# Understanding Psychosocial Distress and the Distressing Items on the Distress Thermometer Problem List: A cross-sectional Study from Nepal

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## ABSTRACT

**Introduction:** Psychosocial distress is common in cancer patients and there are various risk for it. Unfortunately, the prevalence and risk of psychosocial distress are not uniform within the studies. Understanding the prevalence and risk of psychosocial distress could be an effective for its prevention and management. The objective of this study is to evaluate the prevalence and most distressing items for psychosocial distress.

**Methods:** This descriptive cross-sectional study was done in a tertiary cancer center. A total of 253 heterogeneous cancer patients were enrolled in this study. Information regarding socio-demographic and clinical characteristics, psychosocial distress and source of most distressing problems were collected subjectively. Distress thermometer accompanied with problem checklist described their perceived distress and sources of distressing problems respectively. Descriptive statistics was used to analyze the variables. Statistical analysis was done using SPSS version 20.

**Results:** 51.8% of study cohorts were distressed. Among the problems category, most frequent were physical and emotional domains. The most distressing items were fatigue, worry, financial constraints and family health issue.

**Conclusion:** Psychosocial distress is commonly prevalent among cancer patients. These patients need regular screening and appropriate intervention for psychosocial concerns accordingly. Healthcare professionals should prioritize and address vulnerable issues that could be beneficial for preventing psychosocial distress.

**Keywords: Cancer; Distress thermometer; Nepal; Risk factors.**

## INTRODUCTION

Every year a huge number of patients are diagnosed with cancer. It is noted that the number of cancer survivors is in increasing trend and it will keep rising in coming years.[1] At the same time, the cancer survivors experience financial, physical (pain, hair loss, lymphedema, infertility, weight loss, shortness of breath, sexual problem, fatigue and so on) and emotional problems.[2–4] Besides suffering from physical and emotional problems, significant number of cancer survivors suffered from psychosocial distress (PD).[2,5–7]

In cancer patients, PD is common issues throughout the cancer trajectory period and it may be because of reaction to the diagnosis. Studies reported that there were wide variation in the prevalence of PD in cancer patients.[5–11] Furthermore, among Nepali studies the prevalence of PD ranges from 33.0% to 81.7%.[5,12] It varies with geographical location, sociodemographic and clinical characteristics of patients and study methodology. Cancer-related PD have profound negative impacts on patient's health as it is associated with poor quality of life[10] and even suicidal ideation.[13]

Emotional problem, physical problem, practical problem and family problem were established risk factors for PD in cancer patients.[2,6,8,9,12] Study even showed that physical problems/symptoms worsened the survival

of cancer patients.[14] However, evidence suggest that timely identification and management of PD and it's risk, are beneficial in reducing its negative consequences and improved patients overall survival.[15,16] Thus, proper management of risk factors that causes PD can be beneficial in cancer care.

The prevalence of PD and its contributing risk factors differs with studies.[2,3,5–7,10] The limited number of studies has investigated the prevalence and distressing items in Nepali cancer patients.[5,12] Understanding the prevalence and risk of PD could be an effective measure for its prevention in cancer patients. Hence, we aimed to determine the prevalence of PD in Nepali cancer patients and identifying the most commonly reported distressing problems in such cohorts.

## METHODS

This is a quantitative single center study with a descriptive cross-sectional in design. This study was conducted in Bhaktapur Cancer Hospital. The participants in this study were a cancer patients/survivors who were hospitalized in the department of medical, surgical and radiation oncology units or the patients who attended the out-patients clinic and/or cancer survivors those who were on regular follow-up. In this study, purposive sampling technique was adopted. For the estimation of reasonable study sample, Cochran's formula was taken as a basis. Based on the previous studies, the prevalence of PD in Nepali cancer patients was 87.1%[12] with a precision of 5% for a 95% confidence interval. Sample size (n=253) was calculated using the following formula $n= Z2 \times p (1-p)/d2$ considering non-response rate of 10%.

