

## NCCN

# Distress Management

## Clinical Practice Guidelines in Oncology

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### Abstract

The integration of psychosocial care into the routine care of all patients with cancer is increasingly being recognized as the new standard of care. These NCCN Clinical Practice Guidelines in Oncology for Distress Management discuss the identification and treatment of psychosocial problems in patients with cancer. They are intended to assist oncology teams identify patients who require referral to psychosocial resources and to give oncology teams guidance on interventions for patients with mild distress to ensure that all patients with distress are recognized and treated. (*JNCCN* 2013;11:190–209)

### NCCN Categories of Evidence and Consensus

**Category 1:** Based upon high-level evidence, there is uniform NCCN consensus that the intervention is appropriate.

**Category 2A:** Based upon lower-level evidence, there is uniform NCCN consensus that the intervention is appropriate.

**Category 2B:** Based upon lower-level evidence, there is NCCN consensus that the intervention is appropriate.

**Category 3:** Based upon any level of evidence, there is major NCCN disagreement that the intervention is appropriate.

All recommendations are category 2A unless otherwise noted.

**Clinical trials:** NCCN believes that the best management for any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

### Overview

In the United States, an estimated 1,638,910 new cancer cases and 577,190 deaths from cancer will occur in 2012.<sup>1</sup> All patients experience some level of distress associated with the diagnosis of cancer and its effects and treatment regardless of the stage of disease. Distress can result from the reaction to the diagnosis of cancer and to the various transitions throughout the trajectory of the disease, including during survivorship. Clinically significant levels of distress occur in a subset of patients, and identification and treatment of distress are of the utmost importance.

These NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Distress Management discuss the identification and treatment of psy-

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### Disclosures for the NCCN Distress Management Panel

At the beginning of each NCCN Guidelines panel meeting, panel members review all potential conflicts of interest. NCCN, in keeping with its commitment to public transparency, publishes these disclosures for panel members, staff, and NCCN itself.

Individual disclosures for the NCCN Distress Management Panel members can be found on page 209. (The most recent version of these guidelines and accompanying disclosures are available on the NCCN Web site at [NCCN.org](http://NCCN.org).)

These guidelines are also available on the Internet. For the latest update, visit [NCCN.org](http://NCCN.org).

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psychosocial problems in patients with cancer. They are intended to help oncology teams identify patients who require referral to psychosocial resources and to provide oncology teams guidance on interventions for patients with mild distress. These guidelines also provide guidance for social workers, certified chaplains, and mental health professionals who describe treatments and interventions for various psychosocial problems as they relate to patients with cancer.

### Psychosocial Problems in Patients With Cancer

In the past 2 decades, dramatic advances in early detection and treatment options have increased the overall survival rates in patients of all ages with

cancer. At the same time, these improved treatment options are also associated with substantial long-term side effects: fatigue, pain, anxiety, and depression are the most frequently reported cancer-related symptoms that interfere with the patient's ability to perform daily activities.<sup>2</sup> In addition, the physiologic effects of cancer itself and certain anticancer drugs can also be nonpsychological contributors to distress symptoms.<sup>3-6</sup> Furthermore, patients with cancer may have preexisting psychological or psychiatric conditions that impact their ability to cope with cancer.

The prevalence of psychological distress in individuals varies by the type and stage of cancer and by patient age. In a study of 4496 patients with cancer, Zabora et al<sup>7</sup> reported that the overall prevalence of distress was 35.1%, which varied from 29.6% for

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<sup>¶</sup>Surgery/Surgical Oncology; <sup>¥</sup>Patient Advocacy

#### “DISTRESS”

Term “distress” was chosen because it:

- Is more acceptable and less stigmatizing than “psychiatric”, “psychosocial,” or “emotional”
- Sounds “normal” and less embarrassing
- Can be defined and measured by self-report

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#### DEFINITION OF DISTRESS IN CANCER

Distress is a multifactorial 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. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.

