

# Assessment of emotional distress in palliative care: Edmonton Symptom Assessment System-revised (ESAS-r) vs Distress Thermometer

## Original Article

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### Abstract

**Objectives.** To evaluate the sensitivity and specificity of the Distress Thermometer (DT) as a screening tool for emotional distress in oncological palliative care patients and to compare the DT with the Edmonton Symptom Assessment System-revised (ESAS-r) and the gold standard to determine the most appropriate assessment method in palliative psychological care.

**Methods.** Data were collected from psychological screening tests (ESAS-r and DT), and clinical interviews (gold standard) were conducted by a clinical psychologist specialist in palliative oncology from January 2021 to January 2022 in an oncology palliative care service.

**Results.** The sample consisted of 356 first-time patients with a diagnosis of advanced cancer in palliative care. The most frequently reported oncological diagnoses were gastrointestinal tract (49.3%) and breast (18.3%). Most patients were female ( $n = 206$ ; 57.9%), 60.4% were married/with a partner, 55.4% had between 6 and 9 years of schooling, and a median age of 57 (range, 46–65) years. The cutoff of the DT was 5, with a sensitivity of 75.88% and specificity of 54.3%. Emotional problems (sadness and nervousness) had a greater area under the curve (AUC) when measured using the DT than the ESAS-r; however, only in the case of the comparative sadness and discouragement was the difference between the AUC marginally significant.

**Significance of results.** The use of the DT as a screening tool in oncological palliative care is more effective in the evaluation of psychological needs than the ESAS-r. The DT, in addition to evaluation by an expert psychologist, allows for a more comprehensive identification of signs and symptoms to yield an accurate mental health diagnosis based on the International Classification of Diseases-11th Revision and/or Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition.

## Introduction

Cancer diagnosis, treatment, surveillance, and palliative management are fraught with distress. Distress is defined by the National Comprehensive Cancer Network (NCCN) (2023b) as “a multifactorial unpleasant experience of a psychological (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with a person’s ability to cope effectively with cancer, its physical symptoms, and its treatment; extending along a continuum from normal feelings of vulnerability, sadness, and fear to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis,” which changes throughout the course of the oncological disease (Cutillo et al. 2017).

Distress occurs frequently in patients with advanced cancers (Aboshaiqah et al. 2016; Ferrell et al. 2017). Therefore, there is a need to provide palliative care in conjunction with oncological care to address the effects of cancer and its treatment on quality of life (QOL). Unmanageable pain, fatigue, and emotional distress (anxiety and/or depression) are the most frequently reported symptoms and are often considered severe (Basch et al. 2016; Deshields et al. 2014; Hwang et al. 2016; Stark et al. 2012), and the severity and impact of distress are associated with reduced QOL and survival (Hamer et al. 2009; Mitchell 2010; Pirl et al. 2014).

Numerous cancer programs face challenges in implementing routine screening to assess for the presence of distress. In the 1990s, the American College of Surgeons (ACoS) Commission on Cancer established the identification of emotional distress as an essential accreditation standard in cancer care units (Wagner et al. 2013) and proposed 6 components required to facilitate the implementation of an effective, efficient, clinically meaningful, safe, equitable, and sustainable screening program: (1) having a psychosocial representative, (2) identifying the appropriate time to assess distress, (3) method or type of screening,

(4) distress assessment tools, (5) assessment and referral, and (6) documentation (distress screening results, follow-up assessment plan; type, source, and severity of distress; relevant history; suicidal ideation; and types of recommended interventions) (Feldstain et al. 2014).

Assessment of emotional distress and referral to psychosocial services are essential elements of palliative care. However, face-to-face (psychologist-patient) assessment of distress demands both financial resources and time; therefore, screening tools are required to identify the clinical needs of patients and provide the most appropriate psychological treatment (Thalén-Lindström et al. 2016).

