

## The NCCN

# Distress Management

## Clinical Practice Guidelines in Oncology™

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## Overview

In the United States, a total of 1,479,350 new cancer cases and 562,340 deaths from cancer were estimated to occur in 2009.<sup>1</sup> All patients experience some level of distress associated with the diagnosis and treatment of cancer at all stages of the disease. Surveys have found that 20% to 40% of patients with newly diagnosed and recurrent cancer show a significant level of distress.<sup>2</sup> However, fewer than 10% are actually identified and referred for psychosocial help.<sup>3</sup> Many cancer patients who are in need of psychosocial care are not able to get the help they need due to the under recognition of patient's psychological needs by the primary oncology team and lack of knowledge of community resources. The need is particularly acute in community oncology practices that

## Distress Management Clinical Practice Guidelines in Oncology

### Key Words

NCCN Clinical Practice Guidelines, psychosocial, psychological, psychiatric, distress, anxiety, depression, quality of life (*JNCCN* 2010;8:448–485)

### NCCN Categories of Evidence and Consensus

**Category 1:** The recommendation is based on high-level evidence (e.g., randomized controlled trials) and there is uniform NCCN consensus.

**Category 2A:** The recommendation is based on lower-level evidence and there is uniform NCCN consensus.

**Category 2B:** The recommendation is based on lower-level evidence and there is nonuniform NCCN consensus (but no major disagreement).

**Category 3:** The recommendation is based on any level of evidence but reflects major disagreement.

All recommendations are category 2A unless otherwise noted.

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

### Please Note

These guidelines are a statement of consensus of the authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult these guidelines is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network makes no representation or warranties of any kind regarding their content, use, or application and disclaims any responsibility for their applications or use in any way.

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### Disclosures for the NCCN Distress Management Guidelines Panel

At the beginning of each NCCN guidelines panel meeting, panel members disclosed any financial support they have received from industry. Through 2008, this information was published in an aggregate statement in *JNCCN* and online. Furthering NCCN's commitment to public transparency, this disclosure process has now been expanded by listing all potential conflicts of interest respective to each individual expert panel member.

Individual disclosures for the NCCN Distress Management Guidelines Panel members can be found on page 485. (The most recent version of these guidelines and accompanying disclosures, including levels of compensation, are available on the NCCN Web site at [www.NCCN.org](http://www.NCCN.org).)

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

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have few to no psychosocial resources, and cancer care is often provided in short visits.<sup>4</sup>

For many centuries, patients were not told their diagnosis of cancer 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. However, patients are reluctant to reveal emotional problems to the oncologist. The words *psychological*, *psychiatric*, and *emotional* are as stigmatizing as *cancer*. 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. 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 people with cancer.

Failure to recognize and treat distress leads to several problems: trouble making decisions about and adhering to treatment; extra visits to the physician's office and emergency room; and greater time and stress for the oncology team. Early evaluation and screening for distress leads to early and timely management of psychological distress, which in turn improves medical management.<sup>5,6</sup>

The Patients' Bill of Rights does not address psychosocial concerns within total health care. Although regulatory bodies such as the Joint Commis-

Text continues on p. 474

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“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.

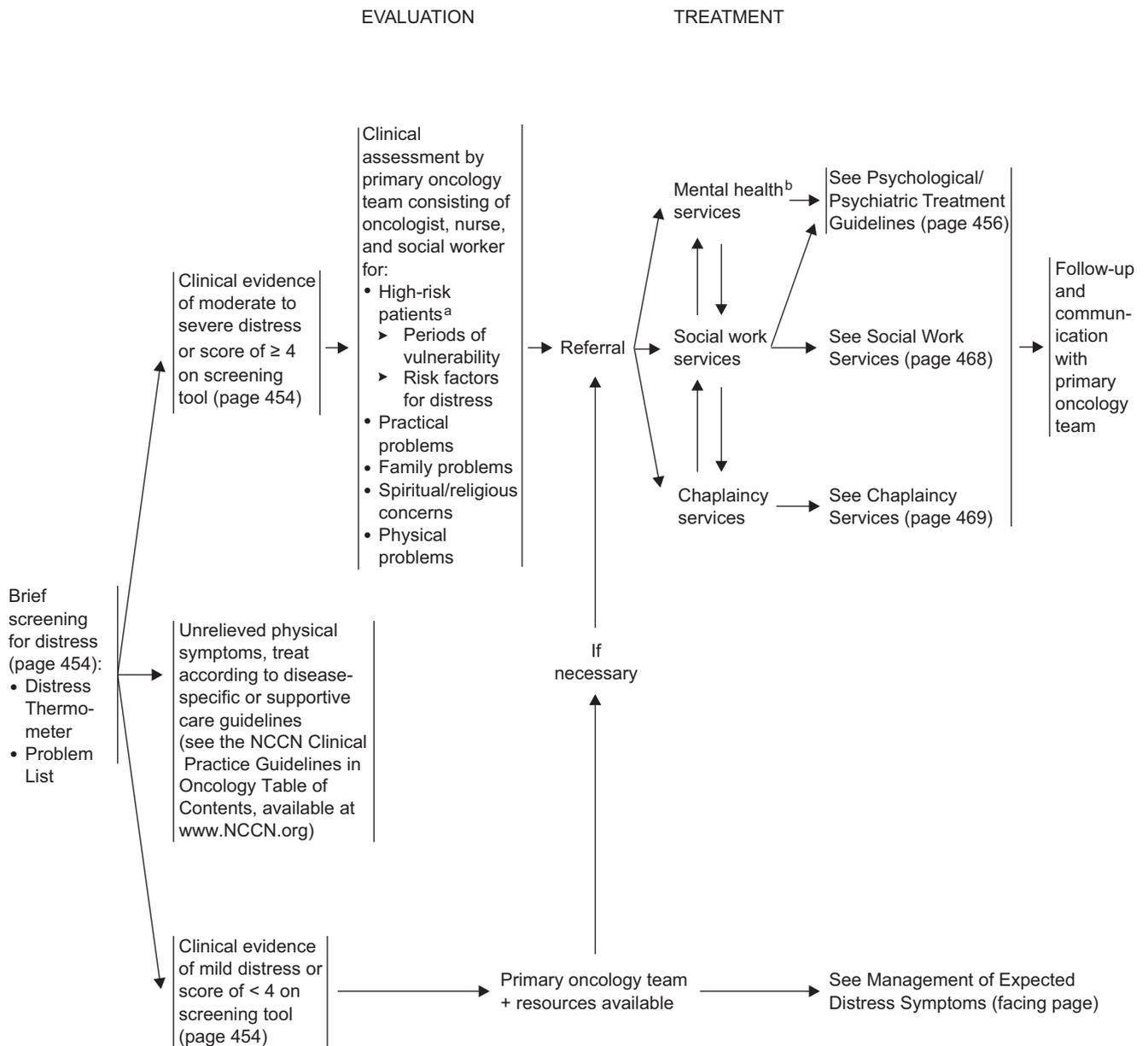
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### STANDARDS OF CARE FOR DISTRESS MANAGEMENT

- 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 (i.e., 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 either as staff members or through 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 (e.g., quality of life, 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 be provided with appropriate information about psychosocial services in the treatment center and community.
- Quality of distress management programs/services should be included in institutional continuous quality improvement (CQI) projects.

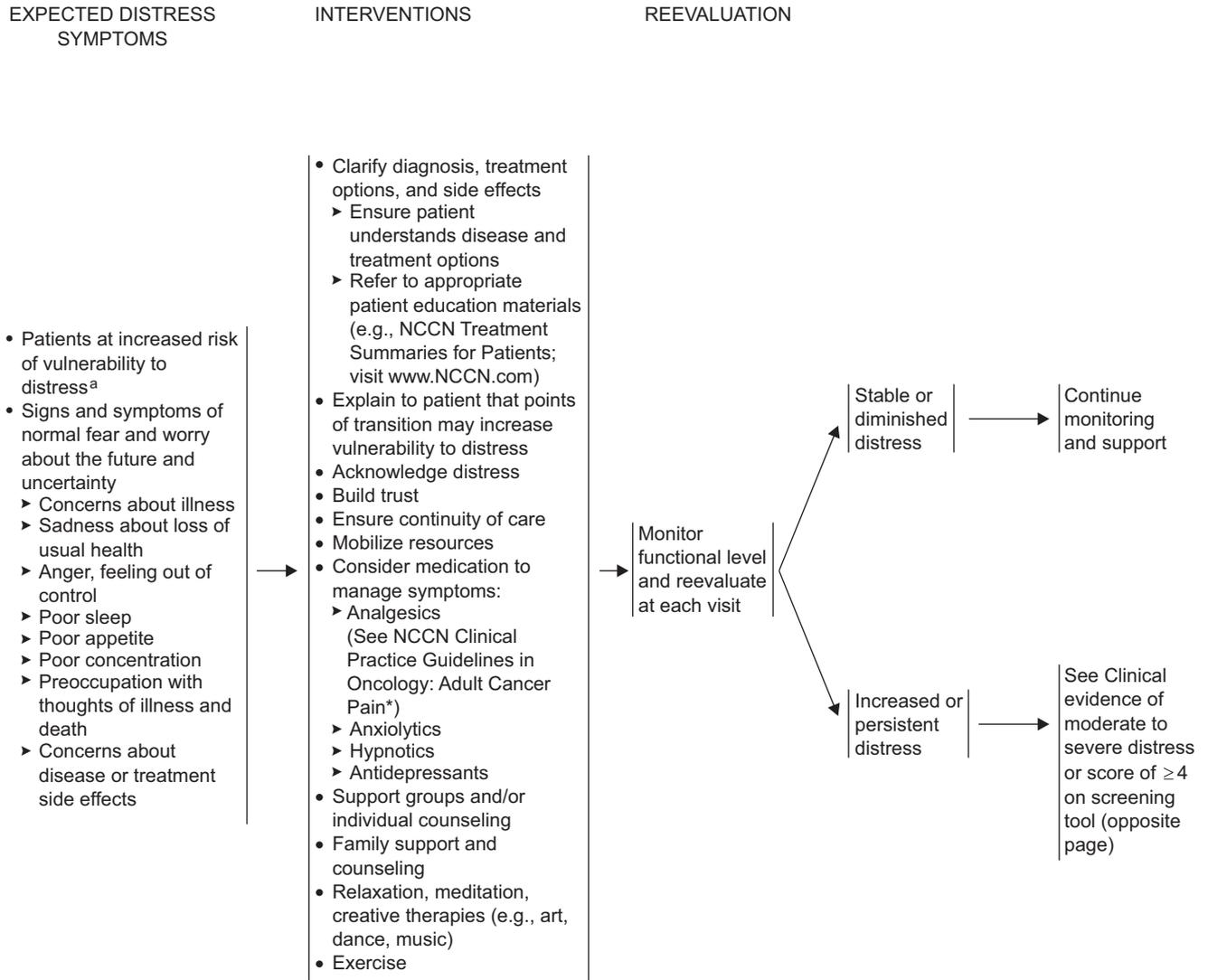
## OVERVIEW OF EVALUATION AND TREATMENT PROCESS



<sup>a</sup>See Psychosocial Distress Patient Characteristics (page 455).

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

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<sup>a</sup>See Psychosocial Distress Patient Characteristics (page 455).