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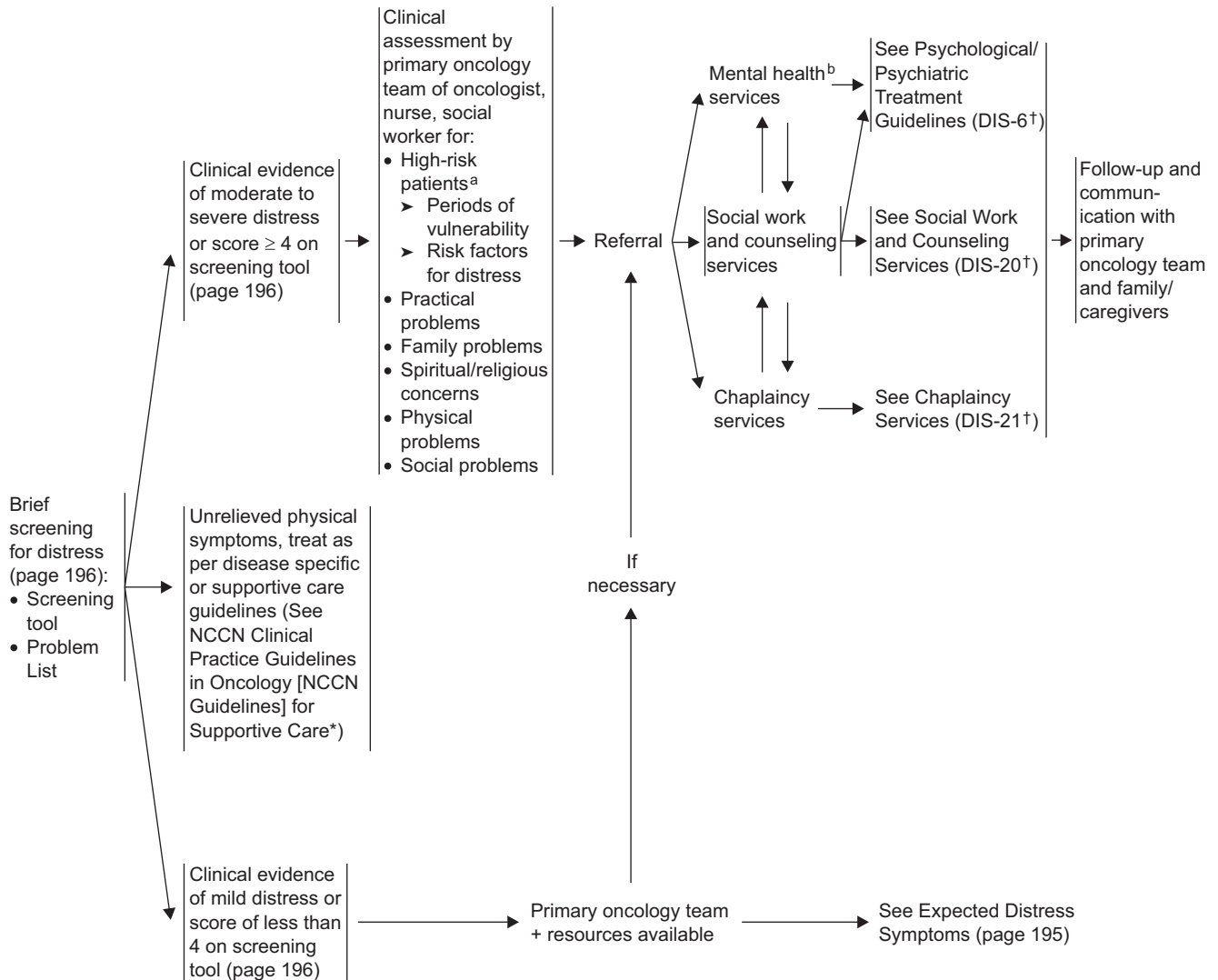
### STANDARDS OF CARE FOR DISTRESS MANAGEMENT

- Distress should be recognized, monitored, documented, and treated promptly at all stages of disease and in all settings.
- Screening should identify the level and nature of the distress.
- All patients should be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated, especially with changes in disease status (ie, remission, recurrence, progression).
- Distress should be assessed and managed according to clinical practice guidelines.
- Interdisciplinary institutional committees should be formed to implement standards for distress management.
- Educational and training programs should be developed to ensure that health care professionals and certified chaplains have knowledge and skills in the assessment and management of distress.
- Licensed mental health professionals and certified chaplains experienced in psychosocial aspects of cancer should be readily available as staff members or by referral.
- Medical care contracts should include reimbursement for services provided by mental health professionals.
- Clinical health outcomes measurement should include assessment of the psychosocial domain (eg, quality of life and patient and family satisfaction).
- Patients, families, and treatment teams should be informed that management of distress is an integral part of total medical care and provided with appropriate information about psychosocial services in the treatment center and the community.
- Quality of distress management programs/services should be included in institutional continuous quality improvement (CQI) projects.

OVERVIEW OF EVALUATION AND TREATMENT PROCESS

EVALUATION

TREATMENT



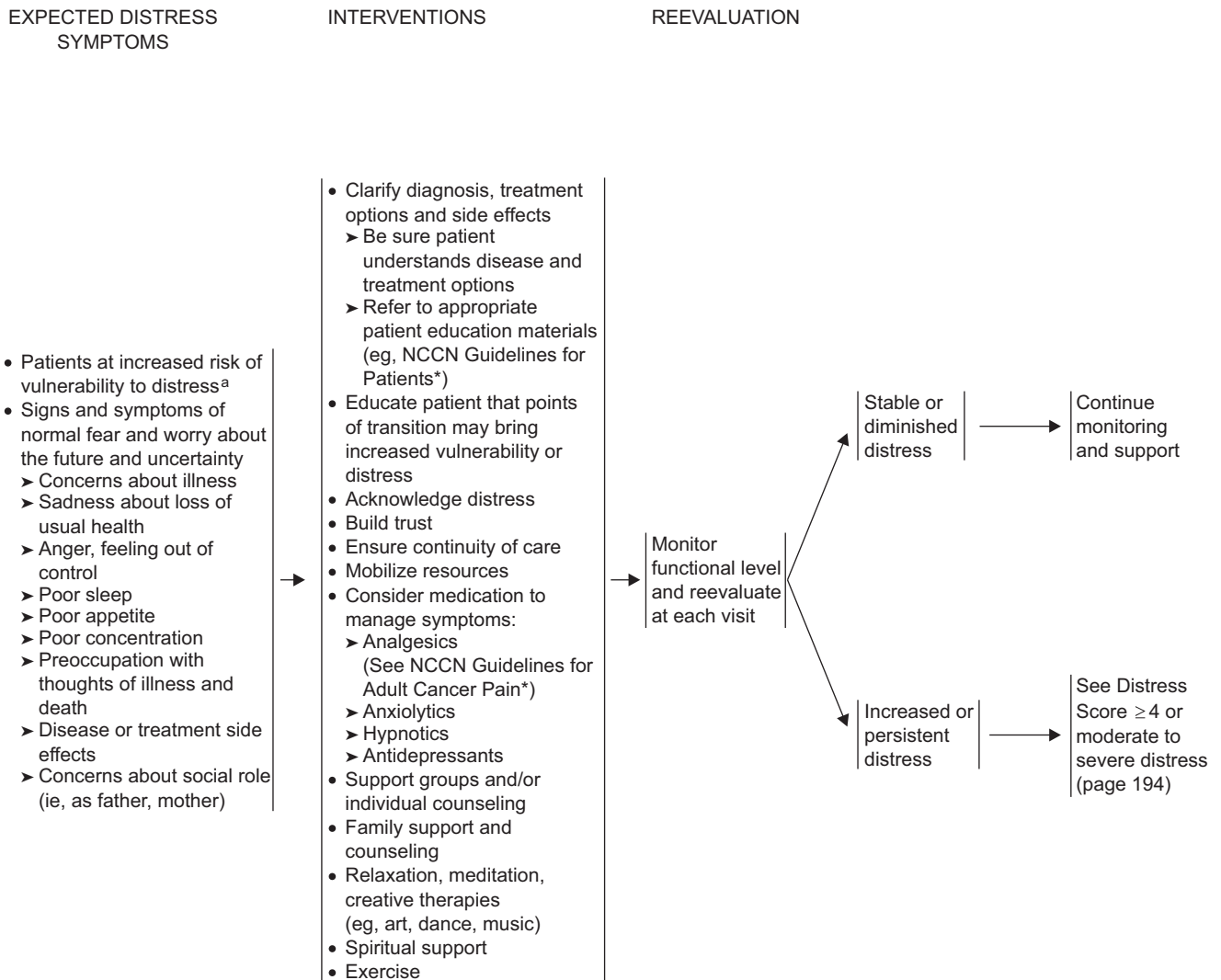
\*To view the most recent version of these guidelines, visit NCCN.org.

