

Use of the Distress Thermometer in Clinical Practice

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Abstract

Distress is experienced by many cancer patients, adversely affecting quality of life and cancer care. Although it is often manageable, it remains woefully underidentified and underreported. Distress can occur anytime during the cancer experience and is associated with depression, anxiety, missed appointments, and adverse outcomes. In 1999, the National Comprehensive Cancer Network (NCCN), recommended routine screening for distress in all cancer patients. The Distress Thermometer (DT) was developed as a simple tool to effectively screen for symptoms of distress. The instrument is a self-reported tool using a 0-to-10 rating scale. Additionally, the patient is prompted to identify sources of distress using a Problem List. The DT has demonstrated adequate reliability and has been translated into numerous languages. The tool is easy to administer and empowers the clinician to facilitate appropriate psychosocial support and referrals.

For many patients, the cancer care journey is fraught with distress, beginning with initial diagnosis, through the treatment decision-making process and cancer treatment, and into survivorship. Uncertainty about the future is commonly present throughout the cancer trajectory (Bultz & Holland, 2006). The National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology (NCCN Guidelines) for distress management define distress as “multifactorial unpleasant experience of a psychological (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature that

may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment” (NCCN, 2019). According to the NCCN Guidelines (2019), “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.”

Whereas 7% of the general population may experience distress at any given time, 25% to 60% of cancer patients report distress when they are assessed (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001).

However, patient distress is an often overlooked but important constellation associated with physical and/or psychological symptoms. Up to 80% of patients with cancer attribute their distress to financial stressors (Khera, Holland, & Griffin, 2017; Yabroff et al., 2016); 58% have symptoms associated with depression, and 34% report symptoms of anxiety (Yabroff et al., 2016).

Research indicates patients who experience high levels of distress are less adherent to treatment plans, are more dissatisfied with overall care, experience poorer quality of life, and have poorer survival rates (Faller, Bülzebruck, Drings, & Lang, 1999; Hamer, Chida, & Molloy, 2009; Holland & Alici, 2010; Von Essen, Larsson, Öberg, & Sjöden, 2002). Untreated distress can result in higher health-care costs and prolonged rehabilitation (Abrahamson, 2010; Mitchell, Vahabzadeh, & Magruder, 2011). Recognizing the impact of distress on the well-being of cancer patients, the NCCN Guidelines recommend routine screening for distress and identifying its sources.

All cancer patients are at risk for distress; however, research studies identified specific risk factors that increase the prevalence of distress among certain cancer groups. Studies have shown gender differences, with women experiencing higher levels of distress (Jacobsen et al., 2005; Shim, Shin, Jeon, & Hahm, 2008). Younger patients experience higher levels of distress (Hegel et al., 2008). Married patients are less likely to experience distress than single patients, and patients diagnosed with specific cancers of the breast, head and neck, colon, lung, brain, or pancreas experience greater distress (Carlson et al., 2004; Hurria et al., 2009; Zabora et al., 2001). A decline in physical, emotional, and/or cognitive functioning has been associated with patient-reported distress as well (Keir, Calhoun-Eagan, Swartz, Saleh, & Friedman, 2008). Stressors may include family relationship problems and feeling that the information provided about their cancer diagnosis and treatment was inadequate (Graves et al., 2007).

All patients with cancer must be viewed as being at risk for distress. Numerous cancer-related organizations, including the NCCN and the American College of Surgeons Commission on Cancer, advocate for screening for distress (American College of Surgeons, 2012; NCCN, 2019). Beginning in

2015, the Commission on Cancer requires institutions to screen for distress as part of their accreditation process. Institutions are required to develop a comprehensive plan that addresses six conditions: (1) inclusion of a psychosocial representative on the cancer committee; (2) determination of when distress screening occurs; (3) a method of screening; (4) selection of a well-validated screening tool; (5) protocols for further assessment and referrals; and (6) documentation of the process and program evaluation (Buxton et al., 2014). One commonly used screening tool is the NCCN Distress Thermometer (DT) and Problem List for patients (Figure 1).

NCCN DISTRESS THERMOMETER AND PROBLEM LIST

The NCCN introduced the DT as a screening tool to identify sources of distress. The NCCN recommends screening patients at the initial visit soon after diagnosis and at each visit, although the screening schedule may be revised as clinically indicated (NCCN, 2019). Important time points may include changes in disease activity such as remission, recurrence, or progression, or upon referral to palliative care (Carlson, Waller, & Mitchell, 2012; Pirl et al., 2014).