## 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.

Extreme distress

No distress

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	<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"/>	Diarrhea
		<u>Family Problems</u>	<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
<input type="checkbox"/>	<input type="checkbox"/>	Ability to have children	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
			<input type="checkbox"/>	<input type="checkbox"/>	Getting around
		<u>Emotional Problems</u>	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Sexual
			<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
<input type="checkbox"/>	<input type="checkbox"/>	<u>Spiritual/Religious Concerns</u>	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
			<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet

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 problems
  - 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

PERIODS OF INCREASED VULNERABILITY

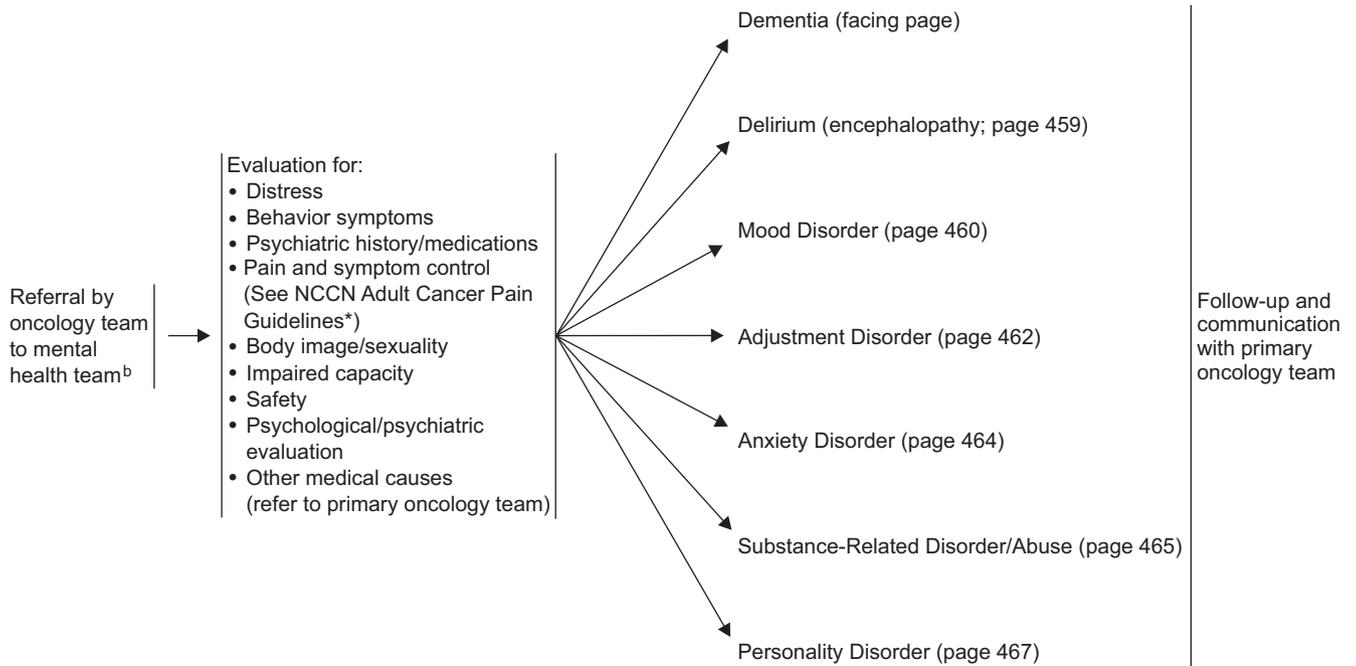
- Finding a suspicious symptom
- During workup
- Finding out the diagnosis
- Awaiting treatment
- Change in treatment modality
- End of treatment
- Discharge from hospital after treatment
- Stresses of survivorship
- Medical follow-up and surveillance
- Treatment failure
- Recurrence/progression
- Advanced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

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

<sup>d</sup>From the NCCN Clinical Practice Guidelines in Oncology: Palliative Care. To view the most recent version of these guidelines, visit the NCCN Web site at [www.NCCN.org](http://www.NCCN.org).

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

## PSYCHOLOGICAL/PSYCHIATRIC TREATMENT GUIDELINES



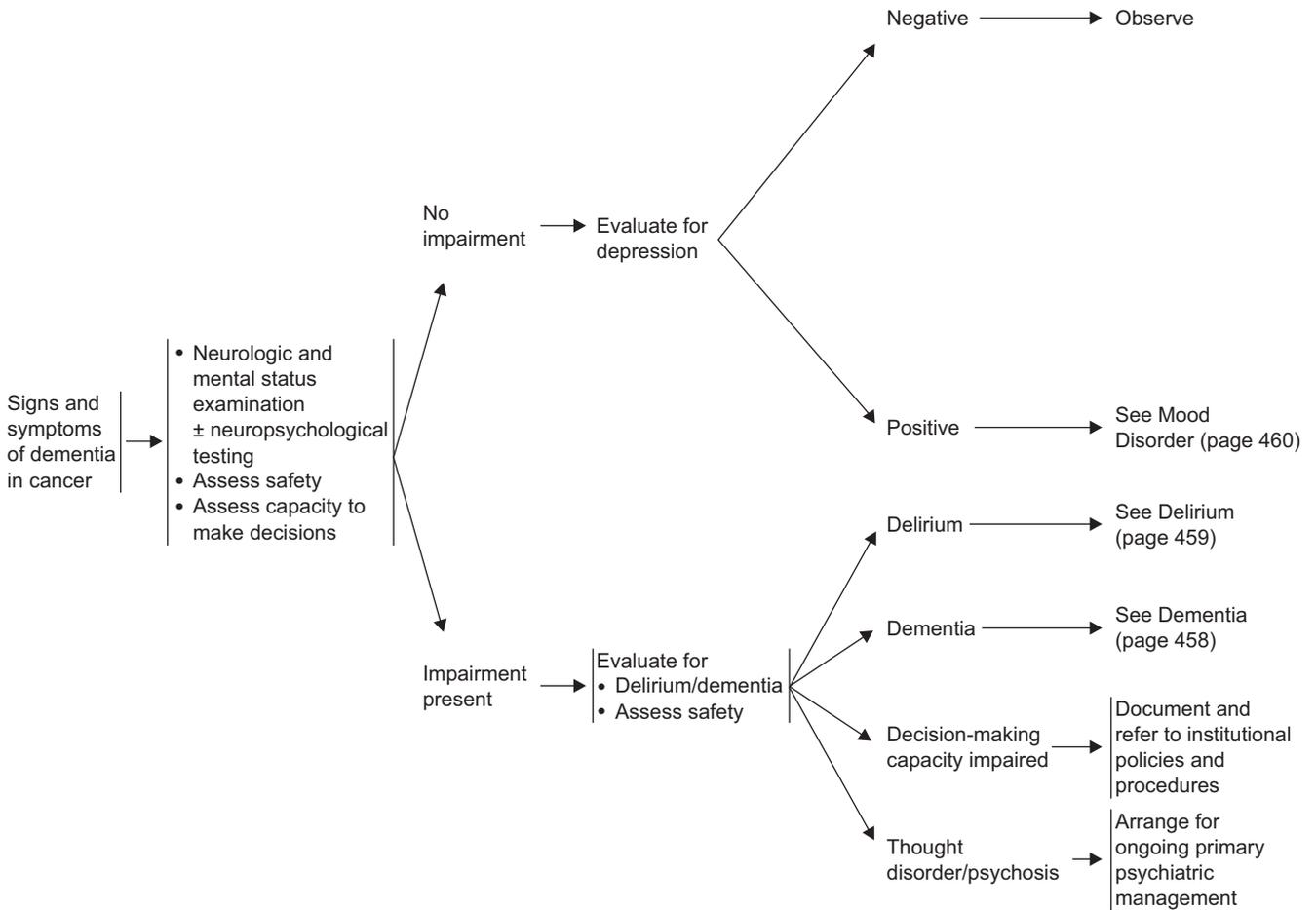
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<sup>b</sup>Psychiatrist, psychologist, advanced practice clinicians, social worker, and certified chaplain.

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DEMENTIA  
(ICD-10 codes: F00-F03)

EVALUATION



DEMENTIA (continued)  
(ICD-10 codes: F00-F03)

TREATMENT

FOLLOW-UP

Evaluation, diagnostic studies, and modification of factors related to:

- Cancer
- Treatment
- Medications
- Medical causes
- Withdrawal states
- Pain, fatigue, sleep disorders, cognitive impairment, and other symptoms

Assess safety

Cognitive rehabilitation  
± medications

No response

- Consider capacity to make decisions
- Reevaluation
- Refer to social services
- Consider alternate level of care

Response

Follow-up and communication with primary oncology team

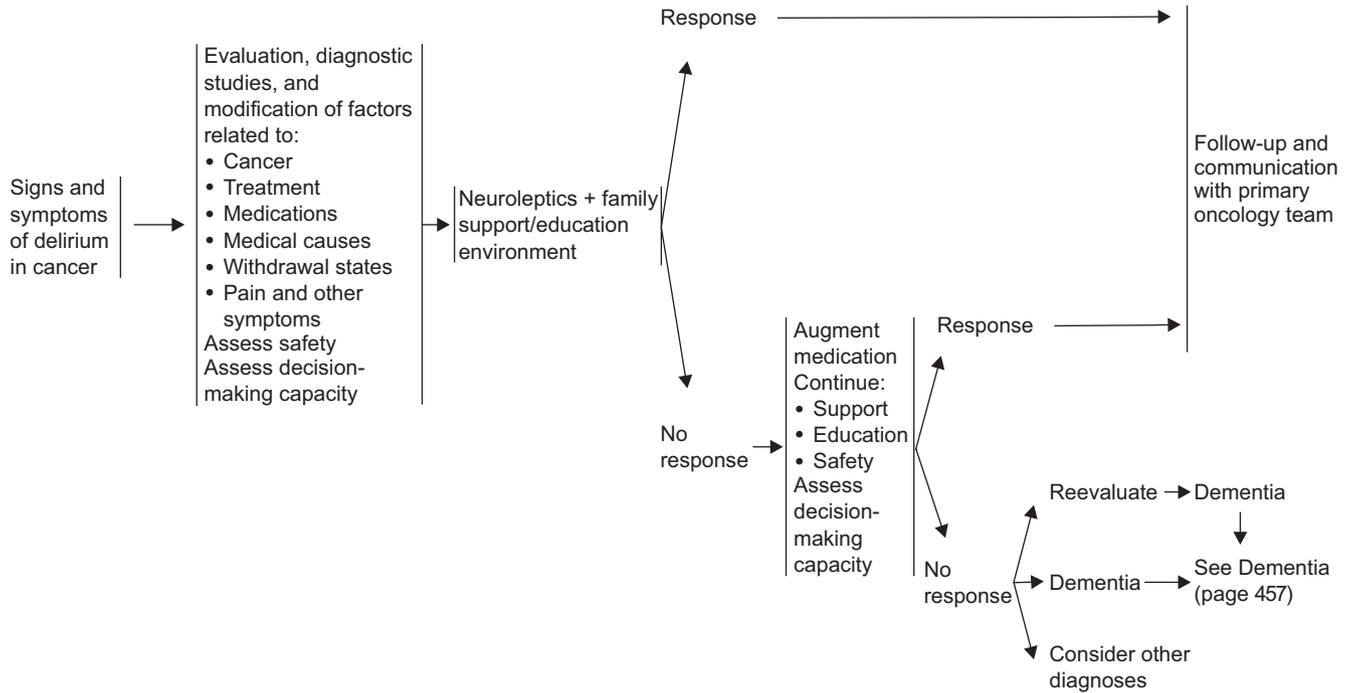
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**DELIRIUM**  
(Encephalopathy)  
(ICD-10 code: F05)