There are several tools that vary in length, breadth, cultural equivalence, and sensitivity/specificity to identify patients in need of further evaluation (Pirl et al. 2014). However, there is a lack of consensus on the best screening tool for emotional distress. Several brief screening tools have demonstrated high sensitivity in identifying patients with high levels of distress; however, they lack specificity and thus produce many false positives (Parry et al. 2012; Smith et al. 2017). Among the main extensive screening instruments are the Hospital Anxiety and Depression Scale (HADS) (López-Roig et al. 2000), the Brief Symptom Inventory-18 (Martínez-López et al. 2019), and the Psycho-Oncology Screening Tool (Kilbourn et al. 2011), which have low false-positive rates; however, their use may be limited when considering royalties and cost (Zabora and Macmurray 2012).

One of the most used screening tools characterized by brevity and ease of application in the palliative setting is the Edmonton Symptom Assessment System (ESAS), which is validated in a palliative care setting and was reported to be adequate for documenting the subjective experience of major symptoms in patients with cancer (Bruera et al. 1991; Chang et al. 2000; Hui and Bruera 2017). However, the ESAS is not without limitations; symptom monitoring and follow-up in the face of deterioration or improvement is not a standardized practice for all clinicians in the field (Hui and Bruera 2017; Koesel et al. 2019; Rauenzahn et al. 2017). Furthermore, regarding the ESAS-psychological symptoms (depression and anxiety), are hyper-expressed, especially by first-time patients, because the ESAS reports symptoms in the last 24 hours or at the time of assessment (Hui and Bruera 2017; Mercadante et al. 2019).

Another widely used instrument is the Distress Thermometer (DT), which evaluates emotional distress quickly, noninvasively and acceptably in patients with cancer (Roth et al. 1998), and which the NCCN adds a list of problems; to standardize and encourage the presence of emotional distress as a standard part of oncology patient visits. This instrument is free, has been translated into more than 71 languages (National Comprehensive Cancer Network (NCCN) 2023a), has face validity, and allows for the rapid detection of psychological morbidity, mainly depression, anxiety, and emotional distress. The DT was shown to be a suitable screening tool in patients with advanced cancer receiving specialized palliative care in both outpatient and inpatient/hospice settings and can be implemented in routine clinical practice (Graham-Wisener et al. 2021; Guan et al. 2019; Ryan et al. 2012; Thekkumpurath et al. 2009; Wüller et al. 2017). The DT consists of 2 parts: an 11-point visual analog scale (0–10) on which respondents indicate the level of distress they have felt during the last week (from “no distress” to “extreme distress”) and a list of problems that may vary according to the version (36 or 40 problems). The list includes common problems related to the cancer experience and identifies whether the patient is experiencing practical, family, emotional, spiritual-religious, and/or physical problems.

Given the relevant role that instruments, such as the ESAS and DT, can play in the detection of emotional distress, documenting their validity is of utmost importance. Therefore, the main objective of this study was to analyze the sensitivity and specificity of the DT as a screening tool in the detection of emotional distress in patients with advanced cancer in palliative care. A secondary objective was to identify the most appropriate assessment method in palliative psychological care.

## Methods

A study designed to identify the most sensitive test for detecting emotional distress was conducted. We planned to collect information from all psychological screening tests and clinical interviews (gold standard) conducted by a clinical psychologist expert in palliative oncology from January 2021 to January 2022. The data were retrieved via review of the electronic file of patients with a diagnosis of advanced cancer who attended the Palliative Care Unit of the National Cancer Institute of Mexico. The study was approved by the Research Committee of the National Cancer Institute under number 2022/069.

Patients with any oncological diagnosis, of any age and sex, who attended the palliative care service were included. Patients were excluded if they had severe cognitive alterations associated with brain metastases, metabolic decompensation, or any uncontrolled physical symptoms (mainly pain, nausea, and vomiting) at the time of evaluation.

In the clinical evaluation performed by the expert clinical psychologist, we decided to add the list of emotional problems from the DT using a Unique Numerical Evaluation (UNE) with a score from 0 (absence) to 10 (maximum intensity) to quantify the patient's symptoms in the last 2 weeks, including the day on which the interview was conducted. For comparative purposes, the ESAS-revised (ESAS-r) was used, taking into consideration the occurrence of symptoms on the day of the interview.

