The Distress Thermometer: Cutoff Points and Clinical Use

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Purpose/Objectives: To establish an optimal cutoff point for the National Comprehensive Cancer Network's Distress Thermometer (DT) as a screening measure to identify and address psychological distress in individuals with cancer, and to examine whether distress as measured by the DT significantly changes across the treatment trajectory.

Design: Secondary analyses of baseline data from a longitudinal parent study examining a computerized psychosocial assessment.

Setting: Three diverse comprehensive cancer centers across the United States.

Sample: 836 patients with a current or past diagnosis of cancer.

Methods: Study participants were selected from a randomized clinical trial. Patients during any stage of the cancer treatment trajectory were recruited during a chemotherapy infusion or routine oncology appointment.

Main Research Variables: The Behavioral Health Status Index and the DT were administered and compared using receiver operating characteristic analyses.

Findings: Results support a cutoff score of 3 on the DT to indicate patients with clinically elevated levels of distress. In addition, patients who received a diagnosis within the 1–4 weeks prior to the assessment indicated the highest levels of distress.

Conclusions: Providers may wish to use a cutoff point of 3 to most efficiently identify distress in a large, diverse population of patients with cancer. In addition, results indicate that patients may experience a heightened state of distress within 1–4 weeks postdiagnosis compared to other stages of coping with cancer.

Implications for Nursing: Using a brief measure of distress can help streamline the process of screening for psychosocial distress.



Brief screening instruments have been developed to serve as economical and efficient ways to identify potential psychosocial difficulties. Early diagnosis and treatment of distress has the potential to reduce emotional suffering, the severity of physical symptoms, and excessive use of health services (Carlson & Bultz, 2004; Carlson, Groff, Maciejewski, & Bultz, 2010; Faller et al., 2013; Holland & Bultz, 2007; Jacobson & Ransom, 2007; Mehnert & Koch, 2007). Brief screening measures can also improve patient-provider communication and can promote psychosocial referrals (Carlson et al., 2012). In the past decade, efforts have been made to increase the use of psychosocial assessment and subsequent intervention systematically and routinely across hospitals (Jacobsen & Ransom, 2007). Improvements have been made, but a range of patients eligible for psychosocial services often do not receive them (Zebrack et al., 2015). Because of time constraints or treatment demands, oncology providers may avoid using screening or clinical interview measures and, instead, rely on clinical judgment (Mitchell, Hussain, Grainger, & Symonds, 2011; Werner, Stenner, & Schüz, 2012).

The National Comprehensive Cancer Network (NCCN) created distress management guidelines. Included in the guidelines was a global screener of distress (the Distress Thermometer [DT]), an accompanying Problem List, and treatment recommendations for psychosocial issues (Psychosocial Distress Practice Guidelines Panel, 1999). The DT is a one-item, 11-point Likert-type scale represented on a visual graphic of a thermometer that ranges from 0 (no distress) to 10 (extreme distress). Patients use the DT to indicate their level of distress. Patients who report high levels of distress can be administered the accompanying 40-item Problem List, which details common problems related to the cancer experience. The Problem List helps providers identify whether the patient is experiencing practical, family, emotional, spiritual/ religious, or physical problems. The DT has proven to be feasible, accessible, and informative (Jacobson & Ransom, 2007; Mitchell, 2010). Studies have tested the validity of the DT, most of which have compared it to the widely accepted Hospital Anxiety and Depression Scale and the Brief Symptom Inventory (Chambers, Zajdlewicz, Youlden, Holland, & Dunn, 2014; Grassi et al., 2013; Holland & Bultz, 2007; Jacobsen et al., 2005; Mitchell, 2010; Thalén-Lindström, Larsson, Hellbom, Glimelius, & Johansson, 2013). Findings from Akizuki et al. (1997) support the DT as an effective method of identifying psychological distress in cancer populations. Based on the results of diagnostic interviews with psychiatrists, Akizuki et al. (1997) found that patients with clinical diagnoses scored significantly higher on the DT than those without a diagnosis.