**EVALUATION**

**TREATMENT**

**FOLLOW-UP**



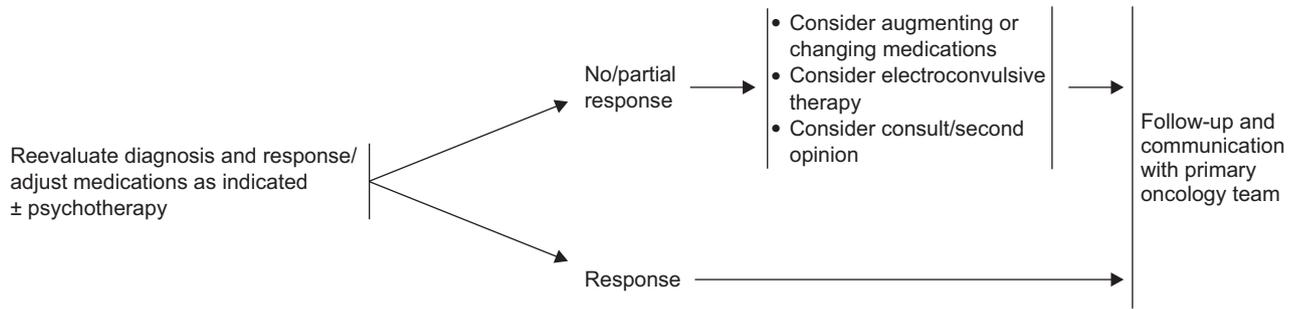


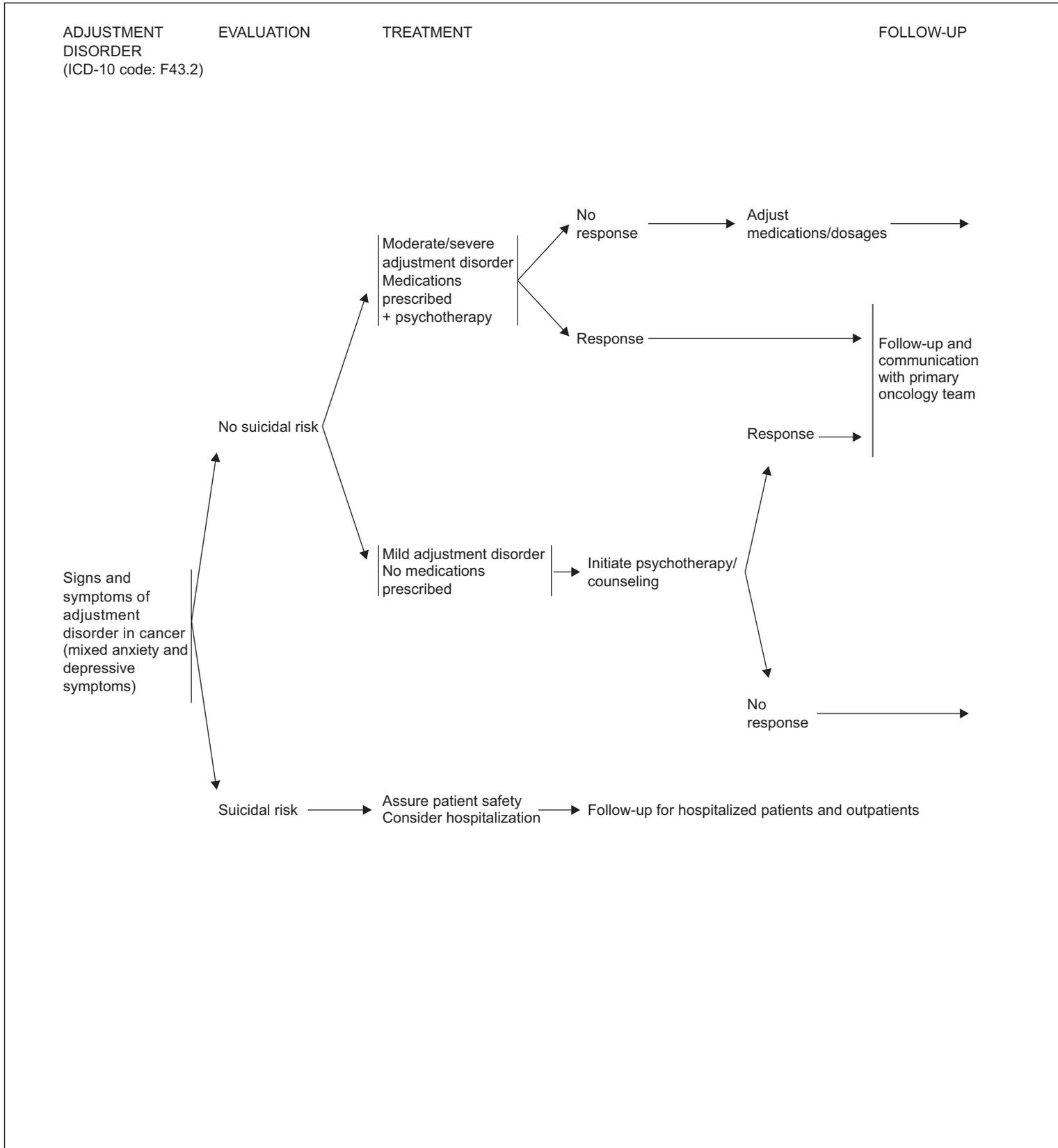
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EVALUATION

TREATMENT

FOLLOW-UP



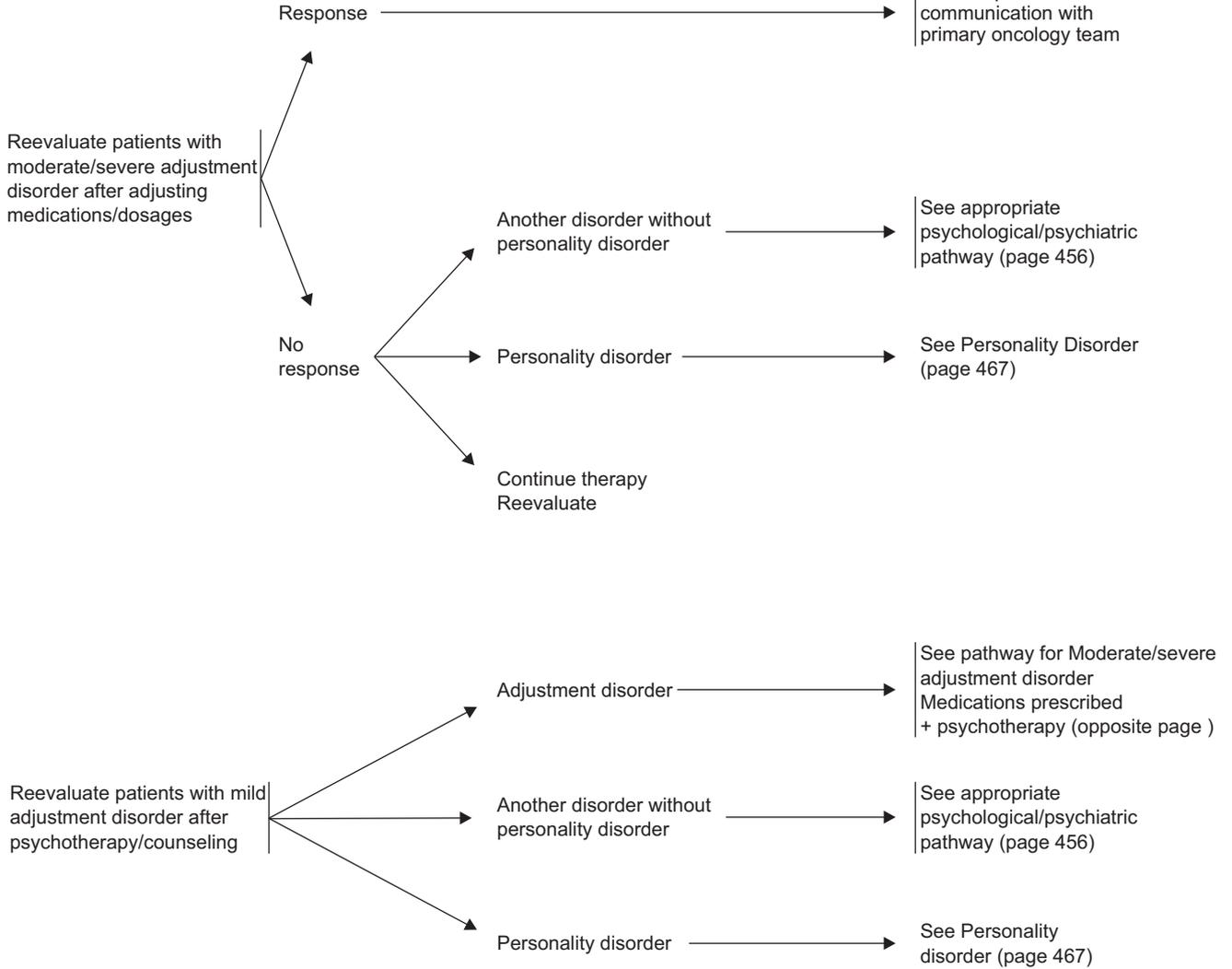


Clinical trials: The NCCN believes that the best management for any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged. All recommendations are category 2A unless otherwise noted.

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EVALUATION/TREATMENT

FOLLOW-UP



**ANXIETY DISORDER**  
(ICD-10 codes: F40, F41)

## EVALUATION

## TREATMENT

## FOLLOW-UP

Signs and symptoms of anxiety disorder in cancer:

- Anxiety caused by general medical condition
- Generalized anxiety disorder
- Panic disorder
- Posttraumatic stress disorder
- Phobic disorder
- Conditioned nausea/vomiting (See NCCN Clinical Practice Guidelines in Oncology: Antiemesis\*)
- Obsessive-compulsive disorder

Evaluation, diagnostic studies, and modification of factors related to:

- Cancer
- Treatment
- Nausea/vomiting
- Medications
- Medical causes
- Withdrawal states
- Pain
- Poor concentration
- Insomnia
- Anxiety or panic attacks
- Hypervigilance
- Fears
- Irritability

Assess safety  
Assess decision-making capacity

Psychotherapy  
± anxiolytic  
± antidepressant  
(category 1)

Reevaluate medication  
(consider neuroleptics),  
psychotherapy,  
support, education