<sup>†</sup>Available online, in these guidelines, at NCCN.org.

<sup>a</sup>See Psychosocial Distress Patient Characteristics (page 197).

<sup>b</sup>Psychiatrist, psychologist, advanced practice clinicians, and/or social worker.

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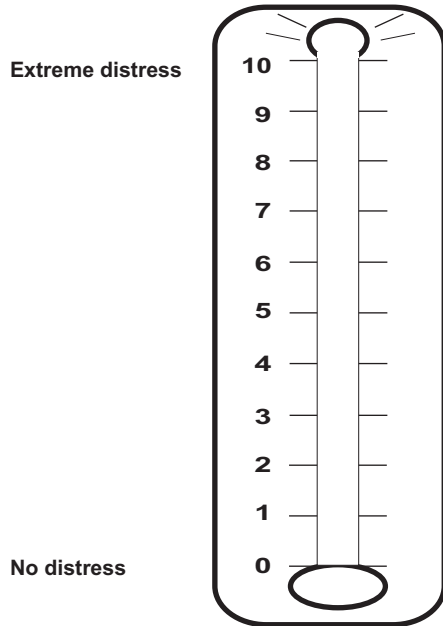
\*To view the most recent version of these guidelines, visit [NCCN.org](http://NCCN.org).

<sup>a</sup>See Psychosocial Distress Patient Characteristics (page 197).

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.



- | YES                      | NO                       | <u>Practical Problems</u>            | YES                      | NO                       | <u>Physical Problems</u> |
|--------------------------|--------------------------|--------------------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | Child care                           | <input type="checkbox"/> | <input type="checkbox"/> | Appearance               |
| <input type="checkbox"/> | <input type="checkbox"/> | Housing                              | <input type="checkbox"/> | <input type="checkbox"/> | Bathing/dressing         |
| <input type="checkbox"/> | <input type="checkbox"/> | Insurance/financial                  | <input type="checkbox"/> | <input type="checkbox"/> | Breathing                |
| <input type="checkbox"/> | <input type="checkbox"/> | Transportation                       | <input type="checkbox"/> | <input type="checkbox"/> | Changes in urination     |
| <input type="checkbox"/> | <input type="checkbox"/> | Work/school                          | <input type="checkbox"/> | <input type="checkbox"/> | Constipation             |
| <input type="checkbox"/> | <input type="checkbox"/> | Treatment decisions                  | <input type="checkbox"/> | <input type="checkbox"/> | Diarrhea                 |
|                          |                          |                                      | <input type="checkbox"/> | <input type="checkbox"/> | Eating                   |
|                          |                          |                                      | <input type="checkbox"/> | <input type="checkbox"/> | Fatigue                  |
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Family Problems</u>               | <input type="checkbox"/> | <input type="checkbox"/> | Feeling Swollen          |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with children                | <input type="checkbox"/> | <input type="checkbox"/> | Fevers                   |
| <input type="checkbox"/> | <input type="checkbox"/> | Dealing with partner                 | <input type="checkbox"/> | <input type="checkbox"/> | Getting around           |
| <input type="checkbox"/> | <input type="checkbox"/> | Ability to have children             | <input type="checkbox"/> | <input type="checkbox"/> | Indigestion              |
| <input type="checkbox"/> | <input type="checkbox"/> | Family health issues                 | <input type="checkbox"/> | <input type="checkbox"/> | Memory/concentration     |
|                          |                          |                                      | <input type="checkbox"/> | <input type="checkbox"/> | Mouth sores              |
|                          |                          |                                      | <input type="checkbox"/> | <input type="checkbox"/> | Nausea                   |
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Emotional Problems</u>            | <input type="checkbox"/> | <input type="checkbox"/> | Nose dry/congested       |
| <input type="checkbox"/> | <input type="checkbox"/> | Depression                           | <input type="checkbox"/> | <input type="checkbox"/> | Pain                     |
| <input type="checkbox"/> | <input type="checkbox"/> | Fears                                | <input type="checkbox"/> | <input type="checkbox"/> | Sexual                   |
| <input type="checkbox"/> | <input type="checkbox"/> | Nervousness                          | <input type="checkbox"/> | <input type="checkbox"/> | Skin dry/itchy           |
| <input type="checkbox"/> | <input type="checkbox"/> | Sadness                              | <input type="checkbox"/> | <input type="checkbox"/> | Sleep                    |
| <input type="checkbox"/> | <input type="checkbox"/> | Worry                                | <input type="checkbox"/> | <input type="checkbox"/> | Substance abuse          |
| <input type="checkbox"/> | <input type="checkbox"/> | Loss of interest in usual activities | <input type="checkbox"/> | <input type="checkbox"/> | Tingling in hands/feet   |
| <input type="checkbox"/> | <input type="checkbox"/> | <u>Spiritual/Religious concerns</u>  |                          |                          |                          |