Originally, a cutoff score of 5 was used to identify those patients experiencing significant distress because of its numerical placement at the midpoint of the 0-10 scale (Psychosocial Distress Practice Guidelines Panel, 1999; Roth et al., 1998). However, a more recent version of the NCCN practice guidelines for distress recommends that a DT score of 4 or higher indicates moderate to severe distress (NCCN, 2016). In research involving mixed samples, cutoff scores indicating distress vary by culture, language, setting, and demographics, but most studies support a DT cutoff score of 4 or 5 (Donovan, Grassi, McGinty, & Jacobsen, 2014; Grassi et al., 2013; Jacobsen et al., 2005; Mansourabadi, Moogooei, & Nozari, 2014; Martinez, Galdón, Andreu, & Ibáñez, 2013). When researchers have attempted to establish cutoffs for disease-specific groups, the findings have demonstrated a range of results. For example, using receiver operating characteristic (ROC) analyses, research has validated the use of the DT in many cancer populations. Cutoff points have been established for patients with intracranial tumors (6), breast cancer (5), and brain cancer (4) (Dabrowski et al., 2007; Goebel & Mehdorn, 2011; Iskandarsyah et al., 2013; Keir, Calhoun-Eagan, Swartz, Saleh, & Friedman 2008). Optimal DT cutoff points may vary over time. In a sample of patients with prostate cancer, the DT cutoff score to identify significant distress decreased from 4 soon after diagnosis to 3 at longer-term assessments (Chambers et al., 2014). Although these disease-specific cutoff points may be the best option for providers working in one specialized area of oncology, many community cancer centers treat diverse groups of patients. Providers in those settings need a tool and validated cutoff points to use with heterogeneous groups of patients (National Cancer Institute, 2007).

The purpose of the current study was to establish a comprehensive DT cutoff point based on a large heterogeneous sample of patients with cancer and to determine whether this cutoff was affected by the time since diagnosis. DT scores were compared to Behavioral Health Status (BHS) Index scores, which were used to indicate low, moderate, and high levels of distress based on patient reports of psychological symptoms (anxiety and depression), functional disability, and subjective well-being (Grissom, Lyons, & Lutz, 2002).

Methods

Participants

Study participants were selected from a previously conducted randomized clinical trial on the efficacy of a computerized psychosocial assessment, the Mental Health Assessment and Dynamic Referral for Oncology (MHADRO) (Boudreaux et al., 2011). A total of 836 patients were included from three comprehensive cancer centers: the University of Massachusetts Medical School Cancer Center (n = 581), the Cancer Institute of New Jersey at Cooper Hospital (n = 126), and the University of Texas MD Anderson Cancer Center (n = 129). Eligibility criteria in that study included having a current or past diagnosis of cancer, being older than age 18 years, and not having a significant cognitive deficit that may affect the ability to consent to the study (Boudreaux et al., 2011). Participant characteristics can be found in Table 1.

Procedure

Participants in the Boudreaux et al. (2011) study completed a baseline assessment on a tablet computer during a chemotherapy or routine oncology appointment. Patients were recruited at all points during the cancer trajectory (i.e., diagnosis, treatment, and survivorship). Patients were approached for enrollment during a chemotherapy infusion or an ambulatory care appointment with an oncologist. Eligible participants were recruited, enrolled into the study, and randomized to the intervention or control group before completing the assessment. The consent form signed by all participants was explicit in that patients would be enrolled and then randomized to either the intervention or control condition. Randomization into the intervention or control group was completed by an internal random number generator. The University of Massachusetts Medical School Institutional Review Board approved all procedures. Participants in the intervention group received three printed reports that included details of their psychological adjustment; one was provided to the patients, one was shared with their oncologist, and one was placed in the electronic health record. Participants in the intervention group who scored high in distress automatically received the contact information for two appropriate mental health providers based on their geographic area and insurance carrier. In addition, these participants were given the option to choose to automatically send a dynamic referral for an appointment with one of these providers at the completion of the MHADRO assessment. Participants in the control group completed the same MHADRO assessment and received standard care for psychosocial issues. The current article uses baseline data from Boudreaux et al. (2011). Follow-up assessments were completed at 2, 6, and 12 months from baseline. The full methodology appears in O'Hea et al. (2013).

