

Screening cancer patients for distress: guidelines for routine implementation

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Screening cancer patients for distress during routine care is beginning to receive the attention it deserves, although it has long been known that distress has a negative impact on patients' mental and physical health and that it can be managed through early identification and intervention. The National Comprehensive Cancer Network and the Institute of Medicine have created screening guidelines and recommendations for integrating routine distress screening as a quality standard in cancer care. In this article, we discuss a brief history of these guidelines, their implementation and barriers to implementation, methods for effective rapid screening in busy clinics, and future directions for networking among clinics and the dissemination of information.

The psychological and social consequences of cancer treatment were largely neglected until the latter part of the 20th century, despite the awareness that cancer patients often struggled with anxiety, depression, and emotional upheaval so severe as to jeopardize adherence to treatment. These psychological and emotional states were attributed to patients' subjective responses to their condition, which were deemed unmeasurable and therefore not easily assessed in routine cancer care. Nevertheless, a study in the early 1980s¹ showed that if newly diagnosed patients were screened for distress, those identified as being distressed could be helped to cope better.

To improve the recognition and treatment of distress in cancer patients, the National Comprehensive Cancer Network (NCCN) created a panel of experts in 1997 to formulate clinical practice guidelines for distress management.² The guidelines, which were based on the evidence and consensus of an expert panel, were the first in the United States designed for clinicians. The term "distress" was chosen because it suggests a normal response, which can vary from an expected level to a severe one (eg, anxiety, depression).³ The term also reduces the stigma attached to words such as "psychiatric."

The NCCN Distress Management Guidelines, which are updated annually, recommend that each new patient be rapidly assessed for distress in the office or clinic waiting room using a brief screening tool.^{3,4} Based on the lessons learned from the success of pain management, the panel suggested using the Distress Thermometer (DT), a self-report

measure with a 0–10 scale in which 0 indicates "no distress" and 10, "extreme distress." Patients who score 4 or more are identified as having clinically significant distress, based on validity studies showing sensitivity and specificity.⁵ They are then asked to check off the domains they identify as causing the distress in a separate Problem List. Depending on the nature of the problem elicited by the nurse or oncologist, patients can be referred to a professional, such as a social worker, nurse, psychologist, chaplain, or psychiatrist.^{6,7} The screen should be repeated at points of transition during clinical treatment.⁷

The IOM 'whole patient' report

In 2007, the Institute of Medicine (IOM), at the request of the National Institutes of Health, conducted a year-long study to identify barriers to psychological care in community-based oncology practices, with the goal of developing a plan of action to improve care. The IOM issued a landmark report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*,⁸ which recommended a new quality standard for cancer care: the integration of the psychosocial domain into routine care. This recommendation was the result of an extensive literature search that revealed a strong evidence base for psychological and pharmacologic

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interventions.⁷ The IOM committee identified a common framework for the effective delivery of psychosocial health services: identify psychosocial needs; link patients and families to services; support patients and families in managing illness; integrate psychosocial care into medical care; and follow up to monitor the effectiveness of services.⁸

The model for integrating psychosocial services follows the earlier recommendations of the NCCN Distress Management Guidelines.^{7,9} The committee also found that there are underused psychosocial services in communities across the United States, many of which are available at no cost to patients through cancer advocacy organizations. However, patients are often not aware that they exist or how they can obtain access to them.⁸ The Alliance for Quality Psychosocial Cancer Care, a coalition of more than 30 member oncology organizations (both advocacy and professional), was formed in 2008 to implement the recommendations of the IOM's 2007 report. The alliance aims to educate and train oncology professionals about the importance of integrating psychosocial needs into routine care (requiring this to be a part of professional certification) and to educate patients and their families about their right to expect this care of the whole person.¹⁰

Implementing the guidelines

Little is known about the extent to which these guidelines are followed in community oncology practices.¹¹ A 2005 survey of 15 NCCN member institutions² found that 8 institutions (53%) were conducting routine screening for distress and 3 (20%) reported routinely screening all patients. In a project that evaluated seven practices in Florida,¹² the rates of assessing emotional well-being within 1 month of a first visit with a medical oncologist ranged between 6% and 84% across sites (mean, 60%). Among

the 12% of patients who were identified as having a problem with emotional well-being, the rates of action taken ranged between 0% and 100% (mean, 51%). Pain, however, was significantly more likely to be assessed (mean, 87%).¹² The findings demonstrate the extent to which routine assessment of emotional well-being continues to lag behind that of pain in cancer patients.

Overcoming barriers to routine screening

Establishing guidelines alone is not enough to change clinical care. To implement guidelines at the clinical level, there are several barriers that need to be overcome. Busy outpatient clinics and offices, poor reimbursement for mental health services, and the stigma associated with psychological issues are major barriers to routine screening.^{7,10} Many medical centers rely on healthcare providers to identify patients with elevated distress levels. However, because of time constraints and a lack of training in this area, physicians are often not effective in identifying these patients.¹³⁻¹⁵ Frequently, a patient is not referred to a mental health professional until the level of distress has reached a crisis point.¹⁶ Organizational barriers also need to be taken into consideration when the guidelines are translated into practice. Studies are needed to show the efficacy and potential cost-effectiveness of implementing psychosocial guidelines in routine care.¹⁷ (See reference 18 for an extensive listing of barriers experienced at multiple levels.)