Other problems: \_\_\_\_\_  
\_\_\_\_\_

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PSYCHOSOCIAL DISTRESS PATIENT CHARACTERISTICS<sup>c</sup>PATIENTS AT INCREASED RISK FOR DISTRESS<sup>d</sup>

- History of psychiatric disorder/substance abuse
- History of depression/suicide attempt
- Cognitive impairment
- Communication barriers<sup>e</sup>
- Severe comorbid illnesses
- Social issues
  - ▶ Family/caregiver conflicts
  - ▶ Inadequate social support
  - ▶ Living alone
  - ▶ Financial problems
  - ▶ Limited access to medical care
  - ▶ Young or dependent children
  - ▶ Younger age; woman
  - ▶ History of abuse (physical, sexual)
  - ▶ Other stressors
- Spiritual/religious concerns
- Uncontrolled symptoms

PERIODS OF INCREASED VULNERABILITY

- Finding a suspicious symptom
- During workup
- Finding out the diagnosis
- Awaiting treatment
- Change in treatment modality
- End of treatment
- Discharge from hospital following treatment
- Transition to survivorship
- Medical follow-up and surveillance
- Treatment failure
- Recurrence/progression
- Advanced cancer
- End of life

<sup>c</sup>For site-specific symptoms with major psychosocial consequences, see Holland JC, Greenberg DB, Hughes MK. Quick Reference for Oncology Clinicians: The Psychiatric and Psychological Dimensions of Cancer Symptom Management. Charlottesville, VA: IPOS press; 2006. (Based on the NCCN Guidelines for Distress Management). Available at [www.apos-society.org](http://www.apos-society.org).

<sup>d</sup>From the NCCN Guidelines for Palliative Care; to view the most recent version of these guidelines, visit [NCCN.org](http://NCCN.org).

<sup>e</sup>Communication barriers include language, literacy, and physical barriers.



RECOMMENDATIONS FOR IMPLEMENTATION  
OF STANDARDS AND GUIDELINES

- Encourage establishment of institutional interdisciplinary committees for implementation of standards and guidelines
- Conduct multicenter trials that explore brief screening instruments and pilot treatment guidelines
- Encourage institutional CQI projects in quality of distress management
- Develop educational approaches to distress management for staff, patients, and family

RECOMMENDED READINGS FOR IMPLEMENTATION OF PROGRAMS THAT INTEGRATE  
PSYCHOSOCIAL CARE INTO THE ROUTINE CARE OF PATIENTS WITH CANCER

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- Fann JR, Ell K, Sharpe M. Integrating psychosocial care into cancer services. *J Clin Oncol* 2012;30:1178-1186.
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- Fulcher CD, Gosselin-Acomb TK. Distress assessment: practice change through guideline implementation. *Clin J Oncol Nurs* 2007;11:817-821.
- Grassi L, Rossi E, Caruso R, et al. Educational intervention in cancer outpatient clinics on routine screening for emotional distress: an observational study. *Psychooncology* 2011;20:669-674.
- Hendrick SS, Cobos E. Practical model for psychosocial care. *J Oncol Pract* 2010;6:34-36.
- Loscalzo M, Clark KL, Holland J. Successful strategies for implementing biopsychosocial screening. *Psychooncology* 2011;20:455-462.
- Lowery AE, Holland JC. Screening cancer patients for distress: guidelines for routine implementation. *Community Oncol* 2011;8:502-505.
- Mehta A, Hamel M. The development and impact of a new Psychosocial Oncology Program. *Support Care Cancer* 2011;19:1873-1877.
- Rodriguez MA, Tortorella F, St John C. Improving psychosocial care for improved health outcomes. *J Healthc Qual* 2010;32:3-12.

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patients with gynecologic cancers to 43.4% for patients with lung cancer. The prevalence of distress, depression, and psychiatric disorders has been studied in many sites and stages of cancer.<sup>8-14</sup> Overall, surveys have found that 20% to 47% of patients with newly diagnosed and recurrent cancer show a significant level of distress. A recent meta-analysis reported that 30% to 40% of patients with various types of cancer have some combination of mood disorders.<sup>15</sup>

Patients at increased risk for moderate or severe distress are those with a history of psychiatric disorder, depression, or substance abuse and those with cognitive impairment, severe comorbid illnesses, uncontrolled symptoms, communication barriers, or social issues. Social issues/risk factors include younger age, female sex, living alone, having young children, and prior physical or sexual abuse.