## Instruments

Edmonton Symptom Assessment System version ESAS-r scale, that was adapted and validated in Spanish in patients with advanced cancer, consists of visual numerical scales (from 0 to 10) to measure the intensity of 10 symptoms: pain, exhaustion (tiredness), drowsiness, nausea, loss of appetite, shortness of breath, discouraged, nervous, insomnia, well-being; with a Cronbach's alpha reliability of 0.86, and discriminant validity between patients with different functional statuses finding significant differences ( $p < 0.01$ ) and between inpatients and outpatients (Mann-Whitney  $U$ ,  $p = 0.02$ ) was used (Carvajal et al. 2011).

DT version 2.2020 was used, which consists of 2 parts: a single item measuring 0 (no distress) to 10 (extreme distress) and a list of 39 problems grouped into 7 practical, 4 family-related, 6 emotional, 1 religious or spiritual, and 22 physical problems, where presence/absence is recorded. The DT has demonstrated good sensitivity and specificity, with a cutoff  $>4$  (indicates distress) (National Comprehensive Cancer Network (NCCN) 2020; Riba et al. 2019).

## Statistics

The population was described using frequencies and percentages for categorical variables and medians with interquartile ranges for

quantitative variables. A receiver operating characteristic (ROC) curve was used to quantify the ability of the DT to discriminate between 2 states, (patients with emotional and physical alterations and patients without these alterations) in comparison with the psychological evaluation conducted by a clinical psychologist expert in palliative oncology, which was the variable that determined the true state of the patient (reference variable). Likewise, sensitivity/specificity values, the area under the curve (AUC), and cutoffs were estimated. In addition, comparisons were made between the nervousness and discouragement portions of the ESAS-r scale and the assessment of the intensity of emotional problems (sadness and nervousness) portion of the DT, considering the reference variable in the ROC curves and areas under the curve. *P* values <0.05 were considered statistically significant.

## Results

During the study period, 471 first-time patients were included in the Palliative Care Service of INCan. Of these patients, 115 were excluded for the following reasons: delirium was identified during screening (34.8%), the patient was emotionally overwhelmed and required crisis psychological intervention (13.9%), and the patient spoke an indigenous language and did not understand Spanish (6.1%).

The final sample consisted of 356 first-time patients with a diagnosis of advanced cancer. Most patients were female ( $n = 206$ ; 57.9%), 60.4% were married/with a partner, 55.4% had between 6 and 9 years of schooling, and a median age of 57 (range, 46–65) years. The most frequently reported oncological diagnoses were gastrointestinal tract (stomach, liver and biliary tract, rectum, pancreas, and colon) (49.3%) and breast (18.3%), and most participants had a Karnofsky Performance Status of 70–80 (see Table 1).

### Diagnostic accuracy of the DT

Considering the accuracy of the DT in determining attention problems, including emotional disturbances, in comparison with the clinical interview conducted by an expert clinical psychologist in palliative oncology, an AUC of 0.6995 was obtained, which is the measure of validity of the DT (Fig. 1). Sensitivity and specificity were also calculated.

Table 2 outlines the sensitivity and specificity values and cutoffs of the DT. In this study, a patient with practical, interpersonal relationship-related, emotional, spiritual, and physical problems was considered to be a patient who obtained a score  $\geq 5$  on the DT, with a sensitivity of 75.8% and specificity of 54.3%. This cutoff resulted in a frequency of emotional and physical disturbances of 60.1% in the sample. Increasing the cutoff to  $\geq 6$  would have decreased the sensitivity to 54.7%, increased the specificity to 74.2%, and decreased the frequency of disturbances to 39.6%, while reducing the cutoff to 4 would have increased the sensitivity, decreased the specificity, and increased the frequency of disturbances to 69.9%.

### Discriminatory ability of DT for sadness and nervousness versus ESAS-r – discouragement and nervousness

In the comparison between DT and ESAS-r, emotional problems (sadness and nervousness) measured using DT showed a greater AUC, a measure of accuracy intended to discriminate between cases and non-cases (Fig. 2), than those using ESAS-r; however,

