



Distress Screening for Oncology Patients

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Practical steps for
developing and implementing
a comprehensive
distress screening program

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Meeting the American College of Surgeons (ACoS) Commission on Cancer (CoC) standard related to psychosocial distress screening will require cancer programs to create a comprehensive system that addresses six requirements:

1. Inclusion of a psychosocial representative on the cancer committee and a committee meeting that includes plans for screening
2. Determination of the timing of screening
3. A method of screening, such as electronic or paper and pencil
4. Selection of a screening tool
5. Identification of an assessment and referral plan
6. Documentation of the process.

Each of these components will need careful consideration based on a program's size, resources, location, and patient population. This article will briefly review the rationale behind distress screening, highlight considerations in implementing a distress screening system, and describe training opportunities to prepare for the standard, which goes into effect in 2015.

Psychosocial Distress

The National Comprehensive Cancer Network (NCCN) defines distress as an “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.”¹ Although distress is common, a multitude of studies have demonstrated that 50 to 94 percent of patients with cancer who have significant distress are not identified as such during routine oncology visits.²⁻³ Undetected distress typically goes unaddressed; indeed, 55 percent of patients with cancer who report distress also report that they do not receive psychosocial treatment.⁴

Complex patient-provider communication dynamics contribute to these missed opportunities to manage distress during cancer care. Screening for distress represents an opportunity to better identify patients with psychological, emotional, social, and/or spiritual concerns. Distress screening is defined as a brief method

for prospectively identifying and triaging cancer patients at-risk for illness-related psychosocial complications that undermine the ability to fully benefit from medical care, the efficiency of the clinical encounter, satisfaction, and safety. All patients need to be screened as many report they are unlikely to discuss emotional issues unless asked and oncologists report uncertainty in identifying distress.⁵⁻⁶

Screening for and management of distress leads to better patient outcomes. The awareness of screening for distress alone increases the likelihood of oncologists discussing distress during patient interactions.⁷ Cancer patients who speak to oncologists about the emotional impact of cancer have higher rates of psychosocial care and feel more satisfied with their cancer treatment.⁸ Randomized clinical trials have also shown that screening programs may help to improve levels of distress, anxiety, and depression, but a referral component is necessary.⁹ A study conducted in primary care clinics showed that systematic detection and treatment of distress could even lower rates of cancer deaths in older individuals in primary care clinics.¹⁰

Implementing Distress Screening

Cancer programs will need to plan and organize how best to integrate psychosocial distress screening into their programs by the 2015 deadline. The selection of a screening tool is only one part of this preparation; cancer programs must also identify or create a system of care that ensures adequate treatment for distressed patients.

- A comprehensive distress screening program is one that:¹¹⁻¹²
- Uses a valid instrument to screen patients for distress
 - Assesses patients with distress for the sources of their distress
 - Refers patients and families to appropriate psychosocial services
 - Follows up on referrals and targeted outcomes
 - Uses quality improvement to assess the program's effectiveness.

The process of implementing a comprehensive distress screening program is best delineated into a series of four steps.

1. **Establish a point person for the screening program.** Begin by identifying a psychosocial representative to oversee the distress screening program and report to the leadership committee. The psychosocial representative should be an “oncology social worker, clinical psychologist, or other licensed mental health professional trained in the psychosocial aspects of cancer care.”¹ Once the distress screening is in place, identify an individual, team, or department to help implement, monitor, and evaluate the program. (Training opportunities are on pages 51-52.)
2. **Create a psychosocial care network.** Cancer programs will need to identify procedures and personnel for follow-up evaluations and referrals for distress management. This step is critical before launching screening so that patients who are distressed can get further evaluation and, when indicated, referrals in a timely manner. When feasible, an integrated system that can provide population-based, patient-centered psychosocial care is preferred.¹³ Cancer programs that do not have a psychosocial oncology practitioner or service can develop written referral agreements with community organizations and other specialty providers to help meet the needs of patients. For example, primary care providers often can complete a follow-up assessment with an option to treat or refer to a mental health provider or appropriate community organization. Patients’ insurance companies also have lists of paneled mental health providers who can form part of the referral network. If a patient is an imminent safety risk, emergency rooms can provide acute assessment. Prior to referring patients to psychosocial healthcare providers, cancer programs should offer providers information on patients’ needs, thereby ensuring coordinated care. Patients may need to sign a “Release of Information,” although HIPAA does permit communication among providers to ensure continuity of care.
3. **Design a standardized protocol.** Once a referral source has been identified, cancer programs can put in place a standardized protocol for patients in distress. The protocol should take into account scoring and review of results of the screening instruments, determining the need for a follow-up clinical assessment, and developing a referral plan. Having a protocol ensures that steps are completed in a timely manner so that distress can be promptly addressed in an organized fashion. The protocol should identify personnel and specify their roles in the distress screening process. For example, a non-clinical staff member could oversee initial administration, collection, and triage of screening results to a healthcare team. An identified clinician (oncologist, nurse, nurse navigator, social worker, psychologist, or other

Table 1. Distress Screening Instruments

INSTRUMENT	MEASURES	THRESHOLD
Distress Thermometer	General distress	4 ¹⁴
Psychosocial Screen for Cancer (PSCAN)	General distress	8 ¹⁵
PHQ-4	Anxiety and depression	≥6=yellow flag; ≥9 red flag ¹⁶
ESAS	Symptoms	4 ¹⁷

psychosocial representative) would be responsible for reviewing screening data and ensuring patients receive appropriate follow-up assessment and referral if they meet certain pre-determined criteria. Further evaluation and treatment could be completed by the established referral base discussed in step two of implementation.

