	33	29.377	1	0.000**				
Pain	30.2	13.496	1	0.000**	16.8	13.496	1	0.000**
Sleep	24.1	6.395	1	0.015	15.3	6.395	1	0.015
Skin dry/itchy	23.2	17.195	1	0.000**			1	
Eating	21.2	23.549	1	0.000**	13.8	23.549	1	0.000**

\*Statistically significant at  $P<0.05$  and \*\* $P<0.01$ . Df: Degree of freedom

**Table 3: Correlation between problem categories and intent of chemotherapy among patients’ and caregivers’ daycare unit of a tertiary cancer hospital in Bengaluru, India (February-April 2018)**

Patient-physical problems	Correlation coefficient (r)	P	Caregiver-emotional problems	Correlation coefficient (r)	P
Pain	0.682	0.000**	Sadness	0.576	0.002**
Fatigue	0.735	0.004*	Worry	0.684	0.000**
Sleep	0.472	0.005*	Fears	0.472	0.001**
Intent of chemotherapy***	0.737	0.000**	Intent of chemotherapy***	0.760	0.000**

\*Statistically significant at  $P<0.05$  and \*\* $P<0.01$ , \*\*\*Curative/palliative

children of dependent parents during the patient's treatment exhibited significant distress.<sup>[20,21]</sup>

The findings of our study and earlier conducted studies emphasize that patients and their caregivers report distress on various domains on different tools. It is important to consider patients and caregivers individually for screening and then plan for appropriate interventions to reduce the reported distress. The patients and caregivers that were screened for distress in our study reported interest in availing psycho-oncology services. A study found that breast cancer patients (42%) undergoing radiotherapy had expressed interest in receiving supportive counseling to manage their distress.<sup>[22]</sup> The interest shown by patients and caregivers toward adjunct support services such as psycho-oncology shows that they are open to receiving help from mental health professionals, which is contrary to popular belief that stigma exists toward psychological support.

Our study has a number of strengths. First, the need to understand and recognize both patient and caregiver distress individually has been highlighted. Second, our participants showed interest in receiving psychological support once levels of distress were addressed. Third, having in-house psycho-oncology services can prove beneficial for providing holistic care to patients diagnosed with cancer and their caregivers. Our study has limitations of being from a single-center and the sample size may not be representative of a larger population.

Future research warrants specific assessments to identify depression and anxiety for patients and caregivers at our center. Clinical implications suggest the need to routinely screen patients and their caregivers for distress at pivotal points and provide appropriate interventions to cope effectively during chemotherapy.

## CONCLUSION

Distress is prevalent among patients with cancer undergoing chemotherapy and their caregivers. Future research warrants specific assessments to identify depression and anxiety for patients and caregivers at our centre. Clinical implications suggest the need to routinely screen patients and their caregivers for distress at pivotal points and provide appropriate interventions to cope effectively during chemotherapy.

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## Conflicts of interest

There are no conflicts of interest.

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