**Table 1.** Demographic and clinical characteristics of the sample ( $n = 356$ )

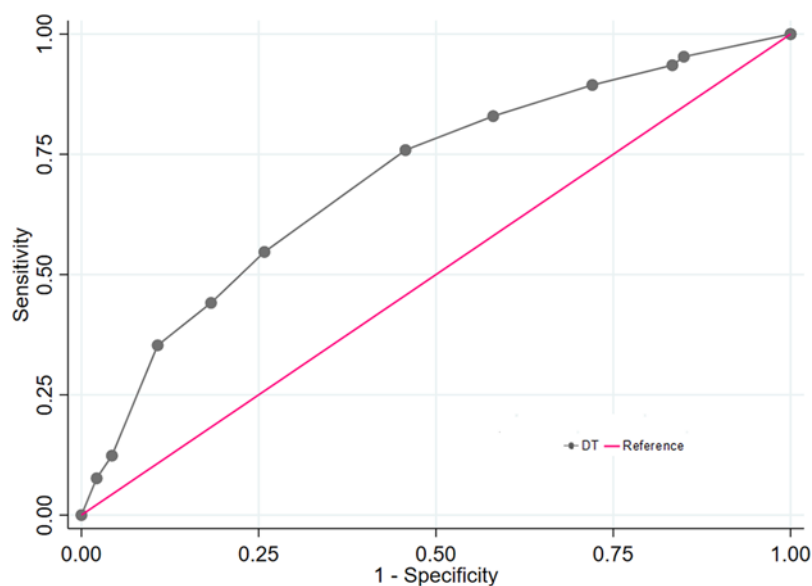
Characteristics	Categories	Overall <i>n</i> (%)
Sex	Female	206 (57.9)
	Male	150 (42.1)
Age (years)	Median (IQR)	57 (46–65)
Marital status	Married/with a partner	215 (60.4)
	Single	141 (39.6)
Schooling	Illiterate	11 (3.1)
	Primary	111 (31.2)
	Secondary	86 (24.2)
	Preparatory	47 (13.2)
	Technical	28 (7.9)
	Bachelor's degree	66 (18.5)
	Master's/Doctorate	7 (2.0)
Monthly income	Median (IQR) <sup>a</sup>	277.4 (181.2–453.0)
Entity of residence	State of Mexico	129 (36.2)
	City of Mexico	111 (31.2)
	Other	116 (32.6)
Oncological diagnosis	Breast cancer	65 (18.3)
	Stomach cancer	46 (12.9)
	Liver and biliary tract cancer	37 (10.4)
	Rectal cancer	35 (9.8)
	Pancreatic cancer	34 (9.5)
	Colon cancer	24 (6.7)
	Other	117 (32.2)
	Karnofsky Performance	40
Status	50	71 (19.9)
	60	64 (18.0)
	70	84 (23.6)
	80	79 (22.2)
	90	51 (14.3)
	100	2 (0.6)

IQR: interquartile range.  
<sup>a</sup>17.66 as of May 29, 2023.

only in the case of the comparison between sadness and discouragement, was the difference between the AUCs marginally significant (Table 3).

## Discussion

Emotional distress is important in palliative care as it is one of the main symptoms presenting in patients with advanced cancer undergoing palliative management (Ascencio-Huertas et al. 2021; Mitchell 2010; Ullrich et al. 2017; Vehling et al. 2017);



**Figure 1.** ROC curve of the psychological diagnosis by the expert and Distress Thermometer.

**Table 2.** Validity values of the Distress Thermometer and percentage of patients correctly classified

Cutoff	Sensitivity (%)	Specificity (%)	Correctly classified patients (%)
≥0	100.0	0.00	47.75
≥1	95.29	15.05	53.37
≥2	93.53	16.67	53.37
≥3	89.41	27.96	57.30
≥4	82.94	41.94	61.52
<b>≥5</b>	<b>75.88</b>	<b>54.30</b>	<b>64.61</b>
≥6	54.71	74.19	64.89
≥7	44.12	81.72	63.76
≥8	35.29	89.25	63.48
≥9	12.35	95.70	55.90
≥10	7.65	97.85	54.78
>10	0.00	100.00	52.25

Bold values show cutoff of DT.

**Table 3.** Comparison of the areas under the curve for each test

Measurement	Observations	Area	P value
DT Nervousness	356	0.6864	0.0773
ESAS-r Nervousness	356	0.6313	
ESAS-r Discouragement	356	0.6906	0.0509
DT Sadness	356	0.7474	

DT: Distress Thermometer.