Evaluate for depression  
and other psychiatric  
comorbidity

Follow-up and  
communication  
with primary  
oncology team

No  
response

No  
response

Response

Response

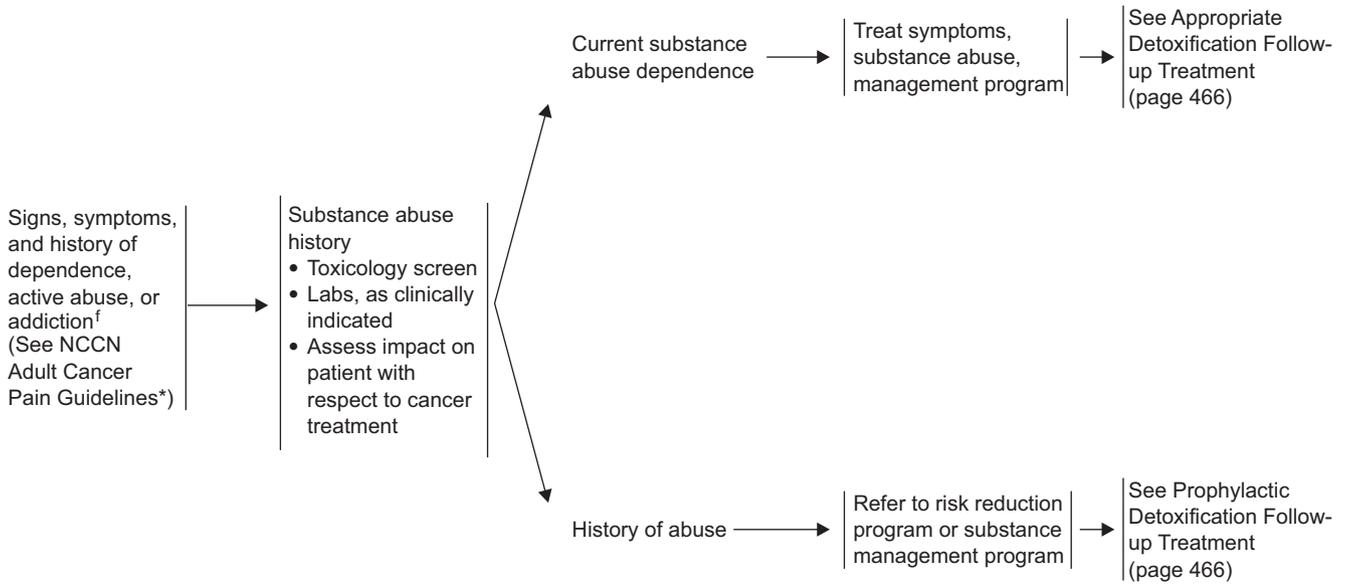
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**SUBSTANCE-RELATED DISORDER/ABUSE**  
(ICD-10 codes: F09-F19)

**EVALUATION**

**TREATMENT**

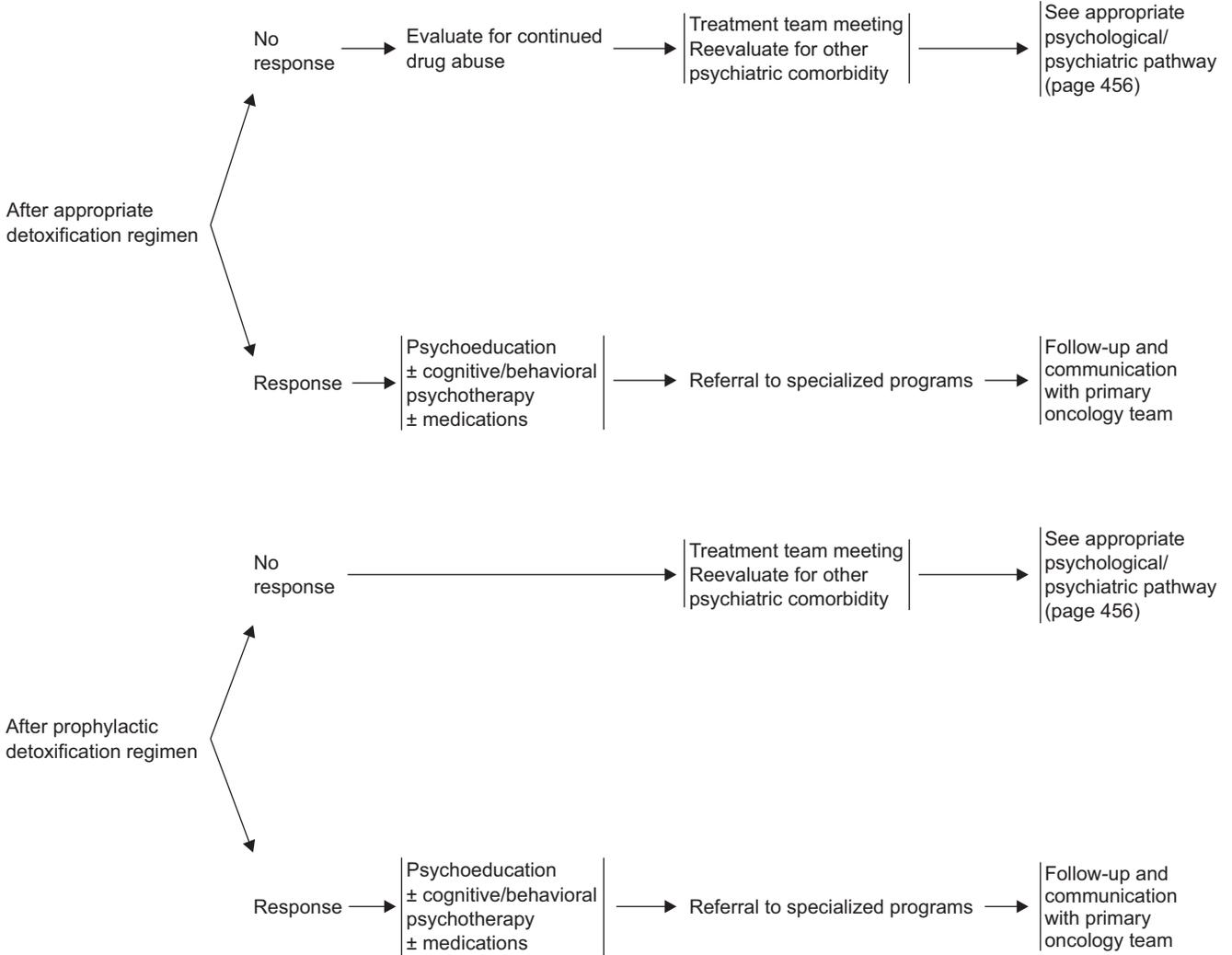


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<sup>f</sup>Opioids, alcohol, tobacco, or other.

SUBSTANCE-RELATED  
DISORDER/ABUSE (continued)  
(ICD-10 codes: F09-F19)

FOLLOW-UP



Clinical trials: The NCCN believes that the best management for any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged. All recommendations are category 2A unless otherwise noted.

# Distress Management Version 1:2010

**PERSONALITY DISORDER**  
(ICD-10 code: F60)

**EVALUATION**

**TREATMENT**

**FOLLOW-UP**

Signs and symptoms of personality disorder in cancer:

- Personality change related to medical or treatment factors
- Borderline
- Dramatic/histrionic
- Schizoid
- Obsessive
- Paranoid
- Antisocial



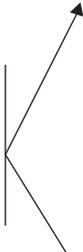
Evaluation, diagnostic studies, and modification of factors related to:

- Cancer
- Treatment
- Medications
- Medical causes
- Withdrawal states
- Pain
- Manipulative behavior
- Anger
- Threatening
- Dramatic/histrionic
- Demanding
- Fearful

Assess safety  
Assess decision-making capacity



Develop coordinated behavioral, psychological, and medical treatment plan with health care team (behavioral management ± medications)  
Staff education for management