Measures

Behavioral Health Status Index: The BHS Index is a global measure of mental health based on phase and dose-response models of psychotherapy outcome (Howard, Kopta, Krause, & Orlinsky, 1986; Howard, Lueger, Maling, & Martinovich, 1993). The BHS Index

is a 45-item composite of three subscales: subjective well-being, psychological symptoms, and functioning. These reflect the three dimensions of the phase model. The psychological symptoms subscale is further broken down into symptoms of anxiety and depression. The BHS Index was validated using a large sample (N = 600) of outpatient mental health patients. Each of the subscales was validated against one or more established scales and has good internal consistency reliability (Grissom et al., 2002). The internal consistency (coefficient alpha) for the BHS Index subscales were all high enough to treat each scale as a single construct (subjective well-being, α = 0.82; psychological symptoms, α = 0.9; functioning, α = 0.84). The composite BHS Index has good reliability (0.88) and concurrent validity (r = 0.87, p < 0.001 versus the Outcome Questionnaire-45, a measure of behavioral health), and good sensitivity to change (effect size = 0.6, p < 0.001). The BHS Index was chosen as the foundation of the MHADRO assessment (Boudreaux et al., 2011) because the goal was to identify patients who would find most benefit from mental health services in conjunction with cancer treatment. The BHS Index has been used clinically with college students, substance abuse outpatients, and patients with cardiovascular

TABLE 1. Sample Characteristics (N = 836)

Characteristic	X	SD
Age (years)	59.35	11.6
Characteristic	n	%
Race/ethnicity		
White/non-Hispanic	723	86
Black/non-Hispanic	39	5
Hispanic	35	4
Other/unknown	39	5
Gender		
Female	718	86
Male	118	14
Marital status		
Married	542	65
Not married	294	35
Education		
Less than college	494	59
College graduate	342	41
Cancer type		
Breast	410	49
Gynecologic	178	21
Colorectal	45	5
Lung	44	5
Prostate/testicular	12	1
Other	147	17
Time since diagnosis		
Today/within the past week	27	3
1-4 weeks	41	5
1–6 months	216	26
More than 6 months	552	66

Note. Because of rounding, percentages may not total 100.

Anxiety: The five-item anxiety subscale evaluated symptoms of worry, feeling tense or "keyed up," irritability and anger, and difficulty concentrating. Each item was presented on a four-point Likert-type scale, with higher scores indicating better outcomes.

Depression: The five-item depression subscale assessed patients on their symptoms of sadness, loss of pleasure from previously enjoyable activities, feelings of worthlessness, hopelessness, pessimism, and difficulty concentrating. Each item was presented on a four-point Likert-type scale, with higher scores indicating better (less severe) outcomes.

Functional disability: The functional disability subscale converted five items to a five-point Likert-type scale. The average of these scores represented participants' activity level and the amount that physical and emotional symptoms impinge on daily life management. Higher scores indicate better functioning.

Subjective well-being: This one-item measurement required participants to indicate how well they had been getting along psychologically and emotionally on a five-point Likert-type scale. The responses ranged from 1 (quite poorly; can barely manage to deal with things) to 5 (quite well; no important complaints).

FIGURE 1. Psychological Symptoms From the Behavioral Health Status Index

disease. One goal of the parent MHADRO study was to validate the BHS Index in oncology populations.

Using the BHS Index, the MHADRO assessment evaluated patients for psychological symptoms (depression and anxiety), physical functioning, and subjective wellbeing (see Figure 1). Patients were appraised based on their ability to function emotionally and physically, given the distress they experienced on a daily basis. The BHS Index placed participants into one of three categories: low, moderate, or high distress. The cutoff points for low, moderate, and high distress were based on percentile scores comparing each patient to a normative database that consisted of other MHADRO patients. This normative database began with phase 1 data and was updated as more data were collected (Boudreaux et al., 2011). Because these normative data were gathered from a population of patients with cancer, it may represent the current article's population of interest more closely than would normative data gathered from a general population. Higher scores signify more severe symptoms and worse functioning. Patients with scores in the 70th percentile or higher were considered clinically elevated in distress, patients who fell below the 30th percentile were considered low in distress, and patients in the 30th to 70th percentiles were considered within normal limits.