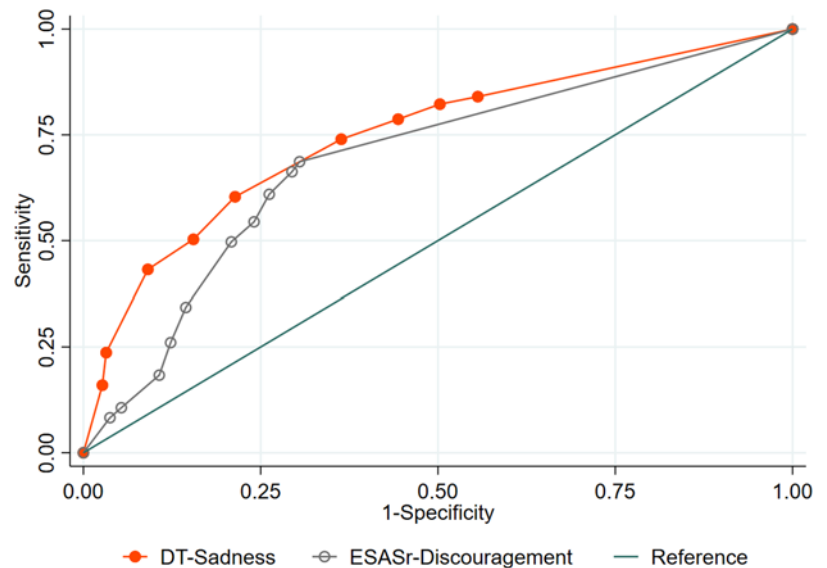
however, it is not always evaluated or addressed, as reported by Hart et al. (2022), despite its association with increased severity of physical symptoms, suffering, and mortality in patients with cancer, and even more so in those with advanced cancer undergoing palliative management. Moreover, emotional distress has

been recognized as a standard of quality of care and accreditation, as established by the NCCN, the Quality Oncology Practice Initiative of the American Society for Clinical Oncology and the ACoS Commission on Cancer (Deshields and Asvat 2023) and the Lancet Oncology Commission (Kaasa et al. 2018).

Applying the DT as a screening tool, in addition to a clinical assessment by an expert psychologist in palliative oncology, provides further clues about the type of interventions and affected areas and can yield an accurate mental health diagnosis based on the Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM-V) or International Classification of Diseases – 11th Revision (ICD-11) and help to prioritize care needs. The DT is key to understanding the link between the problems faced by patients and emotional distress, especially depression and anxiety. In the palliative oncology context, having screening tools, such as the DT, to assess emotional distress in patients has implications for clinical practice. Detecting, monitoring, and addressing distress in all phases of oncological disease allow caregivers to provide more direct, individualized interventions based on the needs of each patient under a stepped care model, as proposed by Holland et al. (2013).

As a tool used for screening symptoms in palliative care, the ESAS-r only assesses patients in the context of psychological needs, discouragement, and nervousness; in contrast, the DT assesses different dimensions (practical, family, religious/spiritual, emotional, and physical problems) that allow clinicians to identify the level of emotional distress and associated factors in palliative oncology patients (Ascencio-Huertas et al. 2021). Therefore, although the ESAS-r is considered a useful screening tool that can improve the clinical management of patients with advanced cancer due to its ease of administration and relative speed of completion, one of its main limitations is that it is a unidimensional scale that only evaluates the intensity of symptoms. Furthermore, the ESAS-r considers these symptoms only in the last 24 hours, limiting the establishment of an accurate psychological diagnosis as these symptoms may be reactive to a stressful event, such as a visit to the hospital, undergoing an examination, or receiving treatment, and may not be attributable to a specific psychological condition (Hui and Bruera 2017).





**Figure 2.** Sensitivity and specificity of the DT-Sadness versus the ESAS-r-discouragement.

Regarding the use of the DT as a screening tool for the detection of emotional distress, we recommend adding the UNE, which provides additional parameters for psychological anamnesis, as reported by Rodríguez García and Rodríguez Pupo (1999). The UNE lists emotional problems and presence/absence of physical symptoms, such as sleep, food, and memory/concentration, as these are symptoms associated with the presence of psychological disorders, such as depression or anxiety.

