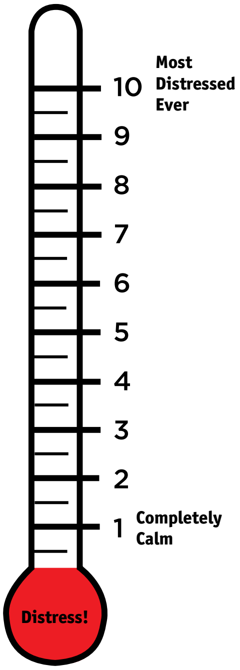
BY JEFF KENDALL, PSYD;
HEIDI HAMANN, PHD; AND
STEPHANIE CLAYTON, MHSM, CMPE

Oncology Distress Screening



Distress prevalence, new standards, and implementation

The diagnosis and treatment of cancer can generate significant levels of distress for cancer patients and their families. Although often considered a normal reaction, symptoms of distress should not be considered benign. Psychosocial distress can lead to disruptions in medical care and negatively influence all aspects of daily life. Recognizing the importance of addressing the emotional and social concerns of oncology patients, the National Comprehensive Cancer Network (NCCN) issued a consensus statement recommending distress screening and management as a standard of care within oncology health services delivery.[1] The label "distress" is used because it:

- Is less stigmatizing to patients and families than psychiatric diagnoses or psychological jargon
- Facilitates an understanding that distress is a normal process which ranges from mild to debilitating
- Facilitates an understanding that distress severity can change across the cancer continuum.

Figure 1. Simmons Cancer Center Distress Screening Procedure

RECEPTION DESK

✓ Staff gives all outpatients the Distress Screening Tool.

✓ Patients complete Distress Screening Tool in the waiting area and return it to the reception desk.

SUPPORT SERVICES

✓ Oncology Support Services team collects the Distress Screening Tool from the reception desk.

More specifically, the NCCN defines distress in cancer as:[1]

> *A multifactorial, unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer, its physical symptoms, and its treatment. Distress extends along a continuum ranging from normal feelings of vulnerability, sadness, and fear to disabling conditions such as clinical depression, anxiety, panic, isolation, and existential or spiritual crisis.*

The American Psychosocial Oncology Society (APOS) subsequently endorsed this consensus statement and distress definition.[2] APOS augmented the NCCN guidelines by recommending that screening tools be easy to administer, score, and interpret, and be brief and non-stigmatizing for the patient population. In 2008 the Institute of Medicine's (IOM) report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs,* underscored the NCCN and APOS recommendations to establish a screening mechanism to identify psychosocial needs in cancer patients.[3] In addition, the IOM report advanced the guidelines for the detection and management of distress by recommending the incorporation of psychosocial services within oncology as a national standard of care to be implemented across all types of cancer treatment settings.

In spite of these recommendations, distress often goes undetected and untreated.[3] The lack of detection and resulting under-treatment of distress has been shown to contribute to a number of negative outcomes:[3]

- Increased suffering
- Decreased quality of life for both patients and family members
- Reduced adherence to medical treatment
- Longer hospitalizations
- The possibility of decreased survival odds.

Several factors contribute to the low rates of distress screening within cancer programs, including lack of training among oncologists and nurses to detect distress, limitations in time allotted for patient visits, and lack of psychosocial professionals within cancer programs.[3]

