

■ Article

Translating Research on the Distress Thermometer Into Practice

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Distress is commonly experienced by people with cancer. The National Comprehensive Cancer Network (NCCN) developed a guideline for screening and managing distress in 1999 and has updated the guideline on an annual basis ever since. Using the five-phase framework for translational research, this article summarizes research findings related to the guideline and associated distress thermometer for each phase of translational research. The NCCN Distress Management Guideline is a useful tool to screen for and manage distress. However, additional research is needed, particularly in the areas of impact on outcomes of importance to patients.

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Distress is a universal experience; however, the degree to which it is experienced, the duration, and the subsequent response to the distress varies widely. People living with cancer often have clinically relevant levels of distress requiring interventions for effective management (Carlson, Waller, Groff, Giese-Davis, & Bultz, 2013; Cohen, 2013; Kendall, Glaze, Oakland, Hansen, & Parry, 2011; Mitchell, Hussain, Grainger, & Symonds, 2011; Roerink et al., 2013; van't Spijker, Trijsburg, & Duivenvoorden, 1997; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001; Zwahlen, Hagenbuch, Jenewein, Carley, & Buchi, 2011). Despite the widespread incidence of cancer-related distress, data indicate that clinicians are not familiar with valid and reliable tools to screen and assess for distress in their patients. In addition, the implementation of such tools in the clinical setting is limited (Jacobsen & Ransom, 2007; Pirl et al., 2007; Tavernier, Beck, & Dudley, 2013).

Assessment of cancer-related distress is best conducted using validated measures (Oncology Nursing Society, 2013). However, using an instrument congruent with the conceptual definition of distress is important. In addition, short, inexpensive measures easily completed by the patient, which also are incorporated into the electronic medical record, are ideal (Mitchell, Vahabzadeh, & Magruder, 2011). Although many instruments are used in research to measure distress, they are not always amenable to implementation in routine oncology practice. In addition, many instruments assess constructs related to distress

such as depression, symptom severity, or unmet needs, but not the global construct of distress. Several excellent reviews of the psychometric properties of such instruments are available (Mitchell, 2010; Vodermaier, Linden, & Siu, 2009; Ziegler et al., 2011), particularly the comprehensive data supplement to the review by Carlson, Waller, and Mitchell (2012).

The purpose of this article is to review research using the National Comprehensive Cancer Network® ([NCCN®], 2013) Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management and the distress thermometer. The American College of Surgeons (2012) Commission on Cancer will require routine screening of distress for all patients for healthcare agencies seeking accreditation beginning in 2015. Acknowledging the need for interdisciplinary collaboration for optimal management of distress, oncology nurses have the opportunity to demonstrate leadership in the selection, implementation, and evaluation of tools for assessing distress (Vitek, Rosenzweig, & Stollings, 2007). In addition, oncology nurses are well positioned to develop and evaluate interventions for improving outcomes related to distress management (Fitch, 2011).

The Distress Thermometer

The NCCN Guidelines for Distress Management was first published in 1999. The authors purposefully used the term *distress* to reduce the social stigma associated with other more

common terms associated with psychosocial problems (i.e., depression, anxiety, and maladjustment). The NCCN (2013) defines distress as

A multifactorial 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 (p. DIS-2).

The NCCN (2013) recommends screening for distress using a tool such as the distress thermometer, a single-item tool asking people to score how distressed they have been over the past week on a picture of a thermometer using a scale from 0 (no distress) to 10 (extreme distress) located at the top (see Figure 1). The person also completes a 39-item problem list, marking “yes” or “no” if the problem was experienced in the past week.