The inclusion criteria were age >18 years, with normal cognitive functions, diagnosed with cancer and willing to participate. Patients with a history of psychiatric illness were excluded from this study. Data collection was started after getting ethical clearance and approval letter from Institutional Review Board, NAMS, Bir Hospital (Ref No: 203/2079/80). Written informed consent was taken from the cancer patients prior to data collection by explaining the process and purpose of the study in detail. The researcher distributed questionnaire to eligible patients and completed the questionnaire by interview method. Data collection was done from September 1, 2022, to Jan 30, 2023. The research instrument was designed to collect information regarding socio-demographic, medical characteristics, PD and concerned problems that cause PD. The National Comprehensive Cancer Network (NCCN) recommended the Distress Thermometer (DT), which is a thermometer shaped visual analogue, ultra-short and non-stigmatizing simple screening scale consisting of 11 points ranging from 0 (no distress) to 10 (extreme distress). The DT is valid in many countries and a recommended cut-off score is 4 and in this study we are using DT with cutoff score of 4 to differentiate distressed vs. non-distressed.[2,6,17] The participants were requested to mark only one number from 0-10, which described their perceived distress over the past 7 days including the day of data collection.

The problem checklist (PL) is list of common concern problems, that is used to identify the nature/sources of the possible problems that cause PD. It helps in triage the patients for proper management. It contains a list of 39 possible problems that are categorized in 5 domains [practical problems (6 items), family problems (4 items), emotional problems (6 items), physical problems (22 items), and spiritual or religious concerns (1 item)].[17] Descriptive statistics (frequency, percentage, mean and standard deviation) was used to analyze the data. Statistical analysis was done using statistical package for social science version 20 (SPSS 20).

## RESULTS

A total of 253 patients were included in this study. Among the included study cohorts, 51.8% were less than 50 years of age, 70% were female, 83.4 % were married, 60.9% attended elementary school or below education and 74.7% were unemployed. Moreover, 39.9% patients had less than six months of illness, 32.4% were in advanced cancer stage, 62.5% received combined treatment and among cancer types 32.0% were breast cancer and so on (Table 1).

The mean score of DT was 4.03±2.445. At DT≥4, 51.8% (131) of participants were suffered from PD. Furthermore, the frequencies PD in regards to socio-demographic characteristic patients were age <50 years (59.5%), female gender (71.1%), single status (57.1%), and un-employed (54.0%). Moreover, among clinical characteristics the frequencies PD were duration of illness <6 months (62.4%), advanced cancer stage (58.5%), received single treatment (60.0%) and among the cancer type gynecological cancer (60.5%), followed by breast cancer (56.8%) and so on had higher PD (Table 1).

The frequencies of concerned problems checked in the PL by study population were assessed using multiple response analyses. Physical problems (96.20%) followed by emotional problems (90.10%), practical problems (81.70%), family problems (32.80%) and spiritual/ religious concerns (8.40%) were more frequent distressing problems for patients with a DT score of ≥4. In the physical category, distressed patients (DT ≥ 4) had more

problems with financial problem (66.4%), transportation (55.7%) and work/school (45.0%). In practical problems domain, the most 7 distressing problems were fatigue (71.0%), pain (58.8%), tingling in hand and feet (42.0%), sleep (41.2), eating (38.2%), appearance (38.2%) and nausea (37.4%) . In emotional problems domain, the most requent problems for distressed patients in descending order were worry (83.2%), sadness (61.1%), depression (58.8%), fears (57.3%), nervousness (58.0%) and loss of interest in usual activities (42.7%). Among the distressed patients with family problem, (22.9%) family health issues was most distressing item (Figure 1 and Figure 2).