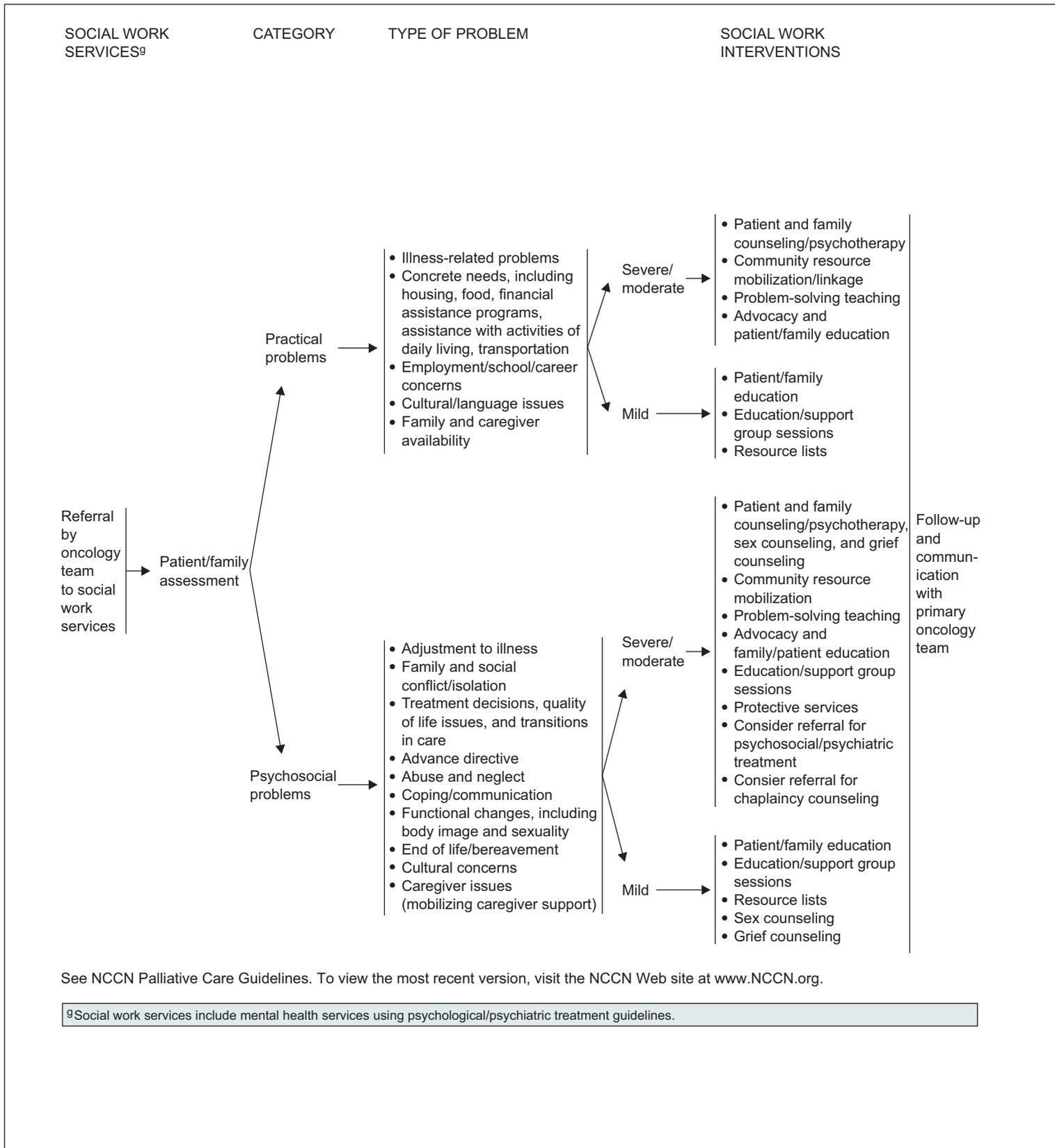
Response

No response



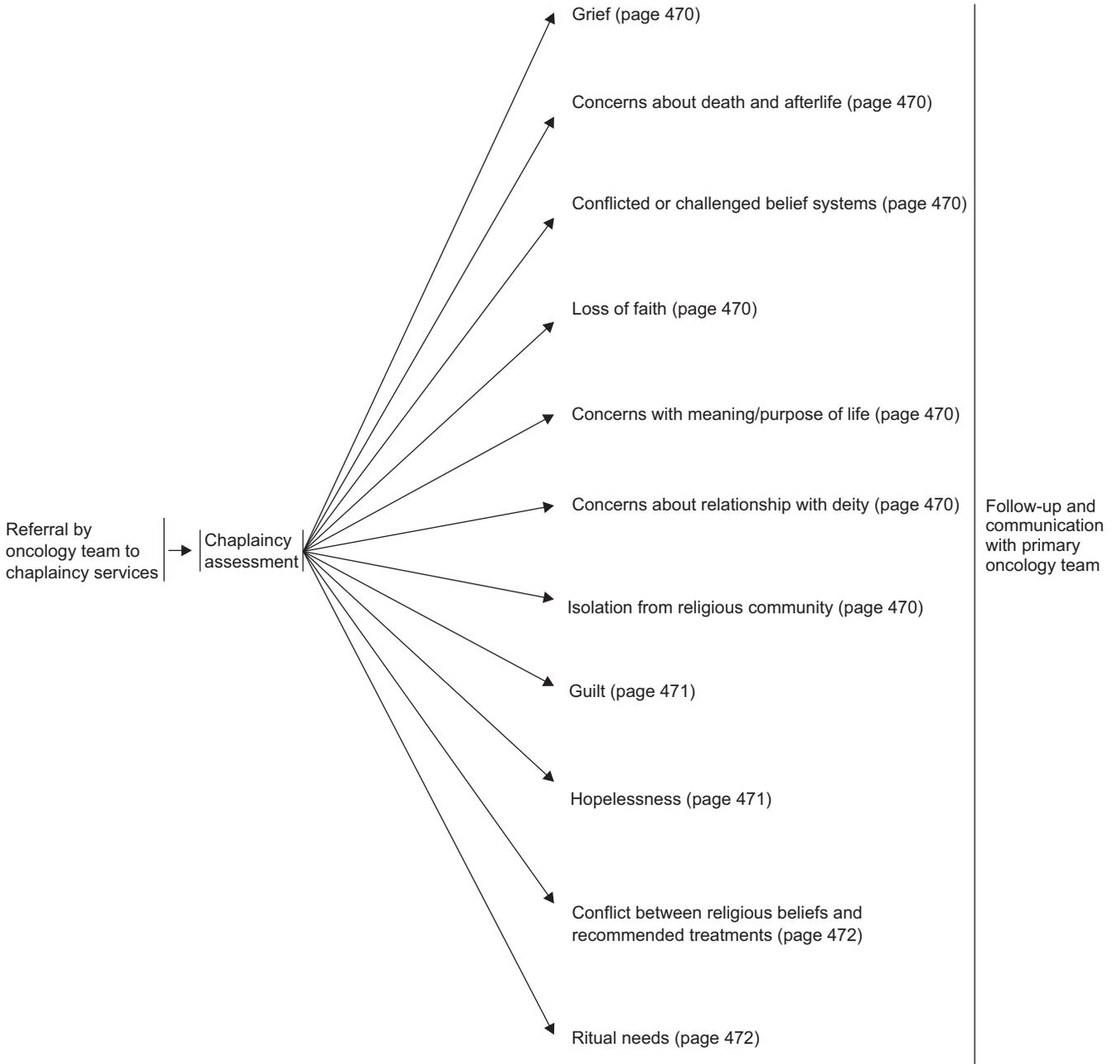
Follow-up and communication with primary oncology team

Reevaluate for other psychiatric comorbidity or substance abuse

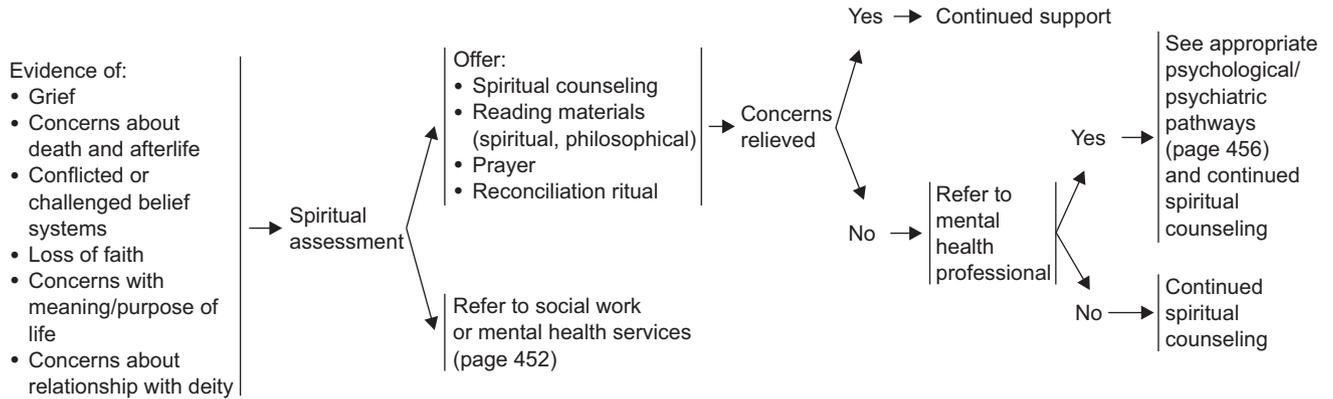


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CHAPLAINCY SERVICES

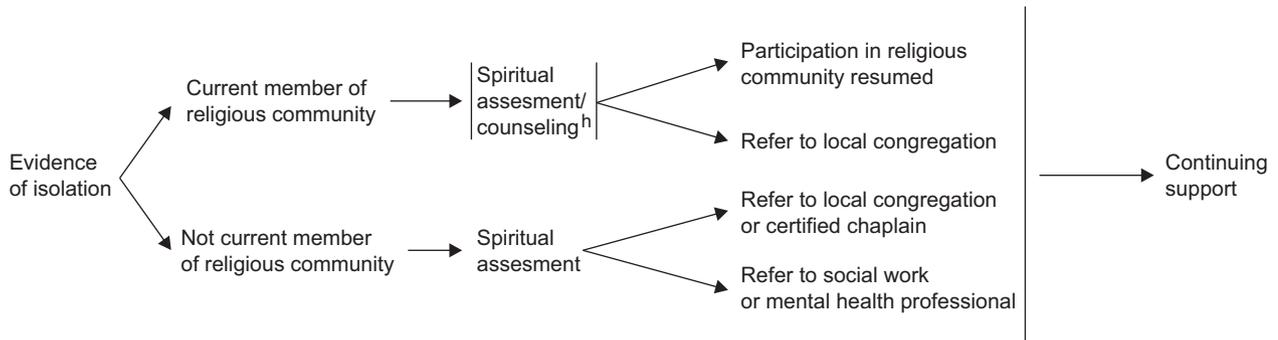


CHAPLAINCY SERVICES



See NCCN Palliative Care Guidelines. To view the most recent version, visit the NCCN Web site at [www.NCCN.org](http://www.NCCN.org).

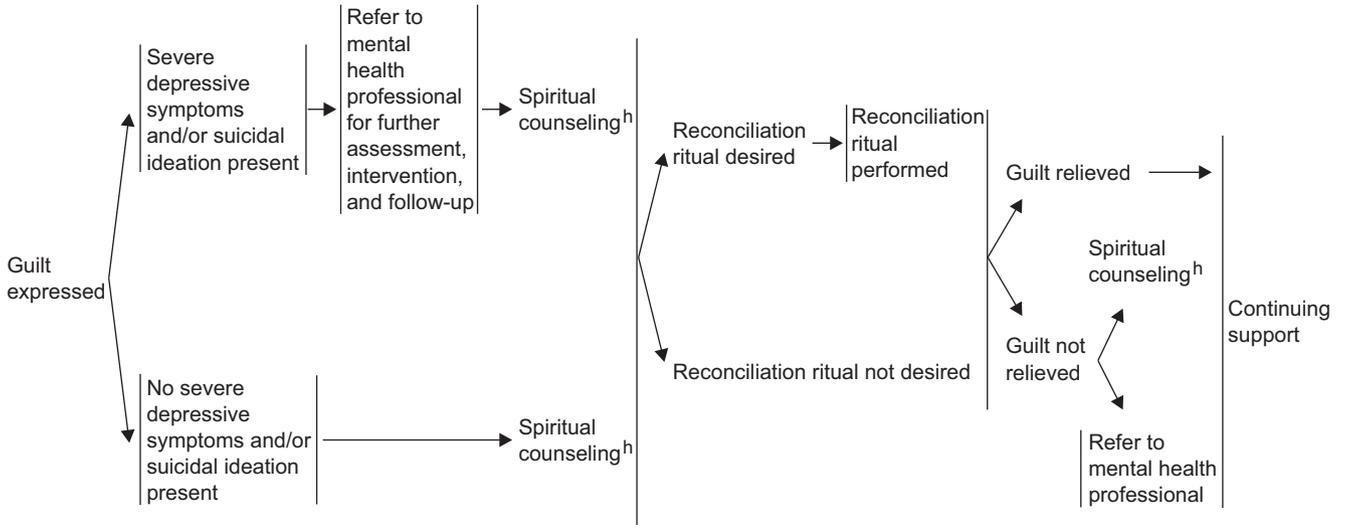
CHAPLAINCY SERVICES: ISOLATION FROM RELIGIOUS COMMUNITY



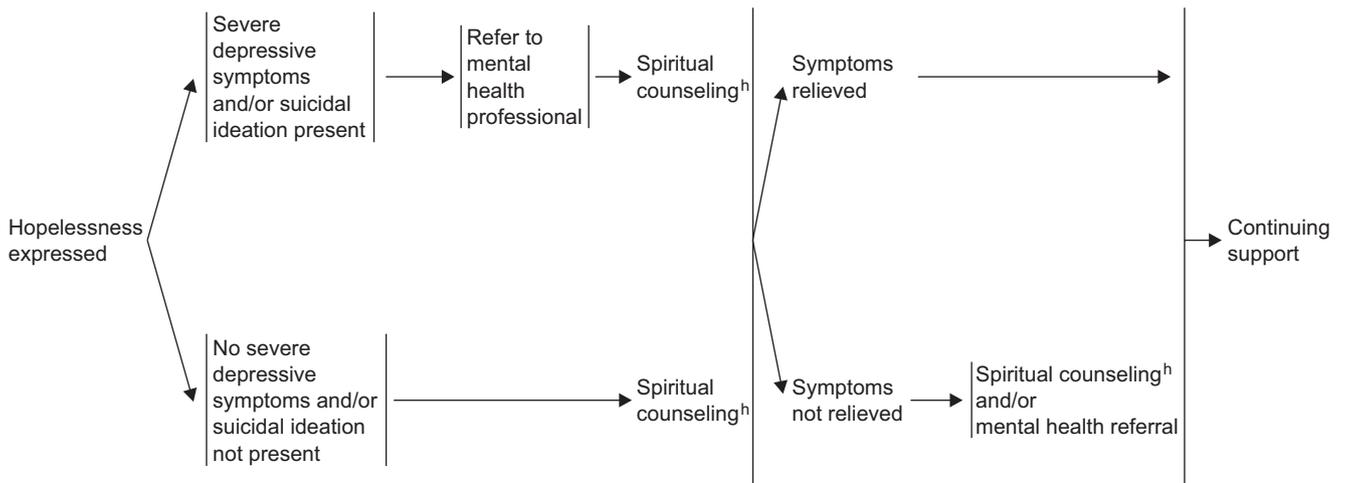
<sup>h</sup>Referral to clergy of person's faith.