Accreditation Standards

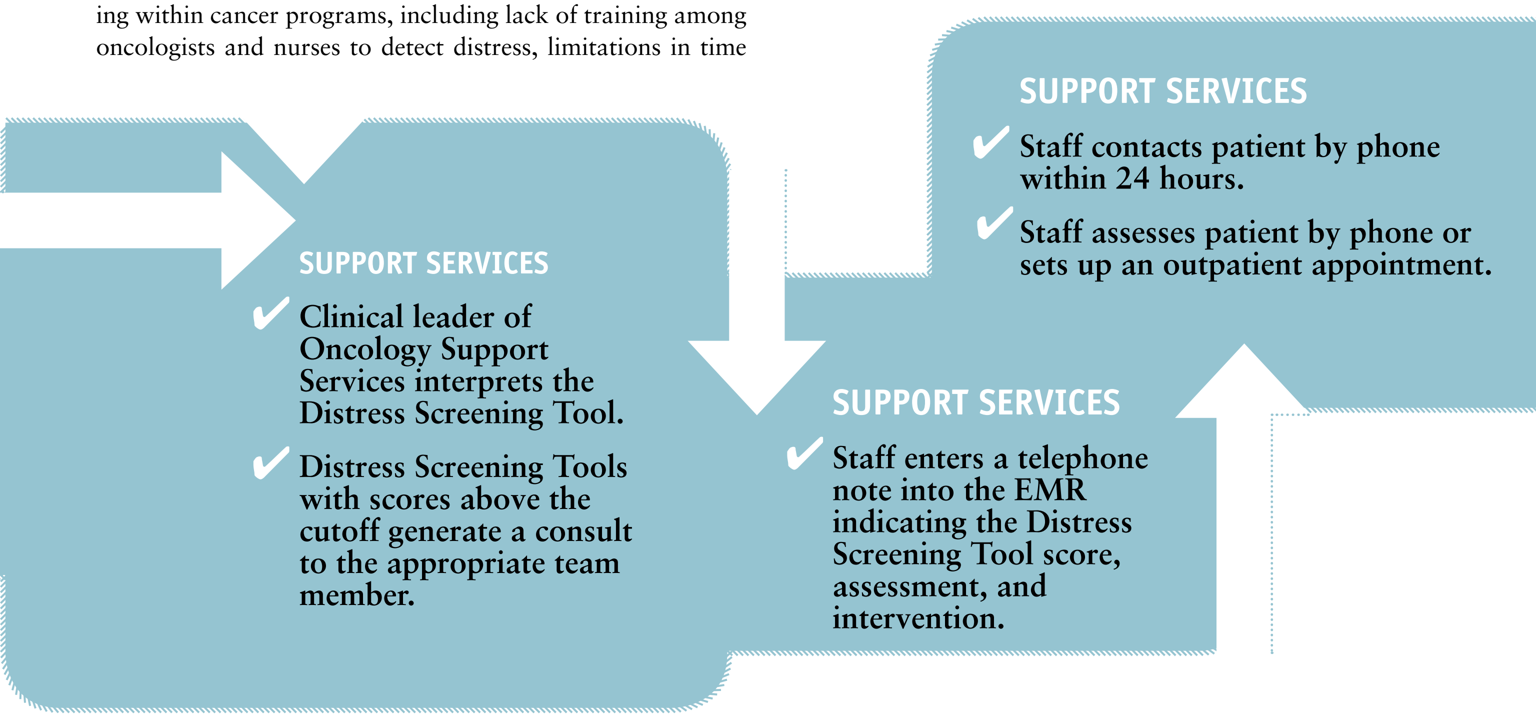
The screening and management of psychosocial distress is garnering significant national attention since the American College of Surgeons (ACoS) Commission on Cancer (CoC) published the *Cancer Program Standards 2012: Ensuring Patient-Centered Care.*[4] These new standards are designed to help accredited programs focus on patient-centered care with the goal of improving the quality of cancer care throughout the United States. The CoC requires that these new standards be in place by 2015.

One of the new standards is Standard 3.2: Psychosocial Distress Screening, which states:[4]

> *The cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care.*

In order to comply with this standard, cancer programs are required to screen their patients at least once during the cancer patient's course of treatment; this screening should occur during a pivotal medical visit. Cancer programs determine for themselves the mechanism used to screen for distress. Common methodologies range from self-report patient questionnaires to clinician administered questionnaires to clinical interview. The CoC prefers that patients are screened using standardized, validated instruments with established clinical cutoffs; however cancer programs are not penalized for developing their own instruments and constructing their own cutoff scores. Specific examples of screening tools are discussed in the sidebar on page 26.

The American Society of Clinical Oncology's (ASCO) Quality Oncology Practice Initiative (QOPI®) also supports



SUPPORT SERVICES

- ✓ Clinical leader of Oncology Support Services interprets the Distress Screening Tool.
- ✓ Distress Screening Tools with scores above the cutoff generate a consult to the appropriate team member.

SUPPORT SERVICES

- ✓ Staff enters a telephone note into the EMR indicating the Distress Screening Tool score, assessment, and intervention.