Overall, studies support the validity of the distress thermometer as a measure of cancer-related distress in adult and pediatric populations. Studies most often test construct validity of the distress thermometer with the Hospital Anxiety and Depression Scale (HADS), using HADS to determine specificity and sensitivity for identifying clinical cases. The distress thermometer was adapted and tested using English and Spanish versions in a pediatric oncology sample (Patel et al., 2011). A Danish version demonstrated validity in a study involving women with newly diagnosed breast cancer (Bidstrup et al., 2012). Validity is further supported in patients with advanced cancer (Ryan, Gallagher, Wright, & Cassidy, 2012) and family members of patients with cancer (Zwahlen et al., 2011). One limitation to validity studies is the predominance of studies occurring outside of the United States. Although a systematic review of cultural equivalence supports reliability, sensitivity, and specificity of the distress thermometer across languages and countries of study origin, Kayser, Acquati, and Tran (2012) identified the need for determining conceptual validity among immigrants and minority racial and ethnic groups within the United States.

Translation of the Distress Guideline Into Practice

Khuory et al. (2007) described five phases of translational research. The first phase (T0) focuses on a basic research question: “Do people with cancer experience distress?” T1 research is targeted toward a specific group: “What is the association between distress and people receiving cancer treatment?” The third translational research phase (T2) synthesizes research primarily for the goal of developing an evidence-based guideline. This level of research requires the use of valid measures of distress as well as support for interventions to decrease distress. The scope of the psychometric evidence is well presented in meta-analyses and systematic reviews of the measures used to assess distress and related concepts (i.e., anxiety and depression) (Carlson et al., 2012; Mitchell, 2010; Vodermaier et al., 2009; Ziegler et al., 2011).

Interventions to reduce distress are tested during the T2 phase of translational research. The NCCN Guidelines for Distress Management guideline provides a decision tree for referral based on the source of distress: physical, mental, social, spiritual, family, or practical problems. Therefore, interventions are targeted at the source of distress. Interventions to reduce distress related to physical symptoms are extensive and beyond the scope of this article, but more information can be found via the Oncology Nursing Society’s Putting Evidence Into Practice (PEP) guidelines, the NCCN’s Guidelines for Supportive Care, the Cochrane Review database, the National Guideline Clearinghouse, and the Joanna Briggs Institute, to name a few.

Interventions evaluating the efficacy of social interventions to reduce distress are inconclusive because of the poor quality of studies (Faller et al., 2013). Interventional research to alleviate cancer-related distress from spiritual sources is understudied. Published reports are primarily of qualitative design and in the area of palliative or end-of-life spiritual care. Care focusing on relationships and communication is viewed by patient participants as facilitators of spiritual care (Edwards, Pang, Shiu, & Chan, 2010).

A meta-analysis of randomized, controlled trials of psychological interventions for emotional distress concluded that interventions had a positive effect on reducing distress (Faller et al., 2013). The effect of the intervention was stronger in those with breast cancer or those who had metastatic disease. Most significantly, the investigators found that those interventions occurring during a longer period of time had a higher degree of sustained outcomes (Faller et al., 2013). Other studies support those conclusions (Carlson, Groff, Maciejewski, & Bultz, 2010; Franchi et al., 2013).

The fourth phase of translational research (T3) sometimes is referred to as dissemination, diffusion, or implementation research. In this stage, research focuses on using a guideline in the real-world setting. The research addresses the challenges of implementation because of the differences between the highly controlled environment in which research is conducted and the complexities of the clinical setting (Cochrane et al., 2007).

Three studies reported the diffusion of the NCCN Guidelines for Distress Management into practice. One study reported the uptake of the Guideline by NCCN institutions, with about half of the responding institutions routinely screening for distress, most using a tool other than the distress thermometer (Jacobsen & Ransom, 2007). A second survey of 448 oncologists found that 65% routinely assessed for distress, but only 14% used a validated instrument, and only 33% were at least somewhat familiar with the guideline (Pirl et al., 2007). The third study surveyed Oncology Nursing Society members (N = 420) working in ambulatory settings and reported that 38% of nurses were not at all familiar with the NCCN Guideline for Distress Management, and only 30% used a tool to assess for distress (Tavernier et al., 2013).