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CHAPLAINCY SERVICES: GUILT

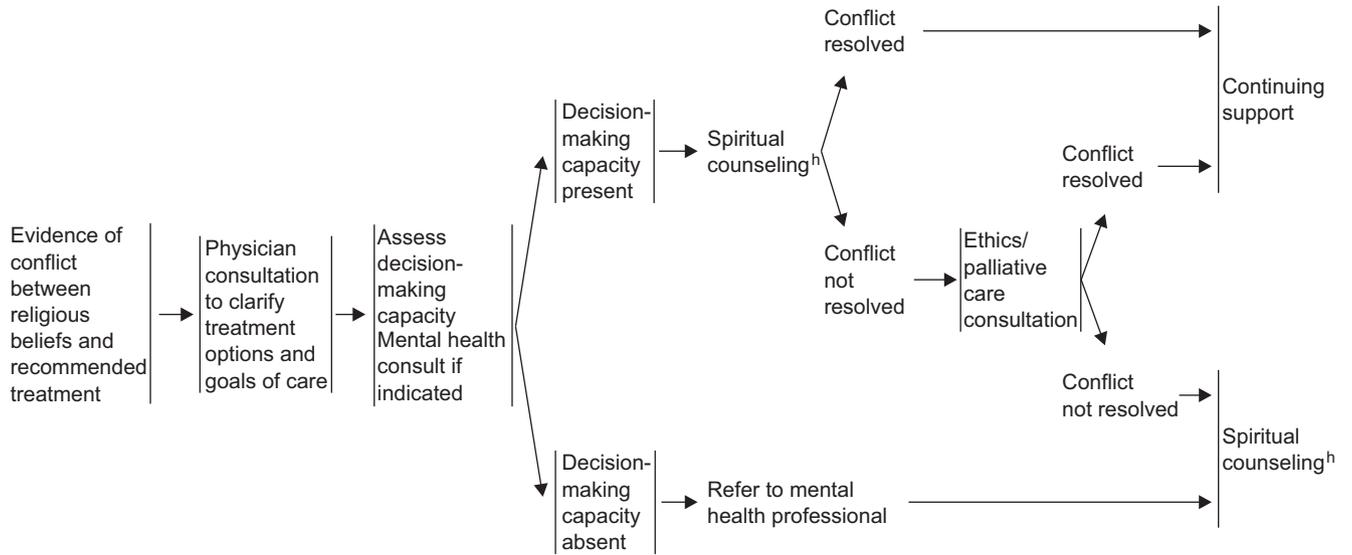


CHAPLAINCY SERVICES: HOPELESSNESS



<sup>h</sup>Referral to clergy of person's faith.

CHAPLAINCY SERVICES: CONFLICT BETWEEN RELIGIOUS BELIEFS AND RECOMMENDED TREATMENTS



CHAPLAINCY SERVICES: RITUAL NEEDS



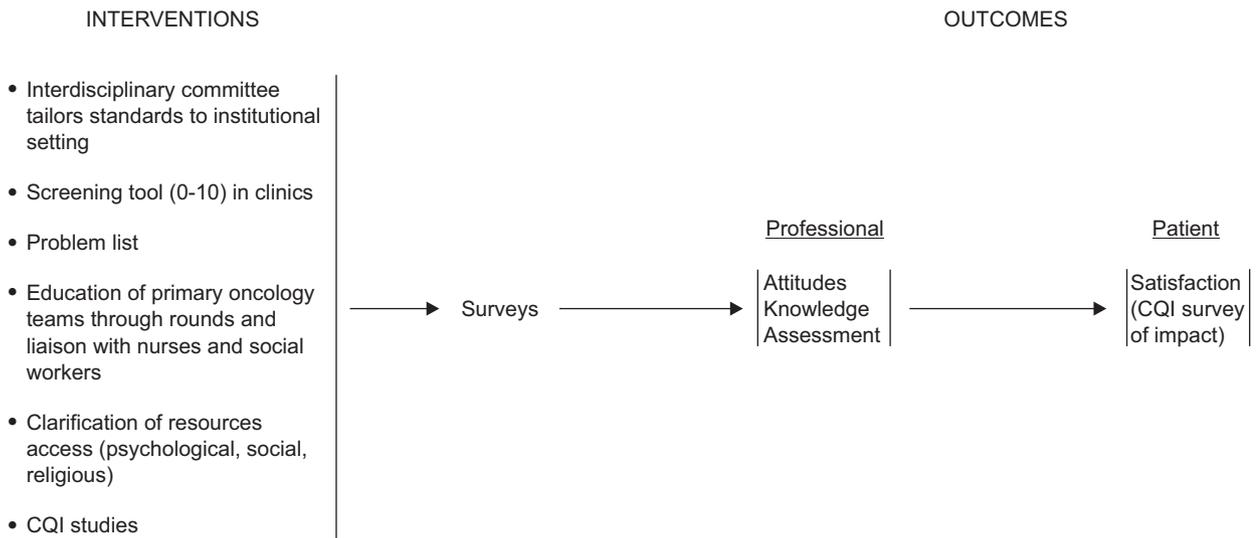
<sup>h</sup>Referral to clergy of person's faith.

# Distress Management Version 1:2010

## 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

## INSTITUTIONAL EVALUATION OF STANDARDS OF CARE<sup>i</sup>



<sup>i</sup>Based on implementation/evaluation of pain management guidelines.

## Distress Management

Text continued from p. 449

sion on Accreditation of Healthcare Organizations have included concerns for decision-making and the ethical aspects of care, psychosocial care was not considered an aspect of quality care until publication of the 2007 Institute of Medicine (IOM) report.<sup>7</sup> Psychosocial care is now a part of the new standard for quality cancer care, which states that it must be integrated into routine care.<sup>7-10</sup> In Canada, emotional distress is the sixth vital sign, which is checked routinely along with pulse, respiration, blood pressure, temperature, and pain (the 5 vital signs).<sup>11</sup> Patients and families should be made aware that this new standard exists and that they should expect it in their oncologist's practice.<sup>12</sup>

### Psychosocial Problems in Cancer Patients

In the past 2 decades, dramatic advances in early detection and treatment options have increased 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>13</sup> The prevalence of psychological distress in individuals varies by cancer type. In a study of 4496 patients, Zabora et al.<sup>14</sup> reported that the overall prevalence of distress was 35.1%, which varied from 29.6% for patients with gynecologic cancers to 43.4% for those with lung cancer. The prevalence of distress, depression, and psychiatric disorders has also been studied in all sites and stages of cancer.<sup>15-17</sup>

Cognitive impairment related to chemotherapy (sometimes known as "chemobrain") has also been described in patients with advanced cancer.<sup>18-20</sup> Cognitive impairment is more common in patients with primary central nervous system (CNS) cancers. Recent evidence has shown that chemotherapy-related cognitive dysfunction is also prevalent in patients with non-CNS cancers and brain metastases.<sup>18,19</sup> Although subtle, it may be long-lasting and can adversely affect the quality of life of long-term cancer survivors. 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>21</sup>

Nonadherence to treatment occurs, especially with oral medications. In women with primary breast

cancer, Partridge et al.<sup>22</sup> observed that the overall adherence to tamoxifen decreased to 50% in the fourth year of therapy, and that nearly one fourth of patients may be at risk for inadequate clinical response from poor adherence. Depression and anxiety are risk factors for noncompliance. In a meta-analysis, DiMatteo et al.<sup>23</sup> found that noncompliance was 3 times greater in patients experiencing depression.

### Psychosocial Interventions

Psychosocial interventions have been effective in reducing distress and improving overall quality of life among cancer patients.<sup>7,10,24</sup> The 2007 IOM report examined the range of interventions (psychological, social, and pharmacologic) and their impact on quality of life, symptoms, or survival, and noted a strong evidence base supporting the value of psychosocial interventions in cancer care.<sup>7</sup> The extensive review found randomized clinical trials, systematic reviews, and meta-analyses that supported the conclusion that quality cancer care today must integrate psychosocial aspects into routine care. Cognitive-behavioral therapy (CBT), supportive psychotherapy, and family and couples therapy are the 3 key types of psychotherapies discussed in the report.<sup>7</sup>

#### CBT

CBT involves identification and correction of inaccurate thoughts associated with depressed feelings, relaxation, and enhancing problem-solving skills. In randomized clinical trials, CBT has been shown to effectively reduce psychological symptoms (anxiety and depression)<sup>25</sup> and physical symptoms (pain and fatigue)<sup>26</sup> in patients with cancer.

No standard treatment exists for the management of cognitive changes associated with chemotherapy in patients with cancer. Some studies have shown that the use of psychostimulants, such as methylphenidate and modafinil, improved cognitive function.<sup>27-29</sup> Donepezil, a reversible acetylcholinesterase inhibitor (recently approved to treat mild to moderate dementia in patients with Alzheimer's disease), also improved cognitive function, mood, and health-related quality of life in patients with primary low-grade glioma.<sup>30</sup> Further placebo-controlled trials are needed to confirm these preliminary findings.

Ferguson et al.<sup>31</sup> developed a brief cognitive-behavioral treatment (Memory and Attention Adaptation Training [MAAT]) aimed at helping breast

cancer survivors manage cognitive dysfunction associated with adjuvant chemotherapy. In a single-arm pilot study, improvements in self-report of cognitive function, quality of life, and standard neuropsychological test performance were observed in all patients (29 women at an average of 8 years after adjuvant chemotherapy for stage I–II breast cancer). The authors have initiated a randomized study to evaluate the efficacy of MAAT.

In October 2006, the International Cognition and Cancer Task Force (ICCTF) was formed, comprising a multidisciplinary group of health professionals and health advocates. Their mission is to advance understanding of the impact of treatment-related cognitive and behavioral functioning in patients with non-CNS cancers.<sup>32</sup> ICCTF is also creating 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 symptoms associated with cancer treatment.

### Supportive Psychotherapy

Supportive psychotherapy, aimed at flexibly meeting patients changing needs, is most widely used. Group psychotherapy has also been evaluated in clinical trials. Supportive–expressive group therapy has been shown to improve psychological outcome, especially in patients with metastatic breast cancer. In randomized clinical trials, it has improved quality of life and psychological symptoms, especially mood and pain control.<sup>33,34</sup> Cognitive–existential group therapy was found to be useful in women with early-stage breast cancer undergoing adjuvant chemotherapy.<sup>35</sup>

### Family and Couples Therapy

Family and couples therapy has not been widely studied in controlled trials. Family-focused grief therapy has the potential to reduce morbid effects of grief in families of patients with terminally ill cancer.<sup>36</sup> In couples coping with early-stage breast cancer, mutual constructive communication was associated with less distress and more relationship satisfaction for both the patients and partner than demand–withdraw communication.<sup>37</sup>

### Screening Tools for Distress and Meeting Psychosocial Needs

Identification of patient’s psychological needs is essential to develop a plan to manage those needs.