**Table 1: Frequency distribution of sociodemographic and clinical characteristics of study population**

| Demographic and clinical characteristics | No. of patients (%) n = 253 | Non-Distressed <4(%) n=122(48.2) | Distressed ≥4(%) n=131(51.8) |
|---|---|---|---|
| **Age** | | | |
| <50 | 131(51.8) | 53(40.5) | 78(59.5) |
| >50 | 122(48.2) | 69(56.6) | 53(43.4) |
| **Gender** | | | |
| Male | 76(30.0) | 46(60.5) | 30(39.5) |
| Female | 177(70.0) | 76(42.9) | 101(57.1) |
| **Marital status** | | | |
| Married | 211(83.4) | 104(49.3) | 107(50.7) |
| Single | 42(16.6) | 18(42.9) | 24(57.1) |
| **Education level** | | | |
| Elementary school or less | 154(60.9) | 74(48.1) | 80(51.9) |
| Secondary school or above | 99(39.1) | 48(48.5) | 51(51.5) |
| **Occupation** | | | |
| Employed | 64(25.3) | 35(54.7) | 29(45.3) |
| Un-employed | 189(74.7) | 87(46.0) | 102(54.0) |
| **Type of cancer** | | | |
| Lung | 20(7.9) | 9(45.0) | 11(55.0) |
| Digestive | 71(28.1) | 42(59.2) | 29(40.8) |
| Breast | 81(32.0) | 35(43.2) | 46(56.8) |
| Gynecological | 43(17.0) | 17(39.5) | 26(60.5) |
| Others | 38(15.0) | 19(50.0) | 19(50.0) |
| **Cancer staging** | | | |
| 0-III | 171(67.6) | 88(51.5) | 83(48.5) |
| IV | 82(32.4) | 34(41.5) | 48(58.5) |
| **Treatment received** | | | |
| Single treatment | 95(37.5) | 38(40.0) | 57(60.0) |
| Combined treatments | 158(62.5) | 84(53.2) | 74(46.8) |
| **Duration of Illness** | | | |
| <6months | 101(39.9) | 38(37.6) | 63(62.4) |
| >6months | 152(60.1) | 84(55.3) | 68(44.7) |
| **Distress Thermometer (Mean±SD)** | 4.03±2.445 | | |

Single (Unmarried, Separate, Divorce, Widow), Combined treatments (Chemotherapy + Surgery + Radiotherapy + Targeted treatment), Single treatment (Palliative Chemotherapy, Palliative Targeted, Continuous maintenance treatment), Others (Bone and soft tissue, Hematological, Urogenital, Head and neck)

