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NCCN Distress Thermometer Problem List Update

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The NCCN Distress Thermometer (DT), first described by Roth et al¹ in 1998, was developed for the purpose of assessing distress in patients with cancer. A list of common concerns, called the “Problem List” (PL), was added the following year to identify potential sources of distress and to personalize triage by facilitating access to the most appropriate support services.² The grouping of the PL items into physical, practical, family, emotional, and spiritual/religious categories aligned with the 4 categories of Cicely Saunders’s concept of total pain: physical, emotional, social, and spiritual.³ Specific items were included in the PL based on expert consensus and evidence available at the time.

The DT and accompanying PL are included in the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Distress Management.⁴ These guidelines are updated annually by a multidisciplinary panel of healthcare professionals based on new evidence and current practice in psycho-oncology. Over the years, the panel has reviewed and evaluated various aspects of the DT, including the appropriate cutoff score for clinically significant distress, general validation concerns, and how widely the instrument is used in clinical practice.

The PL has received less attention and has evolved in an ad hoc fashion, with items added or removed with little consideration of the PL as a whole. This process is, in part, because the PL was never meant to be a mandated set of concerns. Instead it was meant to provide context for the DT score and to help direct clinical practice. This process has also led to the creation of different versions of the PL over time, and many institutions have rightly customized it for their setting. Therefore, the panel also recognizes that routine changes may impose a significant burden on institutions when the DT and PL are used for distress screening and are embedded in the electronic health record.

During the August 2020 annual review of the NCCN Guidelines for Distress Management, a proposal was adopted by the panel to update the PL, and over the next year, a subcommittee consisting of the authors of this commentary endeavored to do so. The full panel reviewed and discussed changes in detail during the August 2021 annual review, and the updated PL was approved by the full panel in September 2021.

The subcommittee’s efforts were driven by several observations. First, the original PL was heavily weighted toward physical concerns because that was the category best understood as a source of distress. However, many of these concerns have become standard for symptom management in the oncology clinic, thus making them redundant. Additionally, emotional concerns such as loneliness have emerged as additional risk factors for poor health outcomes, whereas many guidelines recommend screening and assessing patients with cancer for depression and anxiety in routine cancer care. The list of practical and family concerns was out of step with current practice and ideas about caregiving, and the lists were missing several concerns that increasingly fall under the rubric of social determinants of health. Last but certainly not least, since the publication of the original PL, research has grown significantly on spiritual issues in health, supporting an expansion of the spiritual/religious category. Although space limitations preclude us from providing a detailed account of the subcommittee’s approach and rationale for each change, the following sections provide a general overview and several examples in each category.

The subcommittee sought to maintain the 5 existing categories to support a biopsychosocial-spiritual model of distress in cancer and to ensure continued

consistency with the content of the guidelines and the algorithms outlined therein. The word *problems* accompanying 4 of the 5 categories (eg, “Physical Problems”) was replaced with *concerns* to minimize any sense of pathologizing the distress caused by a particular item and to ensure consistency with the existing “spiritual/religious concerns” category. The ability of a respondent to endorse and describe “other” concerns was maintained. To support proposed changes, the subcommittee relied on data from distress screening at NCCN Member Institutions and a brief online survey of panel members seeking their input on the PL. In general, in addition to addressing PL content, the subcommittee sought to simplify and soften language and reduce ambiguity and redundancy of terms, and, when the PL was in final draft form, ensure it had an appropriate literacy level.

Physical

Using clinical data from NCCN Member Institutions, low prevalence physical items such as “mouth sores” and “nose dry/congested” were removed, and high prevalence items such as *sleep* and *fatigue* were retained because nonpharmacologic interventions delivered by psychosocial professionals are known to be effective in relieving distress caused by these symptoms.⁵ “Tobacco use” was added to distinguish it from other substances. The subcommittee considered adding “marijuana use,” but recognized that doing so might stigmatize the increasing use of medical marijuana, and so retained the more general “substance use” item.

Emotional

The terms “sadness” and “depression” were combined because most laypersons seem to not distinguish between the two. Similarly, the term “anxiety” was included with “worry,” and the more nebulous term “nervousness” was removed. “Loss of interest in usual activities” was reworded to read more broadly as “loss of interest or enjoyment.” The term “appearance” was relocated from the list of physical concerns and reworded to read more generally as “changes in appearance.” Several terms, including “grief or loss, loneliness, anger,” and “feelings of worthlessness or being a burden,” were added. The intent of adding these common emotional concerns was to reduce the likelihood that such concerns would be pathologized by clinical staff or perceived by patients as a source of shame.⁶