In addition, the UNE considers the symptoms in the last 15 days, including the day of the evaluation. In this sense, the DT provides information that allows the patient to identify the different dimensions in which they perceive that there is a problem. In clinical practice, the DT more comprehensively identifies signs and symptoms to infer a psychological diagnosis so that management strategies can be designed based on the specific needs of each patient.

Furthermore, using this screening tool (DT or ESAS-r), a proper anamnesis can be performed by an expert in palliative psychology to obtain a more in-depth understanding of certain aspects, such as the appearance (date and form), localization and irradiation (in case of referring pain as a symptom), quality or character (peculiar sensation of the symptom), intensity (light, moderate, or severe), alleviating factors (with substances or circumstances), frequency (periodicity, rhythm, and schedule), duration (time), evolution, and accompanying or associated symptoms (symptoms that have intimate or simultaneous presence). In certain cases, psychological diagnostic scales can be used to establish a more accurate diagnosis.

When identifying the sensitivity and specificity of the DT, we found that a cutoff  $\geq 5$ , unlike other studies reporting a level of evidence for a cutoff of 4, maximizes sensitivity and specificity for an established criterion, with a good balance between pooled sensitivity (0.81, 95% confidence interval [CI] 0.79–0.82) and pooled specificity (0.72, 95% CI 0.71–0.72) (Donovan *et al.* 2013; Ma *et al.* 2014; Sun *et al.* 2021).

With this cutoff, the expected frequency of emotional distress increased to 60%, a value that is considered relevant in the context of patients with an advanced cancer diagnosis. Furthermore, it was determined that the DT is an excellent tool for detecting people with emotional distress, although it is not as effective

in excluding those without distress. The hypothetical increase in detection due to false positives is compensated considering that emotional distress is the gateway to other more complex emotional disorders and possibly to their early manifestation; therefore, detection becomes highly relevant.

It is difficult, especially in Mexican culture, to identify and express emotions due to sociocultural expectations. In this regard, Páez *et al.* (2000) report that interpersonal relationships and social roles play a relevant role in emotional expression; on the one hand, they favor emotional expression through sharing and being affectionate, while on the other hand, they discourage revealing emotions that may be socially undesirable or inappropriate, such as sadness, anger, and fear, as mentioned by Sanchez-Aragon and Diaz-Loving (2009). However, the importance of detecting and managing these emotions in palliative cancer patients is clear, so timely detection is a priority.

Among the main strengths of this study are that the screening instruments and clinical evaluations were performed by a psychologist with expertise in palliative oncology care; therefore, both processes were standardized, and reliability was high. Among the main limitations of the study is that we did not consider the parameter of QOL, which is one of the main indicators of comprehensive patient care in palliative care. Therefore, our recommendation for future studies is to include the measurement of QOL as part of the standard evaluation of this population. Another limitation is that this study population included a large proportion of patients with breast cancer and gastrointestinal tumors, so we recommend including patients with other oncological diagnoses, such as gynecological, urological, and head and neck cancers, in future studies. Furthermore, only a single evaluation was performed, and the trajectory of disease progression to outcome was not considered in this study.

## Conclusions

The use of the DT as a screening tool in palliative oncology is effective in the assessment of psychological needs in clinical practice because it allows clinicians to more comprehensively identify

signs and symptoms to infer a probable psychological diagnosis. Applying the DT as a screening tool provides clinicians with a greater indication regarding the optimal interventions and affected areas. Together with clinical evaluation by an expert psychologist in palliative oncology, the DT can yield an appropriate mental health diagnosis based on ICD-11 and/or DSM-V, which has a positive impact when determining psychological interventions as they are based on the individual needs of each patient.

**Data availability statement.** According to data protection regulations, the data set cannot be made public. However, the data are available from the authors upon reasonable request.

**Author contributions.** LA: original idea, design of the study, application of the instruments, capture, and review of the integrity of the database, drafting and critical revision of the paper, and drafting of the final manuscript.

SA: critical revision of the draft and drafting of the final manuscript.

AP: data analysis, critical review of the paper, and participation in drafting the manuscript.

All authors reviewed and approved the final version of the article.

**Competing interests.** The authors declare no conflicts of interest.

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