Distress is a risk factor for nonadherence to treatment, especially with regard to oral medications. In women with primary breast cancer, Partridge et al<sup>16</sup> observed that the overall adherence to tamoxifen decreased to 50% in the fourth year of therapy and nearly one-fourth of patients may be at risk of inadequate clinical response because of poor adherence. In a meta-analysis, DiMatteo et al<sup>17</sup> found that non-compliance was 3 times greater in depressed patients compared with nondepressed patients. In addition to decreased adherence to treatment, failure to recognize and treat distress leads to several problems: patients may have trouble making decisions about treatment and they may make extra visits to the physician's office and emergency room, which takes more time and causes greater stress for the oncology team.<sup>18,19</sup> Distress in patients with cancer also leads to poorer quality of life and can even negatively impact survival.<sup>14,20,21</sup> Furthermore, cancer survivors with untreated distress have poorer compliance with surveillance screenings and are less likely to exercise and quit smoking.<sup>22</sup>

Early evaluation and screening for distress leads to early and timely management of psychological distress, which in turn improves medical management.<sup>23,24</sup> A recent randomized study showed that routine screening for distress, with referral to psychosocial resources as needed, led to lower levels of distress at 3 months than did screening without personalized triage for referrals.<sup>25</sup> Those with the highest level of initial distress benefitted most. In addition, evidence from randomized trials shows that

psychologically effective interventions may lead to a survival advantage in patients with cancer.<sup>26</sup> Overall, early detection and treatment of distress leads to

- better adherence to treatment
- better communication
- fewer calls and visits to the oncologist's office
- avoidance of patients' anger and development of severe anxiety or depression

### Barriers to Distress Management in Cancer

Fewer than half of distressed patients with cancer are actually identified and referred for psychosocial help.<sup>27,28</sup> Many patients with cancer who are in need of psychosocial care are not able to get the help they need because of the underrecognition of patient's psychological needs by the primary oncology team and lack of knowledge of community resources.<sup>29</sup> The need is particularly acute in community oncologists' practices that have few to no psychosocial resources and in which cancer care is often provided during short visits.

An additional barrier to patients receiving the psychosocial care they require is the stigma associated with psychological problems. For many centuries, patients were not told of their cancer diagnosis because of the stigma attached to the disease. Since the 1970s, this situation has changed and patients are well aware of their diagnosis and treatment options.<sup>30</sup> However, patients are reluctant to reveal emotional problems to the oncologist. The words "psychological," "psychiatric," and "emotional" are as stigmatizing as the word "cancer." The word "distress" is less stigmatizing and more acceptable to patients and oncologists than these terms, but psychological issues remain stigmatized even in the context of coping with cancer. Consequently, patients often do not tell their physicians about their distress and physicians do not inquire about the psychological concerns of their patients. The recognition of patients' distress has become more difficult as cancer care has shifted to the ambulatory setting, where visits are often short and rushed. These barriers prevent distress from receiving the attention it deserves, despite the fact that this is a critical component of the total care of the person with cancer.

### NCCN Guidelines for Distress Management

A major milestone in the improvement of psychosocial care in oncology occurred when NCCN estab-

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lished a panel to develop clinical practice guidelines for distress management using the NCCN format. The panel began to meet in 1997 as an interdisciplinary group. The clinical disciplines involved were oncology, nursing, social work and counseling, psychiatry, psychology, and clergy. A patient advocate was also on the panel. Traditionally, clergy have not been included on NCCN Guidelines Panels, but NCCN recognized that many distressed patients prefer a certified chaplain.<sup>31</sup>

The first step was to understand why this area has been so difficult to develop. The panel members decided that words like “psychiatric” or “psychological” are stigmatizing; patients and oncologists are reluctant to label any symptoms or patients as such. The way around this barrier was developed by using a term that would feel “normal” and nonstigmatizing. This led to the first published guidelines in 1999 for the management of distress in patients with cancer. This accomplishment provided a benchmark, which has been used as the framework in the handbook for oncology clinicians published by the IPOS press (The International Psycho-Oncology Society).<sup>32</sup>

The panel defines *distress* as a multifactorial 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. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.

Recommendations in the guidelines are based on evidence and on consensus among panel members. In addition to the guidelines for oncologists, the panel established guidelines for social workers, certified chaplains, and mental health professionals (psychologists, psychiatrists, psychiatric social workers, and psychiatric nurses).<sup>33</sup>

### The New Standard of Care for Distress Management in Cancer

Psychosocial care had not been considered as an aspect of quality cancer care until a 2007 Institute of Medicine (IOM) report, *Cancer Care for the Whole Patient*.<sup>34</sup> The IOM report is based on the pioneering work of the NCCN Distress Management Panel,

which recommends screening for distress and the development of a treatment plan with referrals as needed to psychosocial resources.<sup>33</sup> Psychosocial care is now a part of the new standard for quality cancer care and should be integrated into routine care.<sup>34,35</sup> The IOM report supported the work of the NCCN Guidelines for Distress Management by proposing a model for the effective delivery of psychosocial health services that could be implemented in any community oncology practice:

- Screening for distress and psychosocial needs
- Making a treatment plan to address these needs and implementing it
- Referring to services as needed for psychosocial care
- Reevaluating, with plan adjustment as appropriate

In Canada, routine psychosocial care is part of the standard of care for patients with cancer; emotional distress is considered the sixth vital sign that is checked routinely along with pulse, respiration, blood pressure, temperature, and pain.<sup>18,36</sup>

In August 2012, the Commission on Cancer (CoC) of the American College of Surgeons (ACS) released new accreditation standards for hospital cancer programs (<http://www.facs.org/cancer/coc/programstandards2012.html>). Their patient-centered focus now includes screening of all patients with cancer for psychosocial distress.

The standards of care for managing distress proposed by the NCCN Distress Management Panel are broad in nature and should be tailored to the particular needs of each institution and group of patients. The overriding goal of these standards is to ensure that no patient with distress goes unrecognized and untreated. The panel based these standards of care on quality improvement guidelines for the treatment of pain.<sup>37</sup> The standards of care developed by the NCCN Distress Management Panel, which can also be found in the guidelines, are as follows:

- Distress should be recognized, monitored, documented, and treated promptly at all stages of disease and in all settings.
- Screening should identify the level and nature of the distress.
- All patients should be screened to ascertain their levels of distress at the initial visit, at appropriate intervals, and as clinically indicated, especially

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with changes in disease status (remission, recurrence, or progression).