SUPPORT SERVICES

- ✓ Staff contacts patient by phone within 24 hours.
- ✓ Staff assesses patient by phone or sets up an outpatient appointment.

the importance of screening for emotional distress in cancer patients.[5] QOPI is a voluntary quality assessment and improvement program for outpatient hematology and oncology practices within the United States, and is designed by oncologists with a goal of improving patient-centered cancer care. Practices can obtain QOPI certification by achieving a defined performance level on QOPI measures. QOPI includes distress screening and intervention within its Core Module measures:

- Core Module #24: Patient emotional well-being assessed by the second office visit.
- Core Module #25: Action taken to address emotional problems by the second office visit.

Distress Prevalence: How Big is the Problem?

Considerable empirical evidence demonstrates the psychological and social morbidity of a cancer diagnosis. Research shows that 25 to 50 percent of all cancer patients experience significant levels of distress. More specifically, within this 25 to 50 percent exists two sub-groups: those who meet the criteria for psychiatric illnesses, such as major depression or adjustment disorders (up to 25 percent of all patients), and patients who report distress levels that do not meet criteria for a psychiatric diagnosis but experience distress that significantly interferes with quality of life and functional status (15 to 20 percent of all patients).[6-8] Using the term "distress" allows cancer programs to identify patients who fall into either of these two groups and provide interventions that decrease the impact of the distress etiology in order to reduce suffering and improve quality of life variables.

The literature reports that intensity of distress levels may increase with recurrence,[6–8] advanced disease,[8,9] and increased pain and disability, which would suggest that cancer patients' distress levels may fluctuate as they progress through cancer treatment.[6-8] These data come from a limited number of studies and National Cancer Institute-designated comprehensive cancer center patient samples. Therefore, these data may not fully represent patient populations found in community cancer center settings.

One study presented distress screening data for 1,281 cancer patients from a community cancer center.[10] In this study, Kendall and colleagues reported that 32 percent of the cancer patients treated within a community cancer center reported distress intensity above the cutoff value for the distress measure used.[10] These data mirror the distress ranges reported in previous studies, which indicated 25 to 50 percent of cancer patients have distress levels that interfere with adaptation and functioning. To put this study's findings into perspective, in this sample of 1,281 patients, 410 patients would require additional assessment and possible intervention from a psychosocial professional.[10] To meet the requirements of the CoC, QOPI, and the IOM report, this cancer program would need to have adequate psychosocial staffing to not only administer and score the screening instrument, but also provide the appropriate follow-up assessment and necessary clinical interventions resulting from the assessments.

Screening Implementation: One Program's Experience

Although screening and detection for distress may appear simple, cancer programs throughout the United States are struggling to achieve this standard. When 1,000 randomly selected members of ASCO were surveyed in 2006, only 32 percent of respondents reported awareness of the NCCN Distress Screening Guidelines and a mere 14 percent reported they performed distress screening using a standardized tool. In addition, one third of this sample reported they did not have any mechanism for distress screening. These data are further supported by a NCCN study of screening behaviors that indicated only 8 of 15 NCCN member institutions routinely screen for distress in at least some of their patients.

At the UT Southwestern Harold C. Simmons Comprehensive Cancer Center in Dallas, Texas, a distress screening instrument (at right) was developed for internal use. The distress screening instrument has two sections. The first section consists of eight visual analogue scales (0= no symptoms and 10= severe symptoms) in which patients rate their distress severity for the following concerns:

1. Appetite
2. Weight loss
3. Depression
4. Anxiety
5. Concerns about children
6. Insurance
7. Spouse and family concerns
8. Other concern(s).

The second section provides patients with an opportunity to request contact from a member of the supportive care team regardless of the symptom severity rating in the first section. For instance, a patient can indicate that appetite is good with no weight loss (scores 0–4) but still request to be contacted by a dietitian.