National Comprehensive Cancer Network Distress Thermometer: Participants rated their distress level using the DT. As described previously, the DT has been validated using ROC analyses in numerous oncology populations and has held up against other validated and lengthier measures.

Statistical Analysis

Basic descriptive statistics were used to characterize the sample. To characterize the association between DT scores and categorical characteristics of interest, the authors used analysis of variance. When significance was achieved, the authors further examined specific group differences by calculating least squares means. The least squares means approach is preferred because it allows for adjustment for multiple comparison testing and unbalanced designs. Specifically, a Tukey-Kramer adjustment (Kramer, 1956) that accommodates unequal sample sizes in groups was used.

The authors assessed the association between DT scores and the BHS Index through a Spearman correlation. The Spearman correlation was calculated rather than a Pearson correlation because the former only requires the data to be measured at least at the ordinal scale (rather than the interval scale requirement of Pearson correlation) and makes no assumptions about the underlying distribution.

The authors further investigated the relationship between the DT and the BHS Index using analysis of variance. Based on the categorization of low, moderate, and high distress on the BHS Index, the authors determined if a difference existed in the DT score based on group membership (low, moderate, or high distress). When significance was achieved, additional examination was conducted on specific group differences by calculating least squares means.

The authors used ROC curves and the associated c-index to investigate the relationship between psychological distress as measured by the DT and BHS Index scores. Specifically, the authors were interested in determining if a cutoff point with acceptable sensitivity and specificity could be defined on the DT that corresponded to higher distress on the more thoroughly examined and commonly used BHS Index score. As a reference, a BHS Index score in the highest tertile (percentile score greater than or equal to 70%) was considered highly distressed. Several logistic regression models predicting the probability of high distress (as measured by the BHS Index score) with varying cutoff points on the DT score were developed, and the corresponding sensitivity, specificity, positive predictive, and negative predictive values were calculated. All statistical analyses were performed using SAS, version 9.3.

Results

Descriptive Statistics

Eleven mental health diagnoses were indicated in patient demographic information, with the most common being depression (24%, n = 200) and anxiety (14%, n = 117). Four percent of patients (n = 35) had been hospitalized because of an emotional problem at least once in their lifetime. Thirty-one percent (n = 259) of the total sample had been prescribed psychotropic medication, 20% (n = 167) of which were taking medication at the time of enrollment. Thirty-seven percent (n = 309) of patients had seen a counselor or therapist to help manage emotions or stress, and 8% (n = 66) were in therapy at the time of assessment. When asked whether they would benefit from counseling at the time of enrollment, 17% (n = 70) of participants in the intervention group (n = 415) said "yes" and 18% (n = 74) indicated that they were "not sure."

Relationship Between Behavioral Health Status Index and the Distress Thermometer

To examine the relationship between DT and BHS Index scores, a Spearman correlation coefficient and associated p value were calculated and the two variables were found to be significantly related (rho = 0.58, p < 0.0001). As distress measured by the BHS Index increased, the mean DT scores increased. In addition, least squares means analyses revealed that each category of BHS score was related to a significantly different DT score. For all three categories (low distress, within normal limits, clinically elevated distress), mean DT scores ($\overline{X} = 0.79, 2.58$, and 4.78, respectively) differed at the p < 0.0001 level.

Cutoff Point Analyses

Cutoff points were determined using ROC analysis. ROC curve and the associated c-index were used to investigate the relationship between psychological distress as measured by the DT and BHS Index scores. Specifically, the authors were interested in determining if a cutoff point with acceptable sensitivity and specificity could be defined on the DT that corresponded to higher distress on the BHS Index. As a reference, a BHS Index score in the highest tertile was considered highly distressed. Several logistic regression models predicting the probability of high distress (as measured by the BHS Index score) with varying cutoff points on the DT score were developed, and the corresponding sensitivity, specificity, positive predictive, and negative predictive values were calculated.