Suggestions have been made that distress should be considered as the “sixth vital sign” (Bultz & Carlson, 2005; Holland & Bultz, 2007). Feasibility of patients completing the distress thermometer digitally, using a tablet, is supported (Carlson et al., 2010), as is completion via telephone (Hughes, Sargeant, & Hawkes, 2011). The acceptability and usability of the distress thermometer adapted for pediatric patients experiencing

cancer was not supported because the source of distress often was unable to be determined, and nonsignificant differences in the quantity of services were noted (Patel et al., 2011).

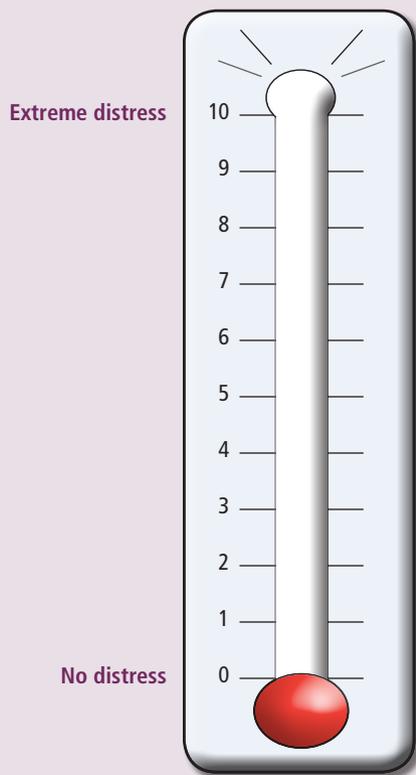
Translational research studies examining the process or outcomes of implementing the NCCN Guideline for Distress Management or distress thermometer include evaluating the impact of screening on referrals, trajectories of distress, and barriers to adoption. An observational study cautiously concluded that when nurses were educated on the use of the distress thermometer, referral rates to psychosocial oncology services were higher and more accurate (Grassi et al., 2011). In a large (N = 505) Canadian study involving patients with a distress thermometer score greater than 4, investigators found that 24% of the patients accessed at least one support service; and, of the 24%, the majority accessed an average of three services (Waller, Williams, Groff, Bultz, & Carlson, 2013). Participants who were older, female, or had a lower education level were less likely to self-refer themselves despite high levels of distress. A study in Japan found that patients experiencing severe distress had sustained distress if they had high-intensity scores on pain, fatigue, or appetite loss when compared with those who had low distress (Yamaguchi et al., 2012). However, distress levels

were observed to be variable on repeated assessments, causing concern for over-referrals based on a single score (Carlson, Waller, Groff, Giese-Davis, et al., 2013; Yamaguchi et al., 2012).

Perceived barriers to adopting the distress thermometer or guideline include time, concern about inability to respond to increased demand for referrals, lack of knowledge about how to screen and manage distress, and no perceived benefit of screening (Absolom et al., 2011; Clark et al., 2012; Hughes et al., 2011; Oktay, Nedjat-Haiem, Davis, & Kern, 2012; Tavernier et al., 2013). Conversely, successful implementation, although reported primarily in case study or quality improvement projects, occurred when the implementation process had clear aims, regular data reporting, clinician comfort with introducing the distress thermometer, was perceived as beneficial to patient care, and was representative of team stakeholders in the planning and evaluation of the process (Absolom et al., 2011; Dudgeon et al., 2012; Hammonds, 2012; Oktay et al., 2012).

The fifth phase of translational research (T4) concerns the impact of a practice on populations. Because the goal of cancer treatment is to improve quality of life and/or increase longevity, an example of a research question related to the new American College of Surgeons standard is, "Does screening for distress