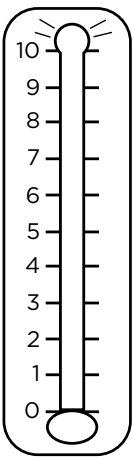
The NCCN DT is a single-item tool using a 0 (no distress) to 10 (extreme distress)–point Likert scale resembling a thermometer. The patient rates his/her level of distress over the past week. The established cutoff score for further screening is a 4 (Donovan, Grassi, McGinty, & Jacobsen, 2014; Jacobsen et al., 2005; NCCN, 2019). A recent study suggests a lower cutoff score of 3 when screening during the first month of a new cancer diagnosis (Cutillo et al., 2017). Studies have found that cutoff scores for specific patient populations vary from the established cutoff, including childhood cancer survivors (cutoff score of 3; van der Geest, van Dorp, Pluijm, & van den Heuvel-Eibrink, 2018), cancer patients receiving palliative home-care services (cutoff score of 6; Ohnhäuser, Wüller, Foldenauer, & Pastrana, 2018), and women recently diagnosed with breast cancer (cutoff score of 7; Ploos van Amstel et al., 2017).

The DT has been translated into 26 languages, including Spanish, and 18 of the translated versions have demonstrated adequate validity in validation studies (Donovan et al., 2014). One advan-

DISTRESS THERMOMETER

Instructions: Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress



No distress

PROBLEM LIST

Please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

YES	NO	Practical Problems	YES	NO	Physical Problems
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Treatment decisions	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
		Family Problems	<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
<input type="checkbox"/>	<input type="checkbox"/>	Ability to have children	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
<input type="checkbox"/>	<input type="checkbox"/>	Family health issues	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
		Emotional Problems	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Sexual
<input type="checkbox"/>	<input type="checkbox"/>	Spiritual/Religious Concerns	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
			<input type="checkbox"/>	<input type="checkbox"/>	Sleep
			<input type="checkbox"/>	<input type="checkbox"/>	Substance use
			<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet

Other Problems: _____

Figure 1. NCCN screening tools for measuring distress. Adapted with permission from the 2019 NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management V.2.2019. © 2019 National Comprehensive Cancer Network, Inc. All rights reserved. The NCCN Guidelines® and illustrations herein may not be reproduced in any form for any purpose without the express written permission of NCCN. To view the most recent and complete version of the NCCN Guidelines, go online to NCCN.org. The NCCN Guidelines are a work in progress that may be refined as often as new significant data becomes available.

tage of the DT is its brevity: studies have shown that nurses need an average of only 2 minutes and 20 seconds to help a patient complete the tool (Musiello et al., 2017). Overall, it is easy to administer, and patients find the tool easy to use. Administration and interpretation of the DT are provided by a cancer provider.

The NCCN Problem List for patients is a 39-item supplemental list of potential sources of distress (NCCN, 2019). The NCCN recommends incorporating the Problem List for patients as part of the assessment to assist the provider in identifying sources of patient distress. The NCCN Problem List provides a comprehensive list of categories, including practical, family, physical, and emotional problems, as well as spiritual/religious concerns. Not surprisingly, patients who score a 4 or higher

on the DT select more items from the NCCN Problem List (VanHoose et al., 2015). Patients who report distress frequently select problems from the emotional domain, and worry is the item most frequently selected. Other items associated with risk for distress include problems from the physical domain, such as sleep and getting around, and problems from the emotional domain, such as nervousness (Clover et al., 2016). A common source of distress later on in the cancer care trajectory is financial strain (VanHoose et al., 2015).

Once screening has been completed and the results have been interpreted, the provider determines whether the patient needs to be referred for psychosocial support. Referrals can include psychologists, chaplains, and social workers. The cancer care provider may use community-based

resources as well as resources provided by the institution based on the patient's preference.

BARRIERS TO SCREENING

Barriers to screening for distress do exist. For example, patients may have trouble understanding what the word "distress" means (Mitchell, 2013). Patient barriers to screening include language and cultural differences as well as literacy (Lo, Ianniello, Sharma, Sarnacki, & Finn, 2016). Another barrier occurs when referring distressed patients for psychosocial services. Studies have also shown that patients who score high on the DT may not necessarily want help. Conversely, studies have shown that when patients were screened and did not receive any referrals or assistance, their levels of distress increased (Mitchell, 2013). Institutional barriers identified include insufficient time and training, lack of privacy for screening, poor documentation of results, discomfort discussing results, and a lack of resources for patient referrals (Chiang, Amport, Corjulo, Harvey, & McCorkle, 2015; Girgis, Smith, & Durcinoska, 2018).

CONCLUSION

Distress is considered the sixth vital sign in oncology care. Numerous research studies have demonstrated the prevalence of distress and the significant impact it has on the patient's quality of life and treatment success. Research continues to determine the validity of the DT and Problem List in various cancer populations based on ethnicity, cancer type, language, and age. Research is needed to validate interventions used to manage distress. Because the NCCN DT is a tool with well-established validity and brevity that is available in multiple languages and easy for the provider to interpret, the use of the instrument is being studied in other patient populations, including those with chronic obstructive pulmonary disease and acquired immune deficiency syndrome. ●

Disclosure

The author has no conflicts of interest to disclose.

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