The predictive accuracy of the DT score in predicting high distress as measured by the BHS Index was 0.784 (c-statistic) (see Figure 2). Based on the cutoff point for distress using the DT score, sensitivity ranged from 0.31–0.78 and specificity from 0.69–0.93. The current recommended cutoff point on the DT scale, 4, had a sensitivity of 0.68 and a specificity of 0.79. The corresponding positive and negative predictive values were 0.51 and 0.89, respectively. A cutoff point of 3 on the DT was found to have higher sensitivity (0.78) and a higher negative predictive value (0.91) but lower specificity (0.69) and a lower positive predictive value (0.44).

Distress Thermometer Scores and Time Since Diagnosis

A statistically significant difference in distress was found among patients, depending on the amount of time that had lapsed since the diagnosis of cancer. Figure 3 demonstrates mean levels of distress, measured by the DT, at each of the four times since diagnosis. The following categories are significantly different from each other at the p < 0.05 level: 1–4 weeks postdiagnosis versus 1–6 months, 1–4 weeks versus more than 6 months, and 1–6 months versus more than 6 months.

Discussion

Oncology providers and governing bodies in oncology care agree that the psychosocial needs of individuals with cancer should be identified and addressed. Efficient and accurate screening tools are helpful to providers who are attempting to accomplish these goals. The current study examined the DT as a brief screening tool for distress and was compared to a

FIGURE 2. Receiver Operating Characteristic (ROC) Curve for Predicting High Distress





Note. Labeled points on the ROC curve correspond to the average high distress score (measured on a 0–1 scale from the Behavioral Health Status Index) at each value of the Distress Thermometer. For example, at a Distress Thermometer score of 3, the average high distress score is 0.22.



^a Time 1 is today/within the past week, time 2 is 1–4 weeks postdiagnosis, time 3 is 1–6 months postdiagnosis, and time 4 is more than 6 months ago.

Note. Scores range from 0–10, with higher scores indicating higher levels of distress.

FIGURE 3. Mean Distress Thermometer Scores at Time Since Diagnosis (N = 836)

psychometrically validated assessment of distress. In accordance with previous research, scores on the DT were significantly associated with scores on the lengthier BHS Index (Chambers et al., 2014; Donovan et al., 2014; Goebel & Mehdorn, 2011). In addition, time since diagnosis was related to scores on the DT. Specifically, patients who were 1-4 weeks postdiagnosis indicated more distress than patients at any other time in the cancer trajectory, even those patients who were in the first week postdiagnosis. This poses an immediate need to ensure that patients receive the option for psychosocial services when they are diagnosed with cancer, because this may help them navigate the difficult journey they are about to embark on. Fluctuations of distress levels during the course of the cancer trajectory were consistent with previous research (Chambers et al., 2014; Lam, Shing, Bonanno, Mancini, & Fielding, 2012; Nosarti, Roberts, Crayford, McKenzie, & David, 2002; Wang, Tu, Liu, Yeh, & Hsu, 2013; Ziegler et al., 2011). During the first week, patients may be feeling numb or in a state of disbelief before they have fully processed the diagnosis (National Cancer Institute, 2013). Once the diagnosis has sunk in, but before treatment plans have been determined, patients may experience heightened distress, which could explain the high levels of distress during the 1-4 week postdiagnosis interval. This time from diagnosis to beginning of treatment could be described as the "in limbo" time, when patients are anxious because they have not begun actively fighting the cancer through treatment. Providers may need to screen for distress symptoms in patients during this phase, and it may be helpful to offer mental health services. These proactive measures may serve to help patients transition through the different phases of coping with cancer.

This study may have implications for the clinical use of brief screeners of psychosocial distress in cancer populations. The authors' analyses indicated that using a cutoff point of 3 to indicate high levels of distress may maximize sensitivity and be a more useful option in some heterogeneous clinical settings. Because this score is lower than the one recommended by the NCCN (2016) guidelines, it raises the issue of overdiagnosing distress in a clinical setting and using valuable provider time and resources. Another option would be to use multiple cutoff points, depending on the situation. For example, providers may consider erring on the side of caution and using a lower cutoff point (e.g., DT score of 3) for those individuals who are 1-4 weeks postdiagnosis, but returning to the recommended cutoff score (DT score of 4) for those further from diagnosis, when distress may not be as prevalent. Future research should examine different DT cutoff points at different stages in the treatment trajectory in a heterogeneous sample.