- Distress should be assessed and managed according to clinical practice guidelines.
- Interdisciplinary institutional committees should be formed to implement standards for distress management.
- Educational and training programs should be developed to ensure that health care professionals and certified chaplains have knowledge and skills in the assessment and management of distress.
- Licensed mental health professionals and certified chaplains experienced in the psychosocial aspects of cancer should be readily available as staff members or by referral.
- Medical care contracts should include reimbursement for services provided by mental health professionals.
- Clinical health outcomes measurements should include assessment of the psychosocial domain (eg, quality of life and patient and family satisfaction).
- Patients, families, and treatment teams should be informed that management of distress is an integral part of total medical care and provided with appropriate information about psychosocial services in the treatment center and in the community.
- Finally, the quality of distress management programs/services should be included in institutional continuous quality improvement (CQI) projects.

Patients and families should be made aware that this new standard exists and that they should expect it in their oncologist's practice. The Alliance (<http://www.wholecancerpatient.org/>) is a coalition of professional and advocacy organizations with the goal of advancing the recommendations from the IOM report. Their Web site has hundreds of psychosocial resources for health care professionals, patients, and caregivers, searchable by state.

### Recommendations for Implementation of Standards and Guidelines

Jacobsen and Ransom<sup>38</sup> conducted a study in 2005 evaluating the implementation of the NCCN Guidelines for Distress Management by 15 NCCN

Member Institutions. Eight institutions (53%) conducted routine distress screening of some patient populations and an additional 4 (27%) also performed pilot testing of screening strategies. However, concordance with NCCN Guidelines (screening all patients) was observed in only 20% of the Member Institutions at that time.

Implementation of the IOM standards for integration of psychosocial care into the routine care of patients with cancer can be improved by providing feedback to oncology practices on the quality of their psychosocial care. Quality indicators were thus developed by Jacobsen.<sup>39</sup> They developed a patient chart audit that permits an oncologists' office or clinic to evaluate the quality of their psychosocial care. The survey queries whether there is documentation that the patient's current emotional well-being was assessed and whether any action was taken if the patient was identified as having a problem. These quality indicators can be used widely to determine the quality of psychosocial care given by a clinic or office.

The Quality Oncology Practice Initiative (QOPI) was started in 2002 by ASCO as a pilot project (<http://qopi.asco.org/program.html>).<sup>40</sup> This program became available to all ASCO member medical oncologists in 2006. Jacobson et al's<sup>41</sup> psychosocial quality indicators were added as part of the core measures in the QOPI quality measures in 2008. In a recent analysis, Jacobson et al<sup>41</sup> reported that practices participating in the QOPI demonstrated improved performance, with initially low-performing practices showing the greatest improvement. Blayney et al<sup>42</sup> from the University of Michigan Comprehensive Cancer Center recently reported that the QOPI can be adapted for use in practice improvement at an academic medical center. The American Psychosocial Oncology Society (APOS) has also adopted these quality indicators.<sup>43</sup>

The panel encourages the establishment of institutional interdisciplinary committees to implement and monitor distress management. This interdisciplinary committee should be responsible for evaluating standard care in distress management with CQI studies. The panel encourages interdisciplinary CQI studies to assess the quality of distress management programs, efficacy of standards of care, and implementation of these NCCN Guidelines and the new quality standard established by the IOM report.<sup>34</sup>



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The new CoC accreditation standards for hospital cancer programs include the screening of all patients with cancer for psychosocial distress, and therefore psychosocial care is now on all institutions' report cards.

Multicenter randomized trials and pilot testing are needed to compare the efficacy of brief screening instruments. Educational approaches should be developed for medical staff, patients, and caregivers to increase their awareness of the prevalence of distress and of psychological interventions.

The MD Anderson Cancer Center published a report on their efforts to integrate psychosocial care into clinical care.<sup>44</sup> The authors outline the strategies they used to accomplish the required cultural shift, and describe the results of their efforts. Other groups have also described their efforts toward implementing psychosocial screening in various outpatient settings.<sup>45-49</sup> Additional guidance for the implementation of the new IOM standards has been published.<sup>50-52</sup> In Canada, a national approach has been used to implement screening for distress. Their strategies have been described.<sup>53</sup> Groups in Italy and France have also described results of their preliminary efforts toward implementing psychosocial distress screening.<sup>54,55</sup> A reading list for implementation of programs that integrate psychosocial care into the routine care of patients with cancer is provided on page 198.

Overall, to implement the new standard of integrating psychosocial care into the routine care of all patients with cancer, it is critical to have a fast and simple screening method that can be used to identify patients who require psychosocial care and/or referral to psychosocial resources.<sup>52</sup> The NCCN Distress Management Panel developed such a rapid screening tool.

### Screening Tools for Distress and Meeting Psychosocial Needs

Identifying a patient's psychological needs is essential to develop a plan to manage those needs. Ideally, patients tell their oncologists about their problems or they respond to the oncologist's query about these issues. In routine clinical practice, time constraints and the stigma related to psychiatric and psychological needs often lead to no discussion of these issues. Screening tools have been found to be effective and feasible in reliably identifying distress and the psy-

chosocial needs of patients.<sup>56-58</sup> Mitchell et al<sup>59,60</sup> recently reported that ultra-short methods (PHQ2 or the Distress Thermometer) were acceptable to approximately three-quarters of clinicians. Automated touch-screen technologies have also been used for psychosocial screening of patients with cancer.<sup>61,62</sup> Recently, an Internet-based program was developed that includes distress screening, reporting, referrals, and follow-up components. The screening component was validated in a trial of 319 community-based cancer survivor, and showed good psychometric properties.<sup>63</sup>

A recent meta-analysis compared 8 tools designed to screen for depression in the cancer setting that had been validated by at least 2 separate studies.<sup>64</sup> This analysis included the Hospital Anxiety and Depression Scale (HADS); the Beck Depression Inventory, version 2 (BDI-II); and the Distress Thermometer.

