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## Attending to Distress as part of quality, comprehensive cancer care: Gaps and Diversity Considerations

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### Keywords

Distress; Breast Cancer; Interventions; Oncology; Quality of life

## 1. Introduction

Cancer treatments are multifaceted and require frequent medical appointments and collaborative diagnostic and therapeutic judgments among several oncology specialists including surgeon, radiologist, pathologist, oncologist, nurse, and supportive care. The very impact of the cancer diagnosis and treatments can produce distress stemming from physical, social, emotional, functional, financial and even spiritual burdens. Distress can be associated with significant morbidity that can negatively impact cancer survivors' experience of the treatment phase as well as the post treatment phase as they transition from patient to rehabilitation and survivor, especially for longer-term survivors. Hence, distress screening is a component of the patient responsive, comprehensive cancer care recommended in the IOM report, *Cancer Care for the Whole Patient*<sup>1</sup> and *From Cancer Patient to Survivor*<sup>2</sup> and the CoC Standards 3.2.<sup>3</sup>

## 2. Challenges in Distress conceptualization and measurement influencing research and practice

Oncology professionals and clinicians are seeking and exploring ways to integrate comprehensive distress assessment and intervention into their clinical settings. Emerging research is showing that screening patients and survivors at pivotal visits along the cancer continuum and responding to patient needs with care coordinators can reduce distress and

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### Declaration of Interest

The authors have no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

improve well-being.<sup>4</sup> At City of Hope, Matt Loscalzo has successfully implemented voluntary distress screening of all patients (including Chinese and Spanish language preferred) using an online platform administered using handheld electronic devices.<sup>5, 6</sup> The report is shared and linked with relevant services including medical, psychooncology, supportive care and chaplaincy for rapid and patient responsive triage and care. However, gaps exist in determining the specific measures, format and intervals of distress assessment. Our research and practice are also challenged in providing clear guidelines regarding the appropriateness, type, delivery platforms and dosages of distress interventions and supportive care for our diverse cancer population.

## 2.1

To address the gaps in distress screening and intervention, we must secure the resources to:

### **2.1.1 Conduct translational research to enhance and test distress assessment tools**

—Conduct translational research to enhance and test distress assessment tools that are more clinically responsive and assess not only physical symptoms but broader symptoms and dimensions of personhood. The multidimensional concept of health related quality of life provides a comprehensive guide for distress assessment within clinical practice.<sup>7</sup> The dimensions of distress screening must be rooted in care for the whole person and take into consideration disease related and patient daily living situation – contextual sources of distress. Examining broader patient sources of distress may include assessing: treatment (i.e., treatment effects, understanding and adhering to treatment protocol); medical (i.e., prognosis, fear of cancer recurrence); physical (i.e., pain, GI function, energy, fatigue); functional (i.e., ability to conduct self care and other normal daily functions); emotional (i.e., sadness, depression, anxiety, worry); economic (i.e., financial morbidity); spiritual (i.e., religiosity, God support, spiritual coping); employment (i.e., work and career issues); social (ability, practice and enjoyment of civic and social activities), familial (i.e., family issues, family stability and coping); sexuality (i.e., sexual health); community (i.e., neighborhood characteristics and resources); and health care interaction (i.e., confidence in provider, satisfaction with care and medical communication) concerns.

### **2.1.2 Attend to the applicability and clinical utility of distress diagnostic tools for diverse populations**

—Attend to the applicability and clinical utility of distress diagnostic tools for diverse populations, given the undue burden and disparate outcomes of ethnic minorities. Yet, ethnic and linguistic minorities are understudied and their distress assessment and management under-addressed. Clearly, moving forward cultural and linguistic<sup>8, 9, 10, 11, 12</sup> considerations are a must in order to address the complex socio-cultural challenges of providing quality care to diverse patients. Implementing quality care in increasingly diverse contexts has pushed us to think carefully and critically about “cultural competent” care. More and more efforts are attempting to integrate “cultural competency” in improving care for diverse patients.<sup>13, 14, 15</sup> To further advance health communication and quality care, we present a Health Equity Care approach that embraces three pillars – *cultural competency (i.e., cultural knowledge and experience)*, *cultural humility (i.e., embracing and practicing human dignity, acceptance and respect)*, and *cultural*

*empathy (i.e., self-reflection and sensitivity of provider and patient status in the societal and the health care arenas)*.<sup>16, 17, 18</sup>

**2.1.3 Create a safety net for distress screening, triage and treatment joining institutions, clinics and community**—In providing patient centered care for all, capacity, resources and sustainability factors provide the reality checks. Therefore, training and workforce diversity are key components to providing distress screening and interventions to all patients in the cancer care delivery system. Workforce diversity includes various health professionals i.e., physicians, nurses, social workers, psychologists, psychiatrists. Additionally, wider workforce diversity can facilitate clinically and culturally responsive assessment, triage and treatment for distress. With soaring health care cost and limited resources especially in community settings, we must also train and create an inclusive workforce with chaplaincy, lay health workers and peer navigators (PN). Distress goes beyond medical symptoms, and can originate from innocent violations of cultural beliefs within the clinical setting and interactions. Lay health workers and PNs can address and remedy some these cultural-clinical mishaps as they are familiar with cultural beliefs and practices. PN can establish rapport and trust with patients that allow patients/survivors to share their sources of distress including fears and spiritual practices that are necessary to achieve health and healing.<sup>19</sup>

### 3. In Summary

There are significant gaps that bar the oncology care community in providing comprehensive cancer care, including distress assessment and intervention, for the whole person and for all persons. Researchers and clinicians favor a brief measure, but the complexity to cancer treatments renders a brief distress screening tool almost impossible. Additionally, there are challenges in conceptualization and measurement of distress. Moreover, the cancer patient and survivor population are increasingly diverse. Thus, reaching ethnic and linguistic minorities and patients in community and low-resources settings contribute to reducing disparities by providing comprehensive, patient-centered cancer care to our most vulnerable cancer patients. In addition, we have had tremendous challenges in effectively applying technology to facilitate implementation. We must use technology including wireless platforms to provide distress screening with high usability, reliability and validity. Quality care improvement process and outcome metrics are needed. There is hope in our capacity to provide adequate distress screening and intervention by building multi-disciplinary, including technology, partnerships and engaging other health professionals including primary care physicians, advanced practice nurses, psychologists and behavioral specialists. Thus, we ought to leverage available resources including developing and training multisectoral partners that include cancer centers, community practices, retired professions and lay health workers to provide the intervention and supportive care required to reduce distress and promote well-being.

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