Limitations

The study had limitations that could be addressed through future research. First, the use of the BHS Index does not necessarily predict clinical diagnoses. Optimally, each participant in the study would have undergone clinical psychological evaluation, in addition to administration of the DT, to more accurately predict clinical outcomes. Another major limitation was the demographic characteristics of the sample. Although enrollment did not exclude any cancer type or stage of disease, almost half of the sample consisted of female patients with breast cancer, and cancer survivors comprised more than half of the sample. This may have occurred because those who enroll in a study examining the effectiveness of a psychosocial intervention would likely be those most interested in using such intervention. Women with cancer tend to report greater levels of psychological distress compared to men with cancer (Akin, Can, Avdiner, Ozdilli, & Durna, 2010; Thomas, NandaMohan, Nair, & Pandey, 2010). Although distress levels did not vary among cancer types, previous research suggests that certain types of cancer, specifically brain cancer, might result in higher distress levels (Keir et al., 2008). In addition, race and ethnicity of the sample were largely Caucasian and non-Hispanic, causing generalizability of results to be questionable. Future researchers are encouraged to replicate the current study with more diverse samples regarding disease type, gender, and ethnicity.

The NCCN guidelines on distress are vague as far as how often it is recommended that patients be screened for distress. Perhaps using a cutoff point of 3 at the first assessment will help providers identify patients who are distressed and, from there, make a plan moving forward. The DT can be used once psychosocial resources are established to ensure that distress has decreased. In addition, a DT score of 3 could alert a nurse to conduct further assessment to determine in which domain the concern lies (e.g., practical, emotional, spiritual, physical). Of note, individuals who are female, older, less educated, and carry a higher symptom burden are more likely to endorse symptoms of distress (Waller et al., 2013). Patients who are at higher psychosocial risk should be assessed more frequently and thoroughly.

As noted previously, a majority of participants in the sample were cancer survivors. These patients who were no longer in treatment may have been feeling physically better and less acutely anxious or distressed. Previous research has demonstrated that, as time since diagnosis increases, patients tend to experience an improved physical and mental status. At the same time, survivors face many social and emotional challenges when coming off of treatment (Jarrett et al., 2013). Future research with the DT is needed to establish cutoff points for screening survivors who are experiencing a whole new set of stressors as they enter into formal survivorship.

Implications for Nursing and Conclusion

In a comprehensive cancer center, nurses often are responsible for psychosocial screening of patients, whether using a validated screening measure or clinical judgment (Werner et al., 2012). Screening patients with cancer and providing resources for distress throughout the treatment trajectory is important, even when preparing to transition from acute treatment. Nurses are becoming more involved with a growing practice of survivorship care planning, which helps survivors prepare for the transition back to primary care after the completion of cancer treatment. The process can be emotionally difficult for survivors who have grown accustomed to the social support of the oncology team (Lester, Wessels, & Jung, 2014). These additional demands of assessing and providing resources to patients are being placed on nurses, who are already an overworked and systematically

Knowledge Translation

- A Distress Thermometer (DT) score of 3 may be the optimal cutoff score to help providers identify high levels of distress in adult patients with cancer.
- DT scores differ significantly at different time points on the cancer treatment trajectory.
- Cancer care teams should include psychosocial team members and should routinely assess for psychosocial difficulties and directly refer to services as appropriate.

underappreciated population (Kaddourah, Khalidi, Abu-Shaheen, & Al-Tannir, 2013). However, even brief screening measures of distress have been supported as efficacious. Developing ways to administer measures of distress while minimizing burden on nurses is important. This may be done through brief screeners, such as the DT. Regardless of the assessment tools chosen by oncology care providers, the future of managing psychosocial issues in patients will need to involve efficient options that can minimize burden on nurses and maximize benefits to patients.

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