#### The Distress Thermometer

The NCCN Distress Management Panel developed the Distress Thermometer, a now well-known tool for initial screening, which is similar to the successful rating scale used to measure pain, ranging from 0, indicating no distress, to 10, indicating extreme distress. The Distress Thermometer serves as a rough initial single-item question screen, which identifies distress arising from any source, even if unrelated to cancer. The receptionist administers it to the patient in the waiting room.

The word "distress" was chosen because it is less stigmatizing and more acceptable to patients and oncologists than other terms, such as "psychiatric," "psychosocial," or "emotional." Using this nonstigmatizing word diminishes clinicians' concerns that the patient will be embarrassed or offended by these questions. Asking an objective question such as, "How is your pain today on a scale of 0 to 10?" made it easier and more comfortable for caregivers to learn about patients' pain. Similarly, asking patients, "How is your distress today on a scale of 0 to 10?" opens a dialogue with the oncologist or nurse for a discussion of emotions that is more acceptable.

The patient in the waiting room places a mark on the Distress Thermometer scale answering: "How distressed have you been during the past week on a scale of 0 to 10?" Scores of 4 or higher suggest a level of distress that has clinical significance. If the patient's distress level is mild (score <4 on the Dis-

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tress Thermometer), the primary oncology team may choose to manage the concerns through usual clinical supportive care management. If the patient's distress level is 4 or higher, the nurse looks at the problem list (see next section) to identify key issues of concern and asks further questions to determine to which resources (mental health, social work and counseling, or chaplaincy services) the patient should be referred.

The Distress Thermometer has been validated by several studies in patients with different types of cancer and has revealed concordance with the Hospital Anxiety and Distress Scale (HADS).<sup>56,65-71</sup> The Distress Thermometer has shown good sensitivity and specificity. The needs assessment surveys performed in ambulatory clinics using these screens show that 20% to 40% of patients have significant levels of distress. Two studies validated a version of the Distress Thermometer with an expanded problems list.<sup>72,73</sup> Tuinman et al<sup>73</sup> validated the Distress Thermometer with the 46-item problem list in a cross-sectional group of 227 patients with cancer. Graves et al<sup>72</sup> validated the Distress Thermometer with an adapted problems list with 2 new problem categories ("Information Concerns" and "Cognitive Problems") in patients with lung cancer. The Distress Thermometer is also a useful tool for screening distress among patients undergoing bone marrow transplants.<sup>74,75</sup> In fact, the Distress Thermometer had acceptable overall accuracy and greater sensitivity and specificity when compared with the Center for Epidemiological Studies-Depression Scale (CES-D) in the assessment of depression in patients undergoing bone marrow transplants.<sup>74</sup>

### The Problem List

The screening tool developed by the NCCN Distress Management Panel includes a 39-item Problem List, which appears on the same page as the Distress Thermometer. The Problem List asks patients to identify their problems in 5 different categories: practical, family, emotional, spiritual/religious, and physical (see page 196). The completed list is reviewed by the nurse, who is present at all visits and is the person most likely to ask clarifying questions. Social workers are often not immediately available in busy clinics.

**Cognitive Impairment:** "Memory/concentration problems" is one item on the Problem List. Cognitive impairment is common in patients with primary central nervous system (CNS) cancers, because of

both the effects of brain tumors themselves and the effects of treatment targeted to the brain.<sup>76,77</sup> Recent evidence has shown that chemotherapy-related cognitive dysfunction is also prevalent in patients with non-CNS cancers and without brain metastases.<sup>78-81</sup> Chemotherapy can cause subtle cognitive changes, studied primarily in patients with breast cancer and lymphoma. It can continue over years and, occasionally, when more severe, can impact quality of life and function. The underlying mechanisms for chemotherapy-induced cognitive changes are not known. Recent studies have reported elevated levels of cytokines or DNA damage as some of the possible mechanisms.<sup>82</sup> In addition, evidence suggests that cancer itself and therapies other than chemotherapy, such as hormone therapy, can cause cognitive impairments in patients with cancer.<sup>83-86</sup> A recent national cross-sectional study found that a history of cancer is independently associated with a 40% increase in the likelihood of self-reported memory problems.<sup>87</sup> A better understanding of the mechanisms that cause cancer-related cognitive impairment is essential for the development of treatments to improve cognitive function and quality of life in patients with cancer.<sup>76,77,88</sup>

No standard treatment exists for the management of cognitive changes in patients with cancer. Cognitive behavior therapy, cognitive rehabilitation programs, and exercise may be effective interventions to improve cognitive function in patients with cancer.<sup>89,90</sup> In addition, some studies have shown that the use of psychostimulants, such as methylphenidate and modafinil, improved cognitive function in patients with cancer.<sup>91-93</sup> Donepezil, a reversible acetylcholinesterase inhibitor (approved to treat mild to moderate dementia in patients with Alzheimer disease) also improved cognitive function, mood, and health-related quality of life in patients with primary low-grade glioma.<sup>94</sup> Further placebo-controlled trials are needed to confirm these preliminary findings.