The decision to screen patients using this type of visual analogue scale came after an examination of our site-specific needs and a review of the strengths and weaknesses of available screening instruments (see page 26). We appreciated the ease of administration and empirical support for visual analogue scales, but needed to develop an instrument that provided clearer lines of referral than those of existing measurement tools. For example, on the Distress Thermometer, when a patient endorses high distress and then identifies multiple checklist domains (i.e., diet, emotional, financial), there is no way of knowing how each of those problems contributed to the overall distress score. Therefore, such an instrument does not indicate whether the high-distress rating needs to be addressed by a dietitian, social worker, and/or financial counselor. Similarly, instruments such as the HADS and the ESAS were judged to be too narrow in focus (i.e., primarily focused on anxiety and depression, with insufficient attention to dietary and social work concerns) to suit the breadth of our supportive care resources.

Medical and surgical oncology patients are asked to complete a paper version of the distress screening instrument prior to their outpatient clinic appointment (see Figure 1, pages 22–23). Once the patient completes the form, they are asked to return it to staff at the check-in desk. The distress screening forms are kept

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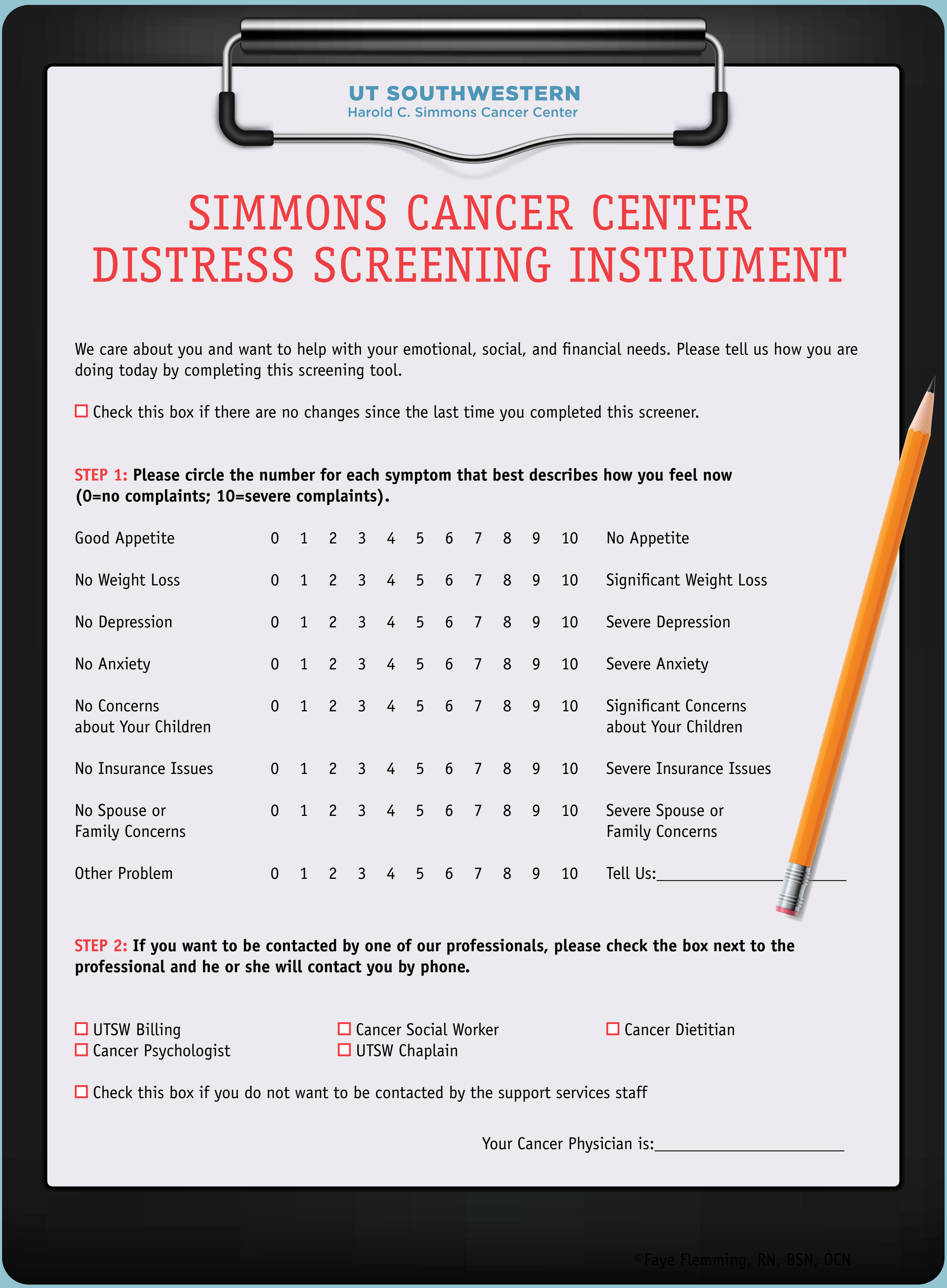