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



Second, 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 | <u>Practical Problems</u> | YES | NO | <u>Physical Problems</u> |
|--------------------------|--------------------------|---|--------------------------|--------------------------|--------------------------|
| <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 |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Eating |
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Family Problems</u> | <input type="checkbox"/> | <input type="checkbox"/> | Fatigue |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with children | <input type="checkbox"/> | <input type="checkbox"/> | Feeling swollen |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with partner | <input type="checkbox"/> | <input type="checkbox"/> | Fevers |
| <input type="checkbox"/> | <input type="checkbox"/> | Ability to have children | <input type="checkbox"/> | <input type="checkbox"/> | Getting around |
| <input type="checkbox"/> | <input type="checkbox"/> | Family health issues | <input type="checkbox"/> | <input type="checkbox"/> | Indigestion |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Memory/concentration |
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Emotional Problems</u> | <input type="checkbox"/> | <input type="checkbox"/> | Mouth sores |
| <input type="checkbox"/> | <input type="checkbox"/> | Depression | <input type="checkbox"/> | <input type="checkbox"/> | Nausea |
| <input type="checkbox"/> | <input type="checkbox"/> | Fears | <input type="checkbox"/> | <input type="checkbox"/> | Nose dry/congested |
| <input type="checkbox"/> | <input type="checkbox"/> | Nervousness | <input type="checkbox"/> | <input type="checkbox"/> | Pain |
| <input type="checkbox"/> | <input type="checkbox"/> | Sadness | <input type="checkbox"/> | <input type="checkbox"/> | Sexual |
| <input type="checkbox"/> | <input type="checkbox"/> | Worry | <input type="checkbox"/> | <input type="checkbox"/> | Skin dry/itchy |
| <input type="checkbox"/> | <input type="checkbox"/> | Loss of interest
in usual activities | <input type="checkbox"/> | <input type="checkbox"/> | Sleep |
| | | | <input type="checkbox"/> | <input type="checkbox"/> | Substance abuse |
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Spiritual/Religious
Concerns</u> | <input type="checkbox"/> | <input type="checkbox"/> | Tingling in hands/feet |

Other Problems: _____

FIGURE 1. Distress Thermometer Screening Tool

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Implications for Practice

- ▶ Use the distress thermometer from the National Comprehensive Cancer Network to assess patients for distress.
- ▶ Assess a patient's distress level on a routine basis because distress is influenced by many variables.
- ▶ Perform a follow-up assessment on patients reporting high levels of distress to ensure appropriate referral or intervention.

improve the quality of life and/or survival of patients with cancer?" The impact of screening with the distress thermometer on overall survival of cancer has not been explored. Screening using the distress thermometer followed by individual triage in patients with lung cancer led to fewer reports of pain and problems with coping and family conflict compared to those receiving usual care or screening alone (Carlson, Waller, Groff, & Bultz, 2013). Screening has been found to reduce the time to referral (Thewes, Butow, & Stuart-Harris, 2009).

Research is one component of evidence-based practice, with the primary goal being the improvement of patient care outcomes (Titler, 2011). Translational research related to the NCCN Guideline for Distress Management and distress thermometer exists for all five phases, albeit sparse for the T4 phase. The distress thermometer is a quick, valid indicator of the degree to which a patient is distressed by cancer and its treatment. Oncology nurses able to articulate the research evidence are better prepared to be engaged and assume a critical role in the decision making and implementation (Scott & McSherry, 2009) of an institution's approach to meet the Commission on Cancer standard.

Conclusion

Understanding that the distress thermometer is designed to screen for distress and is not a diagnostic tool is critical. Although the validity of the distress thermometer has been supported primarily using the HADS, the distress thermometer is not a diagnostic tool for depression or anxiety. When a patient is identified as having significant distress using the distress thermometer, additional assessment must occur to determine the source of distress. Additional assessment guides the appropriate referral or intervention. Using the distress thermometer should occur within those parameters and, as outlined in the NCCN Guidelines, a more in-depth assessment should be made for patients reporting levels of distress above established cutoff points.

Extensive research regarding the need to screen for cancer-related distress and the validity, feasibility, and acceptability of the distress thermometer exist. Although no significant intervention research findings for physical sources of distress have been noted, a need exists for research evaluating the efficacy of interventions related to the social, spiritual, and practical issues identified by the distress thermometer. Oncology nurses using the distress thermometer and the associated NCCN Guideline for Distress Management are encouraged to share the experience and to assist others attempting to integrate its use into routine care.

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