In October 2006, the International Cognition and Cancer Task Force (ICCTF) was formed, comprising a multidisciplinary group of health professionals and health advocates. The mission of ICCTF is to advance understanding of the impact of treatment-related cognitive and behavioral functioning in patients with non-CNS cancers.<sup>95</sup> ICCTF also has a Web site ([www.icctf.com](http://www.icctf.com)) to provide up-to-date information to both physicians and patients seeking assistance in the management of cognitive

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symptoms associated with cancer treatment.

**Fertility:** Another item on the Problem List is the “ability to have children.” Chemotherapy and radiation therapy also have an impact on the fertility of patients, especially in those who are of child-bearing age.<sup>96</sup> Therefore, the panel has included “ability to have children” as one of the items under the family problems category. MyOncofertility.org is a useful patient education resource for those who are concerned about the possible effect of cancer treatment on their fertility.

**Substance Abuse:** For the 2013 version of these guidelines, the panel added substance abuse to the list of possible physical problems. Substance abuse in patients with cancer who do not have a history of abuse or addiction is rare and is usually caused by insufficient symptom control. Improving symptom control often alleviates the substance dependence. This problem is discussed in more detail in “Substance-Related Disorder/Abuse,” available online, in these guidelines, at NCCN.org.

## Oncologist Burnout

The stress and demands of treating patients with cancer and making life and death decisions daily often cause psychologic distress for oncologists. This distress in turn can cause depression, anxiety, and fatigue. It can also cause burnout, characterized by a lack of enthusiasm for work, feelings of cynicism, and a low sense of personal accomplishment with work, in as many as 28% to 38% of oncologists, as recently reviewed by Shanafelt and Dyrbye.<sup>97</sup> Burnout can affect medical care, physician-patient relationships, and personal relationships, and can lead to substance abuse and even suicide. Strategies for avoiding and reducing burnout discussed in the review include training in self-care, personal wellness, mindful meditation, and behavioral change by medical schools, residency programs, hospitals, and private practices. Organizational strategies can also create a culture that is less stressful and less conducive to oncologist burnout.

## The Journal of Clinical Oncology Special Series on Psychosocial Care in Cancer

In April 2012, the *Journal of Clinical Oncology* published a Special Series on psychosocial care ([http://](http://jco.ascopubs.org/content/30/11.toc)

[jco.ascopubs.org/content/30/11.toc](http://jco.ascopubs.org/content/30/11.toc)), demonstrating that this topic is now getting the attention it has long deserved. The Special Series includes a review by Jacobsen and Wagner<sup>98</sup> that describes how the new standard of psychosocial care, the development of clinical practice guidelines for psychosocial care such as these NCCN Guidelines, and the establishment of indicators to measure the quality of psychosocial care can help increase the number of patients with cancer receiving psychosocial care. Integral to the successful integration of psychosocial care into routine cancer care is a distress screening program. In the Special Series, Carlson et al<sup>50</sup> present their recommendations for implementing such a program, and Fann et al<sup>51</sup> discuss the organizational challenges of this new integrated care model, with a focus on the collaborative care service model.

Research on psychosocial care in cancer treatment has expanded greatly in recent years. This fact attests to the growing awareness of the importance of the topic, by both health care professionals and the public.<sup>99</sup> The Special Series includes reviews of evidence-based interventions for 3 common psychosocial problems in patients with cancer: depression, anxiety, and delirium.<sup>100–102</sup>

Worries and concerns about cancer do not necessarily end with the end of acute care. The Special Series thus also includes articles addressing the psychosocial needs of adolescent and young adult and adult cancer survivors.<sup>103,104</sup> An article on the psychosocial needs of caregivers is also included.<sup>105</sup>

An article was also included on oncologist burnout, a problem with an estimated prevalence of 28% to 38%, depending on medical specialty.<sup>97</sup> The Special Series concludes with a review and meta-analysis of studies that provide evidence for the development of an appropriate curriculum for communication skills training of oncologists.<sup>106</sup> Patient benefit from this training (eg, better adherence to treatment) has yet to be demonstrated.

## Summary

Psychosocial care is increasingly being recognized as an integral component of the clinical management of patients with cancer. Treating distress in cancer benefits the patients and their families/caregiver and the treating staff, and helps improve the efficiency of clinic operations. For patients with cancer, integra-

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tion of mental health and medical services is critically important. Spirituality and religion also play an important role for many patients with cancer in coping with the diagnosis and the illness.

The NCCN Guidelines for Distress Management recommend that each new patient be rapidly assessed in the office or clinic waiting room for evidence of distress using the Distress Thermometer and Problem List as an initial rough screen.<sup>107</sup> A score of 4 or greater on the Distress Thermometer should trigger further evaluation by the oncologist or nurse and referral to a psychosocial service, if needed. The choice of which psychological service is needed is dependent on the problem areas specified on the Problem List. Patients with practical and psychosocial problems should be referred to social workers; those with emotional or psychological problems should be referred to mental health professionals, including social workers; spiritual concerns should be referred to certified chaplains.

Health care contracts often allow these services to “fall through the cracks” by failing to reimburse for them through either behavioral health or medical insurance. Reimbursement for services to treat psychosocial distress must be included in medical health care contracts to prevent fragmentation of mental health services for the medically ill. Outcomes research studies that include quality-of-life assessment and analysis of cost-effectiveness are needed to help make this a reality.

The primary oncology team members (oncologist, nurse, and social worker) are central to making this model work. It is critical for at least one team member to be familiar with the mental health, psychosocial, and chaplaincy services available in the institution and the community. A list of the names and phone numbers for these resources should be kept in all oncology clinics and should be updated frequently.

Education of patients and families is equally important to encourage them to recognize that control of distress is an integral part of their total cancer care.

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Individual Disclosures for the NCCN Distress Management Panel					
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<sup>a</sup>Not available at press time. Please visit [NCCN.org](http://NCCN.org) for the most up-to-date information.