Ideally, patients tell their oncologists about their problems or respond to the oncologist’s query about the problems. In routine clinical practice, time constraints and the stigma related to psychiatric and psychological needs often leads to no discussion of these issues. Screening tools have been found to be effective and feasible in reliably identifying distress and the psychosocial needs of patients.<sup>38–40</sup> Mitchell et al.<sup>41</sup> recently reported that ultra-short methods (Patient Health Questionnaire 2 [PHQ2] or the Distress Thermometer [DT]) were acceptable to approximately three quarters of clinicians.

The IOM report supported the work of the NCCN in developing guidelines for distress management by proposing a model that could be implemented in any community oncology practice.<sup>7</sup>

A model for the effective delivery of psychosocial health services consists of:

- Screening for distress and psychosocial needs;
- Making a treatment plan to address these needs and implementing it;
- Referral to services as needed for psychosocial care; and
- Reevaluation as appropriate.

### NCCN Distress Management Guidelines

A major milestone in the improvement of psychosocial care was made by the NCCN when it established a panel to develop clinical practice guidelines. The panel began to meet in 1997 as an interdisciplinary group. The clinical disciplines involved were oncology, nursing, social work, psychiatry, psychology, and clergy. A patient advocate was also on the panel. Traditionally, clergy have not been included, but the panel recognized that many patients prefer a certified chaplain.<sup>42</sup>

The first step was to understand why this area has been so difficult to develop. The panel members decided that words such as *psychiatric* or *psychological* are stigmatizing; patients and oncologists are reluctant to use these terms to label any symptoms or patients. The way around this barrier was developed by using a term that would feel “normal” and non-stigmatizing, which 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.<sup>43</sup>

## Distress Management

The IOM report on “Cancer Care for the Whole Patient” is based on the pioneering work of the NCCN panel, which recommends screening for distress and development of a treatment plan with referrals to psychosocial resources as needed.<sup>7</sup> NCCN has developed several cancer treatment and supportive care guidelines for the management of cancer-related symptoms, including pain and fatigue (to view the most recent version of these guidelines, visit the NCCN Web site at [www.NCCN.org](http://www.NCCN.org)). Recommendations in the treatment guidelines are based on evidence and consensus among panel members.<sup>44</sup> 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).

### Definition of Distress

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* (see page 450). 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.

Distress was defined by the panel as 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 (page 450). Distress extends along a continuum ranging from normal feelings of vulnerability, sadness, and fear to problems that can become disabling, such as clinical depression, anxiety, panic, isolation, and existential or spiritual crisis. Early detection and treatment of distress leads to better adherence to treatment, better communication, fewer calls and visits based on anxiety, and avoidance of patients’ anger and developing severe anxiety or depression.

### The DT

A well-known tool for initial screening is the DT, which is similar to the successful rating scale used to measure pain: 0 (no distress) to 10 (extreme distress). The DT serves as a rough initial single-item question

screen, which identifies distress coming from any source even if unrelated to cancer. The receptionist gives it to the patient in the waiting room. The 36-item Problem List, which is on the page with the DT, asks patients to identify their problems in 5 different categories: practical, family, emotional, spiritual/religious, and physical (page 454). The completed list is reviewed by the nurse, who is present at all visits and is the likely person to look at the DT and Problem List and ask clarifying questions. Social workers are often not immediately available in busy clinics.

Chemotherapy and radiation therapy also have an impact on the fertility of patients, especially in those of child-bearing age.<sup>45</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 patients concerned about the possible effect of cancer treatment on their fertility.

The patient in the waiting room places a mark on the DT 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, and the nurse looks at the Problem List to identify key issues of concern and asks further questions to determine which resource to refer the patient. If the patient’s distress level is mild (score < 4), the primary oncology team may choose to manage the concerns through usual clinical supportive care management.

DT has been validated by several studies in patients with different types of cancer and has shown concordance with Hospital Anxiety and Distress Scale.<sup>38,46–52</sup> The DT has shown good sensitivity and specificity. The needs assessment surveys performed in ambulatory clinics using these screens show 20% to 40% of patients have significant levels of distress. Two recent studies have validated the DT with an expanded problems list.<sup>53,54</sup> Tuinman et al.<sup>54</sup> validated the DT with the 46-item Problem List in a cross-sectional group of 227 cancer patients. Graves et al.<sup>53</sup> validated the DT with an adapted problems list with 2 new problem categories (information concerns and cognitive problems) in patients with lung cancer. The DT is also a useful tool for screening distress in patients undergoing bone marrow transplant.<sup>55,56</sup> The DT had acceptable overall accuracy and greater sensitivity and specificity for assessing depression compared with the Center for Epidemiological Studies-Depression Scale (CES-D).<sup>55</sup>

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**Standard of Care for Distress Management**

The standards of care for managing distress proposed by the 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 has developed a set of standards of care for the management of distress using quality improvement guidelines for the treatment of pain as a model (page 451).<sup>57,58</sup>

- Distress should be recognized, monitored, documented, and treated promptly at all stages of disease and in all settings.
- All patients should be screened to ascertain their levels of distress at the initial visit, at appropriate intervals, and as clinically indicated, especially when changes occur in disease status (remission, recurrence, or progression).
- Distress should be assessed and managed according to clinical practice guidelines.
- Each cancer center should establish an interdisciplinary committee that will assume responsibility for implementing the standards for distress management.
- Educational and training programs should be developed to ensure that the oncology team, mental health professionals, and certified chaplains have the appropriate 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 available either as staff members within the cancer center or through referral.
- Medical care contracts should include reimbursement for services provided by mental health professionals to patients for evaluating and treating distress.
- Clinical health outcomes measurements should incorporate assessment of the psychosocial domain (i.e., cost-effectiveness, quality of life, and patient and family satisfaction).
- Patients, families, and their treatment teams should be informed that the management of distress is an integral part of cancer care and they should be provided with appropriate information about the psychosocial services available in the treatment center and community. This is now an added indicator of quality cancer care by the 2007 IOM report.<sup>7</sup>

- Finally, the quality of distress management programs or services should be included in the institutional, interdisciplinary continuous quality improvement (CQI) projects.

Improvement will occur only through evaluation of patients' needs and identification of system changes required to increase the recognition and treatment of distress. Jacobsen<sup>59</sup> developed a patient chart audit that permits oncology offices or clinics to evaluate the quality of their psychosocial care. The survey queries whether the patient's current emotional well-being was assessed and if any action was taken if the patient was identified as having a problem. This work now allows quality indicators to be used widely to determine the quality of psychosocial care provided by a clinic or office.

Quality Oncology Practice Initiative (QOPI) was started in 2002 by ASCO as a pilot project (<http://qopi.asco.org/program.html>).<sup>60</sup> This program became available to all ASCO member medical oncologists in 2006. Jacobson's psychosocial quality indicators are now included in the QOPI initiative and may become part of the core measures.<sup>61</sup> In a recent analysis, Jacobson et al.<sup>61</sup> reported that practices that participated in QOPI showed improved performance, and initially low-performing practices showed the greatest improvement. Blayney et al.<sup>62</sup> from the University of Michigan Comprehensive Cancer Center recently reported that QOPI can be adapted for use in practice improvement at an academic medical center.

**Initial Evaluation and Treatment**

The panel recommends that all patients be assessed in the waiting room using a simple screening tool. Although several types of screening tools are available, the DT and accompanying Problem List are recommended to assess the level of distress and identify its causes, as described on page 454.

If the patient's distress is moderate or severe (DT score of  $\geq 4$ ), the oncology team must recognize that score as a trigger to a second level of questions that should prompt referral to a mental health professional, social worker, or spiritual counselor, depending on the problems identified in the Problem List. Common symptoms, which require further evaluation, are excessive worries and fears, excessive sadness, unclear thinking, despair and hopelessness, severe family problems, and spiritual crises.

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Patients at increased risk for distress are those with a history of psychiatric disorder or depression, substance abuse, cognitive impairment, severe comorbid illnesses, social problems, and communication barriers (page 455). Risk factors for greater distress include past psychiatric disorder, alcohol or substance abuse, younger age, female gender, living alone, having young children, and prior physical or sexual abuse. Patients are referred to the appropriate supportive service (mental health, social work, or chaplaincy services) based on the identified problem. Patients with moderate to severe distress with a score of 4 or more on the screening tool must be evaluated further by the primary oncology team as the second phase of query.

The supportive care professional who receives the referral for a patient's distress management should evaluate the patient using the clinical practice guidelines for that discipline (e.g., mental health, social work, or chaplaincy services).

Mild distress (score of < 4) is routinely managed by the primary oncology team and represents what the panel termed *expected distress* symptoms (page 453). The "normal" symptoms that the team manages are fears, worry, and uncertainty about the future; concerns about the illness; sadness about loss of good health; anger and the feeling that life is out of control; poor sleep, appetite, and concentration; and preoccupation with thoughts of illness, death, and treatment effects and side effects. These symptoms are most often experienced at diagnosis and during arduous treatment cycles, but might persist long after completion of treatment. Minor symptoms are often misinterpreted by survivors as a sign of recurrence, which causes fear and anxiety until they are reassured.

The primary oncology team is the first to deal with these painful problems; the oncologist, nurse, and social worker each have a critical role. First and foremost is the quality of the physician's communication with the patient, which should occur in the context of a mutually respectful relationship so that the patient can learn the diagnosis and understand the treatment options and side effects.<sup>63</sup> Sufficient time is needed for patients to ask questions and to be put at ease.<sup>64</sup> When communication is handled well at diagnosis, the stage is set for future positive trusting encounters. Clinicians must ensure that patients mentally grasp what is said, which can be reinforced

through drawings or providing the patient with a tape of the session.

The oncology team must acknowledge that this experience is difficult for the patient and that distress is normal and expected. Expressing distress to the staff relieves it somewhat and builds trust. The team must ensure that patients have social supports in place and that they are aware of community resources, such as support groups, teleconferences, and help lines. The IOM report contains the list of national organizations and the toll-free numbers.<sup>7</sup> Some organizations that provide free information services include:

- American Cancer Society ([www.cancer.org](http://www.cancer.org))
- American Institute of Cancer Research ([www.aicr.org](http://www.aicr.org))
- American Psychosocial Oncology Society ([www.apos-society.org](http://www.apos-society.org)) provides a Toll-Free Helpline (1-866-276-7443) that can help patients and caregivers find psychological resources in their community
- CancerCare ([www.cancercare.org](http://www.cancercare.org))
- National Cancer Institute (NCI; [www.cancer.gov](http://www.cancer.gov))
- Cancer.net sponsored by ASCO ([www.cancer.net](http://www.cancer.net)).

Clinicians should be aware of the evidence-supported interventions available for the management of distress. The following clinical practice guidelines will be useful to clinicians:

- NCCN Clinical Practice Guidelines in Oncology: Distress Management ([www.NCCN.org](http://www.NCCN.org))
- Association of Community Cancer Centers Cancer Program Guidelines ([www.accc-cancer.org](http://www.accc-cancer.org))
- Clinical practice guidelines for the psychosocial care of adults with cancer developed by the Australian National Breast Cancer Centre and the National Cancer Control Initiative (<http://www.nhmrc.gov.au/publications/synopses/cp90syn.htm>)
- A Web site developed by the NCI and several partners that provides information about research-tested intervention programs (<http://rtips.cancer.gov/rtips/index.do>)

### Psychological/Psychiatric Treatment Guidelines

**Mental Health Services:** Mental health professionals are expected to conduct a psychological or psychiatric evaluation that includes an assessment of the

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nature of the distress, behavior, and psychological symptoms; psychiatric history; use of medications; pain; fatigue; sleep disorder; cognitive impairment and other physical symptoms; body image and sexuality; and capacity for decision-making and physical safety (page 456). A psychiatrist, psychologist, nurse, advanced practice clinician, or social worker may perform the evaluation. All of these professionals are skilled in mental health assessment and treatment. *The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Text Revision (DSM-IV-TR)* classification of mental disorders is used to identify the psychological and psychiatric disorders that commonly occur in patients with cancer.