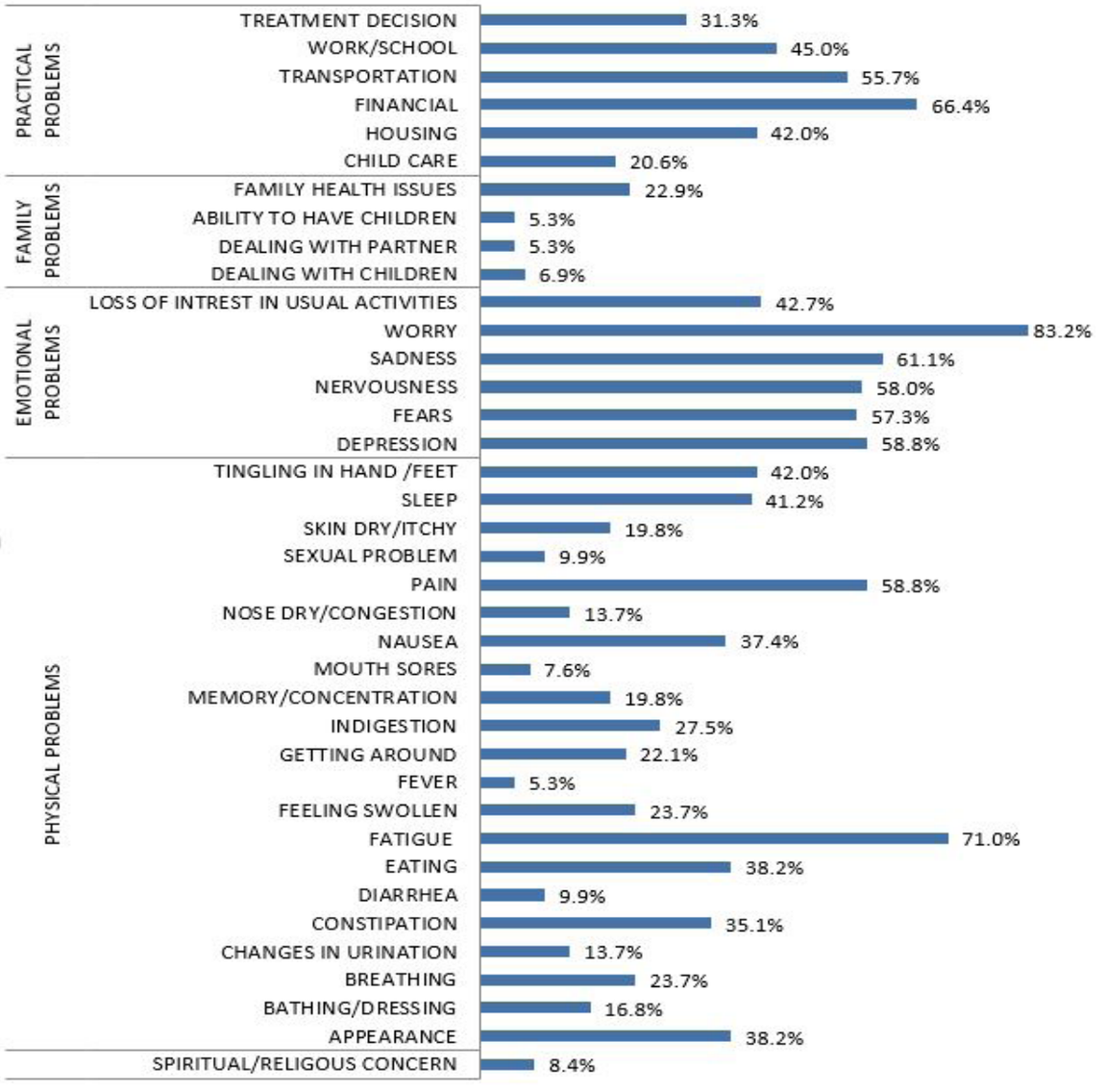


**Figure 1: Prevalence distribution of most distressing problems on distress thermometer problems checklist on distressed study patients.**

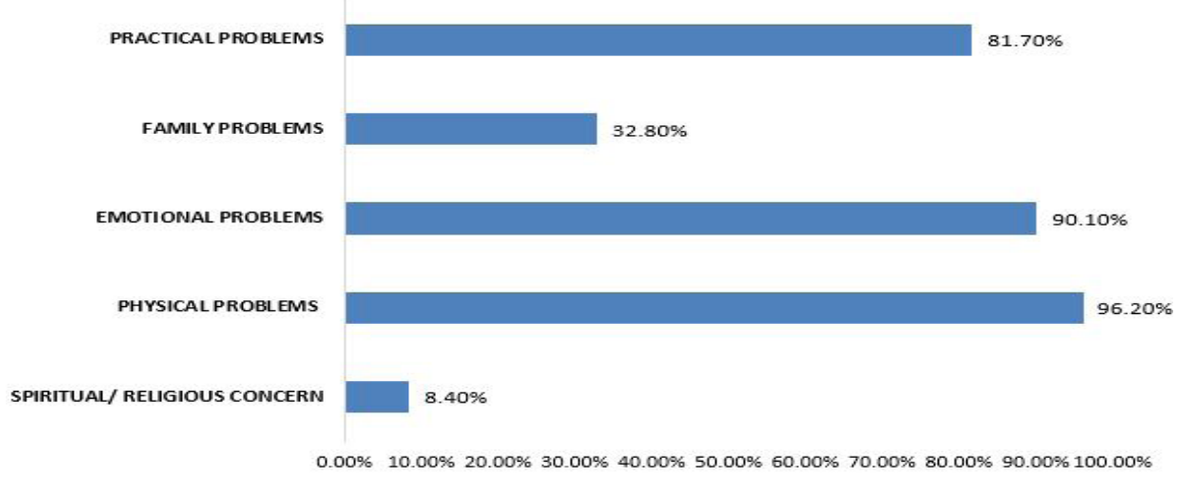


**Figure 2: Prevalence of distressing problems domains on distress thermometer problems checklist by distressed study patients**

## DISCUSSION

An abundance of studies had reported that the PD is commonly present among cancer patients.[2,6–8,12] PD could be because of cancer diagnosis, its aggressive treatments and related adverse effect, changes in lifestyle after diagnosis, and/or the direct effects of the disease itself. The prevalence of PD noted in our study was 51.8%, which was lower (81.7%) to a similar study in other tertiary care hospital of Nepal[12] but higher than another Nepali study done among hematological malignancies (33.0%).[5] Furthermore, our results was comparable with previous studies done among different geographical region with various methodology i.e. United States, Germany, Turkey and Korea.[10,18–21] Furthermore, our results solidifies the previous studies results showing that PD is an globe issue. Studies even showed that PD had negative impacts in cancer patients.[13,22] Interestingly, earlier reports suggest that with timely identification and proper management can reduce PD in cancer patients.[15,16] Hence, it should be screened and managed accordingly.