4. **Tailor the screening program to the patient population.** The last step in the process is determining how to screen for distress in a cancer center’s patient population. This step will include:
 - Selecting a screening tool
 - Deciding how and when to administer the tool
 - Determining who will conduct the second-level assessment, make referrals, and follow-up on referrals
 - Documenting the results
 - Assessing the distress screening program’s effectiveness.

An essential first step is for the cancer committee to reach consensus on the definition of distress it seeks to measure. The NCCN definition mentioned earlier currently represents the standard of care as it covers emotional, social, and spiritual concerns. A variety of tools are available for distress screening, but currently there is no gold standard or consensus on which tool is best. It is important that cancer programs use distress screening instruments that assess more than one symptom and that have been validated in oncology populations (see Table 1, above). There are also commercial electronic distress screening systems that use validated instruments. Published ranges of thresholds should be considered when using “cut-off scores” (Table 1), rather than changing the threshold in an attempt to limit the numbers of patients who screen in as possibly distressed. Altering thresholds could result in medical, legal, and ethical implications, especially with a negative patient outcome.

Cancer programs should next determine how the selected

Table 2. Curriculum Outline of the *Screening for Psychosocial Distress Program*

YEAR	WORKSHOP CONTENT	ONLINE VIDEOCONFERENCE TOPICS
1st – Introductory	• Components of a Comprehensive Distress Screening Program	• Setting up Screening: Who? With What? How?
	• Communication Skills	• Referral Networks: Who? How?
	• Screening Standards	• Achieving Your Screening Goals
	• Screening Instruments	• Achieving Your Network Goals
	• Building a Referral Network	
2nd – Advanced	• Documentation & Quality Improvement	• Understanding Cost & Reimbursement Strategies
	• Using IT Resources for Distress Screening	• Using the RE-AIM Model to Strengthen Implementation & Maintenance of Your Program
	• Demonstration & Pilot Projects to Strengthen Your Distress Screening Program	
	• Marketing Your Distress Screening Program	

instrument will be administered. Instruments can be completed on paper, electronically with a tablet, or even face-to-face in an interview. Some clinicians may prefer to include distress screening as part of the vital signs or in a review of systems, while others may prefer patients to complete electronic questionnaires that can be scored automatically before seeing the provider. Although distress screening could occur with every patient encounter, ACoS recommends that distress screening occurs “a minimum of one time per patient at a pivotal medical visit to be determined by the program.” Pivotal times include initial diagnosis, beginning and ending treatments, and recurrence or progression. Cancer programs might find it administratively difficult to track these pivotal times, so selecting a time anchored to a moment on the cancer-care continuum that happens to every patient, such as initial diagnosis, will ensure that distress screening is conducted at least once. Results of the distress screening should be viewed as important medical information for patient care, and thus, documented in the medical chart. Ideally, the documentation of results should include the name of the clinician who reviewed them and any plans for follow-up.

Implementation Challenges


Implementing new procedures to help manage patient care can bring inherent challenges to a cancer program. Cancer care is often provided across a complex interconnected system between physician-owned oncology practices and hospital-based

services, such as inpatient care and radiation oncology. Additionally, systems often have new or more than one electronic medical record (EMR), which may or may not be linked together. Finally, many cancer programs do not currently have personnel trained in psychosocial oncology on staff or the funding to provide these services on a routine basis. These issues make it challenging to follow a patient across the continuum of care—let alone decide pivotal points for distress screening.

Decisions about the timing and frequency of distress screening may vary based on the treatment setting, type of cancer, and resources available in the institution. For example, in radiation oncology, some programs are opting to screen patients for distress at simulation and again at the end of treatment. In the breast cancer clinic, screening might occur at a second visit or first infusion. There are limited data available to suggest optimal timing and frequency of screening and more studies are needed.

Finally, commitment of financial resources either to invest in a computerized program that is integrated into the EMR and/or in psychosocial oncology personnel can be challenging as cancer programs manage tight budgets with decreasing revenues. There are cost-effective solutions in both distress screening and referral resources that can be implemented to successfully meet the standard and more importantly to ensure that untreated patient distress does not interrupt treatment or lead to costly emergency room or hospital readmissions. For example, the *Screening for Psychosocial Distress Program* (www.apos-society.org/screening) trains cancer

care professionals on how to develop, implement, and maintain a comprehensive distress screening program. Funded by a grant (R25CA177553-01) from the National Cancer Institute, this program is a joint project of Yale School of Nursing and the American Psychosocial Oncology Society (APOS). With an international faculty of leading psychosocial cancer care professionals and researchers, the program will train two cancer care professionals from a cancer program, enrolling 18 cancer centers each year. Successful implementation and ongoing maintenance of a comprehensive distress screening program is enhanced by having two people from each cancer center attend the program. The program's funding allows for a stipend for each person toward covering the cost of attending the program.

The *Screening for Psychosocial Distress Program* will consist of two one-day workshops annually, as well as four online videoconferences in the first year and two in the second. Table 2, page 51, outlines the program's curriculum. The first cohort of trainees will begin the course in February 2014. 

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