UT SOUTHWESTERN
Harold C. Simmons Cancer Center

SIMMONS CANCER CENTER DISTRESS SCREENING INSTRUMENT

We care about you and want to help with your emotional, social, and financial needs. Please tell us how you are doing today by completing this screening tool.

☐ Check this box if there are no changes since the last time you completed this screener.

STEP 1: **Please circle the number for each symptom that best describes how you feel now (0=no complaints; 10=severe complaints).**

Good Appetite	0	1	2	3	4	5	6	7	8	9	10	No Appetite
No Weight Loss	0	1	2	3	4	5	6	7	8	9	10	Significant Weight Loss
No Depression	0	1	2	3	4	5	6	7	8	9	10	Severe Depression
No Anxiety	0	1	2	3	4	5	6	7	8	9	10	Severe Anxiety
No Concerns about Your Children	0	1	2	3	4	5	6	7	8	9	10	Significant Concerns about Your Children
No Insurance Issues	0	1	2	3	4	5	6	7	8	9	10	Severe Insurance Issues
No Spouse or Family Concerns	0	1	2	3	4	5	6	7	8	9	10	Severe Spouse or Family Concerns
Other Problem	0	1	2	3	4	5	6	7	8	9	10	Tell Us:____________________________

STEP 2: **If you want to be contacted by one of our professionals, please check the box next to the professional and he or she will contact you by phone.**

☐ UTSW Billing
☐ Cancer Psychologist
☐ Cancer Social Worker
☐ UTSW Chaplain
☐ Cancer Dietitian

☐ Check this box if you do not want to be contacted by the support services staff

Your Cancer Physician is:______________________

SCREENING INSTRUMENTS

The paucity of distress screening within cancer programs might lead to an assumption there is a lack of screening instruments that meet the criteria of being brief; easy to administer, score, and interpret; and established by multiple organizations. Fortunately many different types of screening instruments are available to cancer programs. A select few are listed below.

Distress Thermometer

One of the best known distress screening instruments is the Distress Thermometer (DT).[11] Endorsed by the NCCN Distress Practice Guidelines panel, the DT consists of simply asking patients to rate their distress using a vertically aligned (thermometer) visual analogue scale with scores ranging from 0 ("no distress") to 10 ("extreme distress"). The NCCN Clinical Practice Guidelines for Distress Management added a 34-item problem checklist to the DT to assist in identifying the source of the patient's distress. The problem checklist is grouped into five categories: practical, physical, family, emotional, and spiritual. Under this screening process, patients are asked to answer the single-item DT and identify any of the problem items in the problem checklist they may have experienced in the past week. Initially, the NCCN Clinical Practice Guidelines for Distress Management recommended a cutoff score of 5 on the DT as indicative of significant distress that warrants a referral to appropriate supportive services.

The DT is a robust and accepted instrument for assessing distress and has been validated through comparison with more comprehensive and lengthy instruments. The Distress Thermometer has been shown to have sensitivity ratings ranging from 0.65 to 0.77 and specificity ratings from 0.68 to 0.78 when compared to the Hospital Anxiety and Depression Scale (HADS). In addition, the DT—with the addition of the problem checklist—satisfies the APOS guidelines for ease in administration, scoring, and interpretation.

Hospital Anxiety and Depression Scale

HADS is a brief screening instrument designed to assess the psychological states of physically ill patients.[12] The strength of this instrument is that it assesses anxiety and depression without emphasizing the somatic symptoms, such as changes in appetite or sleep. This is relevant because when somatic symptoms of anxiety and depression are included in screening instruments for oncology patients, an increase in false-positives occurs. The HADS is accepted as an effective screening tool for anxiety and depression and has been widely used in both research protocols and clinical practice. It consists of 14 items, 7 for depression and 7 for anxiety, and each item is answered on a 4-point (0–3) Likert-type scale. Higher scores indicate greater anxiety and/or depression. The recommended cutoff score of 11 is used for probable cases or 8 for possible cases. Using a cutoff of 8 gives a specificity of 0.78 and a sensitivity of 0.9 for anxiety, and a specificity of 0.79 and a sensitivity of 0.83 for depression in cancer patients. The HADS also produces a total score, which can be used as a measure of distress. The HADS satisfies criteria for ease of administration; however, scoring is more complicated and time consuming than the DT.