Family

This category was renamed “Social concerns” to reflect the multiple levels involved in cancer care and to recognize the importance of a supportive social network; additional groups were added, such as friends and coworkers. The phrase “deal with” was replaced with “relationship with” to soften the language. “Communication with health-care team” was included (surprisingly for the first time) because it is well established that effective patient-provider communication is critical to patient satisfaction and is an essential element of high-quality healthcare.⁷

Practical

The pooled item “insurance/financial” was split into individual items in recognition of the lasting financial impact of cancer even with health insurance⁸ and the recognition that the 2 concerns may require different resources and support services. “Having enough food” was added in recognition of food insecurity as a leading public health issue. “Taking care of myself” and “Taking care of others” were added because of the essential nature of self-care and in recognition that some individuals with cancer are themselves family caregivers of loved ones. Similarly, “access to medicine” was added to convey that not only cost but distance to a pharmacy and having a local pharmacy that does not carry a particular medication, (an opioid, for example) are common

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concerns for many, especially in rural areas. We believe these additions make this category more inclusive and more relevant to traditionally underserved patients.

Spiritual/Religious

The 2019 NCCN Guidelines for Distress Management included considerable revisions to the chaplaincy care section, especially the chaplaincy assessment categories. These revisions were based on research on the spiritual/religious issues reported by individuals receiving healthcare⁹ and research aimed at capturing needs outside the spiritual/religious domain,¹⁰ and supported by clinical data from an NCCN Member Institution.¹¹ The subcommittee drew from the new assessment categories to propose items that seemed to emerge most often in clinical practice and/or be most critical to care planning. “Sense of meaning and purpose” and “changes in faith or beliefs” are taken from the Brief RCOPE¹² and are high prevalence items based on existing data. “Death, dying, or afterlife” is taken from the Existential Concerns Questionnaire¹⁰ and is a concern that transcends the

spiritual/religious domain. An example of the fact that the specific item endorsed (and not just the quantity of items) matters, is “conflict between beliefs and cancer treatment.” This is not typically a high prevalence item. However, when it is endorsed, this conflict may be a source of a high level of distress, causing disruptions in treatment planning, while also absorbing significant staff resources.

The current version of the NCCN Guidelines for Distress Management includes the updated PL (Version 1.2022, available at NCCN.org).⁴ We believe the revisions are more reflective of whole-person care and will increase the clinical utility of the PL. We believe this “new” PL fully aligns with current practices in psycho-oncology and recommendations set forth in the guidelines. As always, the panel welcomes comment and feedback from users.

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References

1. Roth AJ, Kornblith AB, Batel-Copel L, et al. Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study. *Cancer* 1998; 82:1904–1908.
2. National Comprehensive Cancer Network. NCCN practice guidelines for the management of psychosocial distress. *Oncology (Williston Park)* 1999;13:113–147.
3. Clarke D. ‘Total pain’, disciplinary power and the body in the work of Cicely Saunders, 1958–1967. *Soc Sci Med* 1999;49:727–736.
4. Riba MB, Donovan KA, Ahmed K, et al. NCCN Clinical Practice Guidelines in Oncology: Distress Management. Version 1.2022. Accessed December 8, 2021. To view the most recent version, visit NCCN.org
5. Cillessen L, Johannsen M, Speckens AEM, Zachariae R. Mindfulness-based interventions for psychological and physical health outcomes in cancer patients and survivors: a systematic review and metaanalysis of randomized controlled trials. *Psychooncology* 2019;28:2257–2269.
6. Brennan J, Gingell P, Brant H, Hollingworth W. Refinement of the distress management problem list as the basis for a holistic therapeutic conversation among UK patients with cancer. *Psychooncology* 2012;21:1346–1356.
7. Ha JF, Longnecker N. Doctor-patient communication: a review. *Ochsner J* 2010;10:38–43.
8. Carrera PM, Kantarjian HM, Blinder VS. The financial burden and distress of patients with cancer: understanding and stepping-up action on the financial toxicity of cancer treatment. *CA Cancer J Clin* 2018;68:153–165.
9. Exline JJ, Pargament KI, Grubbs JB, Yali AM. The religious and spiritual struggles scale: development and initial validation. *Psychol Religion Spirituality* 2014;6:208–222.
10. van Bruggen V, Ten Klooster P, Westerhof G, et al. The existential concerns questionnaire (ECQ)-development and initial validation of a new existential anxiety scale in a nonclinical and clinical sample. *J Clin Psychol* 2017;73:1692–1703.
11. Handzo G, Bowden JM, King S. The evolution of spiritual care in the NCCN Distress Management Guidelines. *J Natl Compr Canc Netw* 2019; 17:1257–1261.
12. Pargament K, Feuille M, Burdzy D. The brief RCOPE: current psychometric status of a short measure of religious coping. *Religions* 2011;2: 51–76.