The panel developed evaluation and treatment guidelines for the 7 most commonly encountered psychiatric disorders: dementia, delirium (encephalopathy), mood disorder, adjustment disorder, anxiety disorder, substance abuse–related disorder, and personality disorder (page 456). Dementia and delirium are cognitive impairments that may develop during the course of cancer treatment, and can severely impair a patient's decision-making capacity.<sup>65</sup> Although dementia is a permanent cognitive impairment and is not a common complication of cancer treatment, it is often present in elderly patients as a comorbid condition. Dementia can be treated with cognitive rehabilitation, with or without medications, although treatment largely consists of behavior management (page 458). Delirium is a short-term cognitive impairment that is usually reversible and occurs during cancer treatment related to any toxic state and is often related to medication, particularly opioids. Delirium is managed through attention to safety, neuroleptics, and family support and education (page 459).

The incidence of suicide among patients with cancer in the United States is twice that of the general population and the risk is higher in older patients.<sup>66–68</sup> Patients with mood and adjustment disorders can develop suicidal tendencies. In patients with no suicidal risk, mood disorder is usually managed with an antidepressant and psychotherapy with or without anxiolytics. Referral to social work and chaplaincy services may be considered (page 460). No medications are prescribed for patients with mild adjustment disorder, although those with moderate to severe are treated with medication and psychotherapy. Safety measures should be implemented for

patients at suicidal risk, such as removal of sharp objects and psychiatric consultation. Psychiatric treatment and hospitalization may sometimes be necessary (page 462).

All patients with cancer experience anxiety,<sup>69</sup> although it may be related to their general medical condition (e.g., hormone-secreting tumor, effects of certain types of medications [bronchodilators], withdrawal from alcohol or narcotics, pain, other distressing physical symptom). After ruling out medical causes, clinicians should assess symptoms to determine the particular nature of the anxiety disorders. Generalized anxiety disorder is usually preexisting and may be exacerbated by illness. Panic disorder may recur during illness in patients with previous panic symptoms. Posttraumatic stress disorder may develop after arduous cancer treatments or during a cancer treatment, which triggers a traumatic memory of a past frightening event. Obsessive-compulsive disorder is a preexisting disorder that results in difficulty making decisions, ruminative thoughts about illness, and fear of taking medication. Some patients develop phobias of needles, hospitals, and blood or conditioned nausea/vomiting related to chemotherapy (see NCCN Clinical Practice Guidelines in Oncology: Antiemesis [to view the most recent version of these guidelines, visit the NCCN Web site at [www.NCCN.org](http://www.NCCN.org)]).

Research suggests that antidepressants and anti-anxiety drugs are beneficial in the treatment of depression and anxiety in adult patients with cancer.<sup>70–72</sup> In randomized controlled trials, alprazolam (a benzodiazepine)<sup>73</sup> and fluoxetine (a selective serotonin reuptake inhibitor [SSRI])<sup>74,75</sup> have been effective in improving depressive symptoms. The SSRIs are widely used for depression and anxiety symptoms. Psychostimulant drugs help in the management of fatigue.

The NCCN guidelines recommend (category 1) psychotherapy with or without an anxiolytic or an antidepressant for the treatment of anxiety, after eliminating medical causes (page 464). If the anxiety responds to initial treatment, follow-up should occur with the primary oncology team. If no response is noted, patients should be reevaluated and treated with different medications (neuroleptic) with continued psychotherapy, support, and education. If still no response is seen, then patients should be evaluated for depression and other psychiatric comorbidity (page 464).

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Substance abuse is rare among patients with cancer who do not have a history of active abuse or addiction to opioids, alcohol, or tobacco. Substance abuse or dependence developed during the course of treatment may be from insufficient symptom control and can be treated by improving symptom control. If a history of substance abuse is present, its impact on cancer treatment should be assessed and the patient referred to risk reduction or substance management program (pages 465 and 466).

**Social Work Services:** Social work services are recommended when a patient has a psychosocial or practical problem (page 468). Practical problems involve illness-related concerns; concrete needs (e.g., housing, food, financial assistance, help with activities of daily living, transportation); employment, school, or career concerns; cultural or language issues; and caregiver availability. The guidelines outline interventions that vary according to the severity of the problem.

Psychosocial problems are adjustment to illness; family conflicts and social isolation; difficulties in decision-making; quality-of-life issues; advance directives; domestic abuse and neglect; coping or communication skills; functional changes (e.g., body image, sexuality); and issues pertaining to end of life and bereavement (including cultural and caregiver concerns).

Social workers assist people with mild psychosocial problems by providing patient and family education, support groups, and/or sex or grief counseling, and suggesting available local resources. For moderate-to-severe psychosocial problems, counseling and psychotherapy are used (including sex and grief counseling); community resources are mobilized; problem-solving is taught; and advocacy, education, and protective services are made available.

**Spiritual Care:** Many patients use their religious and spiritual resources to cope with illness, citing prayer as a major help. Balboni et al.<sup>76</sup> surveyed 230 patients with advanced cancer treated at Yale University Cancer Center and Memorial Sloan-Kettering Cancer Center for whom first-line chemotherapy failed. Most patients (88%) considered religion somewhat or very important. Nearly half of the patients (47%) reported receiving very minimal or no support at all from their religious community and 72% reported receiving little or no support from their medical system.<sup>76</sup> Religiousness and spiritual support have also

been associated with improved coping and quality of life in patients with advanced cancer. Astrow et al.<sup>77</sup> found that, although most patients had spiritual needs, only a slight majority believed asking about them was appropriate, and that patients whose spiritual needs were not met reported lower quality and satisfaction with their care. A consensus conference on improving the quality of spiritual care as a dimension of palliative care was held in February 2009. The report from this conference provides recommendations for health care professionals on integrating spiritual care into the overall treatment plan.<sup>78</sup> Inclusion of a certified chaplain on the interdisciplinary team is critical for implementing spiritual care into routine clinical practice.

The following guidelines on religion and spirituality in cancer care will be useful for clinicians and patients:

- National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, Second Edition, 2009. These guidelines provide a framework to acknowledge the patient's religious and spiritual needs in a clinical setting. Religion and spirituality are included as 1 of the 8 clinical practice domains in these guidelines (<http://www.nationalconsensusproject.org/guideline.pdf>).
- The NCI's comprehensive cancer information database (PDQ) has information on "Spirituality in Cancer Care" for patients ([www.cancer.gov/spiritualityincancer/patients](http://www.cancer.gov/spiritualityincancer/patients)) and health care professionals ([www.cancer.gov/spiritualityincancer/healthprofessional](http://www.cancer.gov/spiritualityincancer/healthprofessional)).

**Chaplaincy Services:** The panel included chaplaincy services as part of psychosocial services because the diagnosis of cancer presents an existential crisis. All patients should be referred for chaplaincy services when their problems are spiritual or religious in nature or when they request it. The panel identified 11 issues related to illness for which people often seek chaplaincy services (page 469). A treatment guideline is available for each of these issues: grief; concerns about death and the afterlife; conflicted or challenged belief systems; loss of faith; concerns with meaning and purpose of life; concerns about relationship with deity; isolation from the religious community; guilt; hopelessness; and conflicts between beliefs and recommended treatments.

The certified chaplain evaluates the problem and may offer spiritual or philosophical reading ma-

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terials, spiritual advice and guidance, prayer, and reconciliation rituals. Some patients may be referred for social work or mental health services if the problems indicate a need for more than spiritual counseling. Patients who do respond receive continued support. Patients whose concerns are not allayed may be referred for mental health evaluation while continuing to receive spiritual counseling if they wish. For patients who have significant family conflicts, referral to social work may be advisable in addition to chaplaincy services. Patients who experience guilt or hopelessness may also have severe depressive symptoms or suicidal ideation and should be evaluated by mental health professionals for further assessment (page 471).

### Recommendations for Implementing Standards and Guidelines

Jacobsen and Ransom<sup>79</sup> conducted a study to evaluate the implementation of these guidelines by NCCN member institutions and found that 8 institutions (53%) conducted routine distress screening and an additional 4 (27%) also preformed pilot testing and screening strategies. However, concordance to NCCN guidelines was observed in only 20% of the member institutions.

The panel encourages the establishment of interdisciplinary committees in NCCN institutions to implement and monitor distress management. This committee must be responsible for evaluating standard care in distress management using CQI studies. The panel encourages these studies to assess the quality of distress management programs, and the efficacy of standards of care, and the implementation of these guidelines and the new quality standard established by the IOM report.<sup>7</sup>

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

Follow-up at regular intervals or at transition points in illness is an essential part of these guidelines and the IOM model for care of the whole patient. This is particularly important in elderly patients.<sup>80,81</sup>

Presently, the quality of the psychological care patients receive is not routinely monitored. Accrediting bodies have not directly examined the quality

of psychosocial care nor have they established minimal performance standards for its delivery. The panel believes that psychosocial care should and will eventually be a part of institution report cards.

### Summary

Psychosocial care is increasingly being recognized as an integral component of clinical management for patients with cancer. These guidelines recommend that each new patient be rapidly assessed in the office or clinic waiting room for evidence of distress using the DT and Problem List as an initial rough screen (page 454).<sup>82</sup> A score of 4 or greater on the DT should trigger further evaluation by the oncologist or nurse and referral to a psychosocial service, if necessary. The choice of psychological service depends 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; and spiritual concerns should be referred to certified chaplains.

The primary oncology team members (oncologist, nurse, and social worker) are central to making this model work. Team members look at the score on the DT and the items checked on the Problem List as the first stage of screening. The nurse will follow up with further questions as a second stage of screening. At least one team member must be familiar with the mental health, psychosocial, and chaplaincy services available in the institution and community. A list of the names and phone numbers for these resources should be kept in all oncology clinics and updated frequently.

The standards of care should be revised and modified to be compatible with the clinical care offered at each institution. The medical staff and patients should be made aware of the resources available to treat distress and have access to mental health professionals and clergy who are trained to deal with cancer-related distress. The benefits of treating distress in cancer accrue to the patients, their families, and the treating staff, and improve efficiencies in clinic operations. Educating patients and families is equally important to encourage them to recognize that controlling distress is an integral part of cancer care.

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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. For patients with cancer, integrating mental health and medical services is critical. Outcomes research studies that include quality-of-life assessment and analysis of cost-effectiveness are also needed.

Patients and families should be informed that management of distress is part of total medical care. Spirituality and religion also play an important role in helping many patients with cancer cope with the diagnosis and illness. Chaplaincy services should be an integral part of psychosocial services for these patients.

These guidelines are assessed and evidence-based interventions added annually, highlighting the critical role of feedback in implementing, assessing, and improving standards of and guidelines for care.

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Individual Disclosures for the NCCN Distress Management Panel					
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The NCCN guidelines staff have no conflicts to disclose.