Edmonton Symptom Assessment Scale

The Edmonton Symptom Assessment Scale (ESAS) is a brief screening instrument developed for use in palliative care patients and validated with oncology patients.[13] It consists of nine visual analogue scales with which patients rate the severity of the following symptoms:

- Pain
- Activity
- Nausea
- Depression
- Anxiety
- Drowsiness
- Lack of appetite
- Well-being
- Shortness of breath.

There is an optional tenth symptom, which can be added by the patient. Therefore, each symptom is listed with its own visual analogue scale so the patient can indicate the amount of distress caused by that specific symptom. The sum of patient responses to these nine symptoms is the ESAS total distress score. The ESAS satisfies criteria for internal consistency, criterion, and concurrent validity. The ESAS also satisfies the APOS guidelines for ease in administration, scoring, and interpretation.

(continued from page 24)

at the check-in desk until a member of the supportive services team collects them. Once collected, the forms are reviewed by the clinical leader of oncology supportive services who is a licensed psychologist. Distress screeners with distress scores above the cutoff for any of the eight concerns are then directed to the cancer program professional whose expertise is related to that question (see Figure 2, below). For example, if a patient reports a 9 out of 10 symptom severity rating on the appetite question, then that patient information would be relayed to the dietitian. The appropriate professional is notified of this self-reported score and contacts the patient by phone within 24 hours. The psychosocial provider uses the phone contact to assess the patient's responses to the distress screening instrument and then determines the appropriate intervention. The phone assessment is recorded in the cancer center electronic medical record, as well as the intervention employed by the psychosocial provider. Currently, oncology patients are screened at each visit to our outpatient clinics.

Overall, we have found our measure to be patient-friendly in both its administration and responsiveness to patient needs and concerns.

Lessons Learned

Our distress screening instrument satisfies the requirements of being brief; easy to administer, score, and interpret; and does not stigmatize our patients. The instrument is flexible in that it is very simple to add a question based on patient or provider feedback. One limitation of this instrument is the lack of empirical data for a specific cutoff value and specific validity and reliability data. A second limitation is the need to build an electronic administration and referral system that can function with the electronic health record. We look to address those issues in the future.

Adequate and successful distress screening requires input and cooperation from many layers of the cancer program staff. All staff involved should understand the importance of distress screening and the process involved. It is valuable to have distress screening champions identified at multiple stages of the process.