There is, however, substantial evidence that there are significant benefits to training cancer healthcare providers to improve their communication skills: it increases their confidence in responding to emotional cues, managing patient anger and crying, and eliciting patients' emotional concerns—a deeper awareness of the importance of psychosocial issues in

routine care.¹⁷ Patients perceive—and stand to benefit from—a fully integrated care system that focuses on the whole person, not just the disease.¹⁷ Loscalzo and colleagues¹⁹ have outlined methods for engaging key professionals in implementing screening programs. Experts agree that the key to implementation of the IOM's mandate lies in finding a rapid, simple way to assess psychosocial needs during routine visits while assuming that patients identified are referred to appropriate resources.⁶

Rapid screening

Busy oncology practices need a brief measure that can be administered as a part of routine care to assess a patient's distress level and its causes.⁵ Several types of screening tools are available, but the NCCN recommends using the DT and the accompanying Problem List.⁷ In validation studies, the DT has been found to be accurate and efficient²⁰ when compared with longer screening tools. Patients who score 4 or more on the initial screening with the DT should complete the Problem List and meet with an oncology nurse to determine the nature of the distress and the appropriate referral.

Numerous comprehensive psychosocial programs have been developed.^{17,21} They vary from the rapid two-phase screening with the DT to extensive initial patient reporting of psychosocial needs, which often draw on new technologies such as touch-screen tests for patients and the electronic transfer of data to relevant professionals such as social workers and nutritionists.¹⁸

The implementation and function of these models deviate widely. In a review of several existing models²² of screening programs at Johns Hopkins; Memorial Sloan-Kettering Cancer Center; Tom Baker Cancer Centre in Calgary, Canada; and Dana-Farber Cancer Institute's Breast Clinic, results showed that patient satisfaction

increased, the screening was highly feasible and well accepted in the clinic setting, and the psychosocial care system was not overwhelmed with referrals.^{17,21} Findings from another study suggested that touch-screen technology minimizes the need for administrative staff to process paperwork, which in turn reduces costs and data entry errors.²³ Taken together, these findings suggest that the best distress screening model is a computerized assessment with real-time scoring, followed by timely triage to an appropriate psychosocial resource. (A group of practices and centers that are implementing the guidelines are forming an informal network; for more information, e-mail the corresponding author of this article.)

Monitoring performance standards

The quality of the psychosocial care patients receive has not been routinely monitored over the years. Accrediting bodies have not examined the quality of psychosocial care, nor have they established minimal performance standards for its delivery until recently.^{3,7} However, this approach is changing with the availability of validated quality indicators for psychosocial care, which were initiated by the American Psychosocial Society (APOS). One study explored chart audit indicators to determine the quality of psychosocial care in a community oncology clinic,²⁴ and the American Society of Clinical Oncology's (ASCO's) Quality Oncology Practice Initiative (QOPI) includes the psychosocial audit in its core audits of participating practices. The incentive to improve one's practice, relative to other practices that are similarly audited, is a powerful force in support of change. QOPI is moving toward a certification of community practices that meet their quality standards.

APOS, through its Commission on Cancer, which certifies cancer reg-

istries and clinics, has mandated that to be certified, it is necessary to demonstrate a process that monitors and integrates psychosocial care into routine care treatment through screening and triage.¹⁰ In 2010, the Union International for Cancer Control endorsed the new quality standard, stating "global authorities declare distress the sixth vital sign in cancer care,"¹⁰ and the International Society of Pediatric Oncology endorsed the new psychosocial standard. Together, these international care organizations provide a platform from which to improve psychosocial care globally for children and adults with cancer and their families.¹⁰

From paper to practice

Guidelines are promising tools for improving the quality of care, but they are only as effective as the methods that are used to implement them. The NCCN recommends that team members consider the score on a patient's initial DT and the items checked on the Problem List as the first stage of screening. An oncology nurse in the clinic should follow up with additional questions as a second stage of screening if the score on the DT is 4 or more.⁷ At least one team member should be familiar with the patient's mental health and psychosocial status and choice of chaplaincy services, and a list of the names and phone numbers for these resources should be kept in the oncology clinic and updated regularly.⁷ Staff members should have easy access to a list of online patient support resources and toll-free numbers for cancer advocacy organizations so that they can pass them on to patients.

One approach to implementing distress screening is for each practice to examine its processes for assessing and managing pain, given the generally higher rates of pain management.^{12,24,25} Such an in-depth review might reveal that processes that could be adapted or extended to screening

for distress are already in place.^{12,24,25} It is helpful to share information about the problems that can arise in implementing the screening guidelines, such as the recommendations by Loscalzo and colleagues,¹⁹ which are based on their success with implementing several screening programs and include a discussion on engaging key professionals in the process. A network of clinics and centers using NCCN guidelines is forming to provide collegial support and advice.

The good news is that we have effective, evidence-based psychosocial interventions, which can improve patients' quality of life. The IOM's new quality standard notes that the psychosocial domain must be integrated into routine care. Guidelines now recommend that the best way to assure that this happens is to rapidly screen all new patients for distress as a part of their initial workup. The goal now is to disseminate this information so that every patient is treated as a whole person.

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