In this study, we found that distressed patients endorsed various sources of distressing problems, based on the frequency of checked items, the most distressing problem were physical followed by emotional, practical, family and religious/spiritual problems. These findings were in line with few studies done in Turkey,[10] China,[4,23] Germany,[24] Korea,[21] France[25] and India.[9] But unable to confirm the findings of other similar studies done in Malaysia, where the most distressing problem was family followed by emotional, physical, practical and religious/spiritual problems[11] and in Chinese study emotional followed by family, practical and physical.[6] Taken together, the most distressing problems are physical problems and emotional problems. Our finding helps in understanding the major sources of PD, It could help healthcare experts to prioritize the patients for appropriate support and management.

Additionally, among 22 problem items of physical problems domain, fatigue was the most distressing item checked by distressed patients. This physical symptom (fatigue) may be caused by disease itself, cancer treatment and its adverse effect and was consistent with the Asian, Eastern and Western studies with different methodology.[3,19,26–28] Furthermore, the National Comprehensive Cancer Network (NCCN) stated that Cancer-related fatigue is a distressing persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning.[29] Importantly, they advised for regular monitor and proper management fatigue in cancer patients.

In our study, regarding emotional problems category, most distressing reported problem was worry. This findings was exactly in line with study done in Nepal,[12] Norway[19], Sweden[30], China[31] and Saudi Arabia.[2] In general, cancer is the most feared illness and following cancer treatment (surgery, chemotherapy, radiation-therapy, hormonal, target and immune therapy), cancer survivors may face many unexpected challenges i.e. pain, anxiety, depression, low quality of life, weight loss, sexual problem, fear, sleep and so on, which can negatively affect patients health leading to cause worry about upcoming outcomes and challenges. Hence, cancer patients should be properly counselled regarding cancer management and its upcoming events.

Among practical problems category, most distressing reported problem was financial constraints. This is in accordance to the studies done in Nepal[12] and India.[8] Studies showed that low income significantly associated with distress.[2,6] Nepal is low and middle-income country and in real world cancer is costly treatment, hence financial constraints might be the plausible cause for most distressing problem. Additionally, regarding family problem, that most distressing problem was family health issues in our study. This is consistent with earlier done in Nepal[12], Saudi arabia[2] and United States.[20] Finally, among distressed patients, least distressing problem was religious/spiritual problems, which is similar to studies from various cultures countries like United States,[19] Australia,[3] China[4,7] and India.[9] It shows that distress is because of cancer treatments and its side-effect.

In our study, younger age, female, unmarried/single, unemployed, advanced stage, received combined treatments, recent cancer diagnosed and patients with gynecological cancer had higher PD. This finding is in line with studies done on different geographical location with different methodology.[2,5–8,10,23]

Collectively, this study highlights the common source of PD in cancer patients. Our study demonstrates that PD is commonly prevalent in cancer patients. During cancer trajectory period, patients may need regular psychosocial supports that might get easily ignored in the absence of regular screening. In addition, Nepali cancer patients need proper screening and appropriate intervention for psychosocial concerns before they become national burden. Hence, appropriate strategies and treatments plan should developed for its management and while screening, healthcare professionals should prioritize vulnerable patients issues i.e. physical and emotional

problems, which could be helpful in preventing PD. There were some limitations in our study. Firstly, this was a single center cross-sectional study. Secondly, we only used Distress Thermometer and problem checklist to know distress and its source. Finally, multicenter studies are needed to validate our results.

## CONCLUSION

At a DT cut-off score of ≥4, half of study cohorts (51.8%) were distressed. Among the problem domains, most frequent problems were physical and emotional problems. The majority of distressing problems items were fatigue, worry, financial constraints and family health.

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