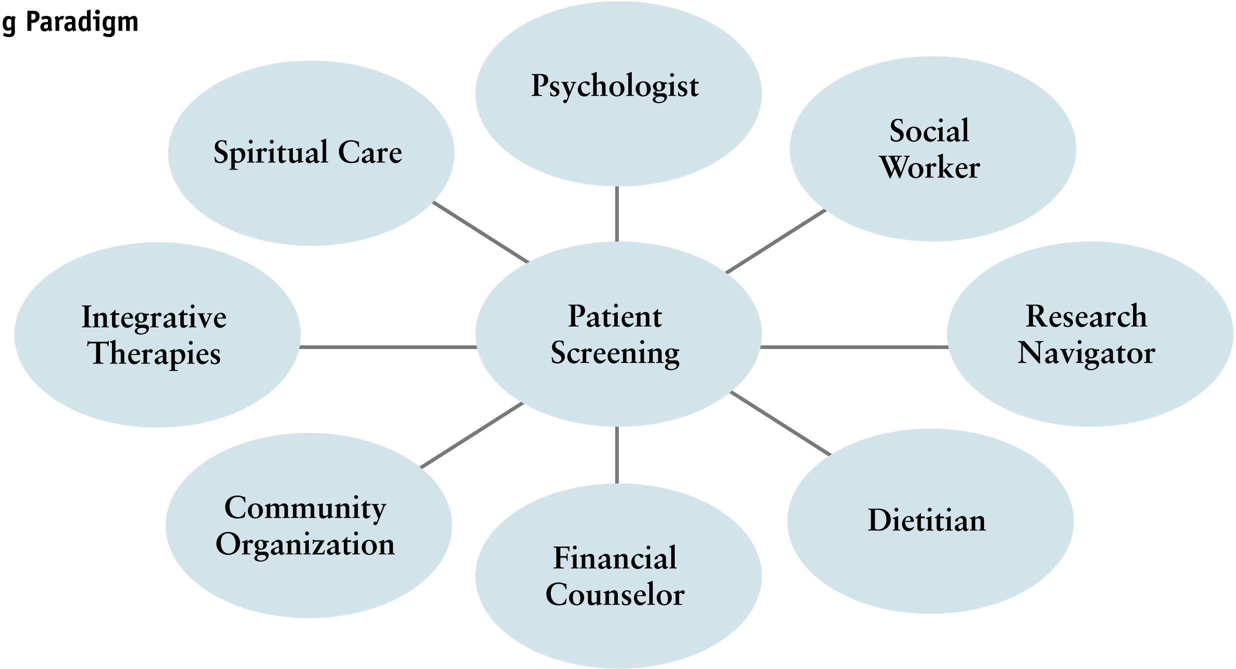
The most difficult barrier to distress screening is that it requires staff resources to accomplish. Cancer programs must have adequate staff to:

- Determine which screening instrument to use
- Develop the screening policies and procedures
- Evaluate and interpret the screening instrument
- Develop the interventions for positively screened patients.

Anecdotally we have found that the distress screening process is helping us uncover patient problems at an earlier point, thus facilitating problem solving while these problems are still manageable. Cancer programs that do not have psychologists, dietitians, social workers, or chaplains should look to professionals in the community, community organizations, and local universities to develop a referral network that can help address the psychological and social concerns of their patients.

Electronic tools for distress screening are available and are more efficient than paper screening instruments. It is important to develop the electronic screening instruments so that these can interface with an electronic health record. For example, an efficient system for distress screening could allow patients to complete a distress screening instrument electronically, populate the data within the EHR,

Figure 2. Simmons Cancer Center Distress Screening Paradigm



and generate automatic referrals to the appropriate supportive services staff.

Distress screening can be accomplished within community cancer centers. Screening and appropriate intervention for psychosocial concerns are just the beginning of a truly integrative model of cancer care. In addition, prospective and systematic screening may address psychosocial problems before they become time consuming and disruptive to the medical treatment plan. Once needs are identified, it is important to have internal and/or external resources available to meet the identified needs.

—Jeff Kendall, PsyD, is clinical leader of Oncology Supportive Services; Heidi Hamann, PhD, is research leader of Cancer Survivorship Research; and Stephanie Clayton, MHSM, CMPE, is the associate vice president for Cancer Programs for the Harold C. Simmons Comprehensive Cancer Center at UT Southwestern Medical Center in Dallas, Tex.

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OUR PROGRAM AT-A-GLANCE

In 1988 Harold C. Simmons and his wife Annette, through a generous endowment, made provision for the Harold C. Simmons Cancer Center and Clinics, part of the University Of Texas Southwestern (UT Southwestern) Medical Center. UT Southwestern consolidated in January 2005, and now consists of two hospitals, University Hospital Zale Lipshy and University Hospital St. Paul, and outpatient ambulatory clinics that provide comprehensive patient care to Dallas and surrounding areas. The Simmons Cancer Center sees nearly 3,000 analytic patients per year and has comprehensive cancer treatment programs in the following 10 areas:

1. Brain and spinal cord
2. Breast
3. Gastrointestinal
4. Gynecological
5. Head and neck
6. Lung
7. Hematological (including BMT)
8. Melanoma
9. Sarcoma
10. Urologic.

In addition to medical care, we offer a full complement of support services, including nutrition, clinical social work, psychology, and integrative therapies to enhance each medical treatment program. In 2010 Simmons Cancer Center was granted NCI cancer center designation; the entire program is currently working to achieve comprehensive cancer center designation.