

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

Distress Management

Version 2.2013

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NCCN Guidelines Version 2.2013 Panel Members

Distress Management

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[Discussion](#)

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 ρ Internal medicine
 ξ Supportive Care including Palliative, Pain
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 ξ Bone Marrow Transplantation
 $\#$ Nursing
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Continue

[NCCN Guidelines Panel Disclosures](#)

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[NCCN Distress Management Panel Members](#)

[Summary of the Guidelines Updates](#)

Key Terms:

- [Distress \(DIS-1\)](#)
- [Definition of Distress in Cancer \(DIS-2\)](#)
- [Standards of Care for Distress Management \(DIS-3\)](#)
- [Overview of Evaluation and Treatment Process \(DIS-4\)](#)

[Expected Distress Symptoms \(DIS-5\)](#)

[Screening Tools for Measuring Distress \(DIS-A\)](#)

[Psychosocial Distress Patient Characteristics \(DIS-B\)](#)

[Psychological/Psychiatric Treatment Guidelines \(DIS-6\)](#)

[Social Work and Counseling Services \(DIS-20\)](#)

[Chaplaincy Services \(DIS-21\)](#)

[Recommendations for Implementation of Standards and Guidelines \(DIS-28\)](#)

[Recommended Readings for Implementation of Programs That Integrate Psychosocial Care Into the Routine Care of Patients With Cancer \(DIS-28\)](#)

[Institutional Evaluation of Standards of Care \(DIS-29\)](#)

[For End of Life Issues, See the NCCN Guidelines for Palliative Care](#)

[For Cancer Pain, See the NCCN Guidelines for Adult Cancer Pain](#)

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.

To find clinical trials online at NCCN member institutions, [click here: nccn.org/clinical_trials/physician.html](#)

NCCN Categories of Evidence and Consensus: All recommendations are Category 2A unless otherwise specified.

See [NCCN Categories of Evidence and Consensus](#)

The NCCN Guidelines® are a statement of evidence and consensus of the authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult the NCCN 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® (NCCN®) makes no representations or warranties of any kind regarding their content, use or application and disclaims any responsibility for their application or use in any way. The NCCN Guidelines are copyrighted by National Comprehensive Cancer Network®. All rights reserved. The NCCN Guidelines and the illustrations herein may not be reproduced in any form without the express written permission of NCCN. ©2012.



Updates in version 2.2013 of the NCCN Guidelines for Distress Management from Version 1.2013 include:

- The “Recommended Readings for Implementation of Programs that Integrate Psychosocial Care into the Routine Care of Patients with Cancer” reference list was moved from the Discussion to the algorithm. ([DIS-28](#))
- The Discussion text was updated to correspond to the changes in the algorithm. ([MS-1](#))

Updates in version 1.2013 of the NCCN Guidelines for Distress Management from Version 3.2012 include:

[DIS-5](#)

- Under Interventions: “Spiritual support” was added.

[DIS-A](#) Screening Tools for Measuring Distress

- “Substance abuse” was added to the list of Physical Problems.

[DIS-B](#) (Psychosocial Distress Patient Characteristics)

- Periods of Increased Vulnerability: The second bullet changed to “During diagnostic workup”.

[DIS-10](#) (Mood Disorder)

- Danger to self or others: The third bullet changed to “Consider removing ~~sharp~~ dangerous objects”.

[DIS-14](#) (Adjustment Disorder)

- Danger to self or others: The third bullet changed to “Consider removing ~~sharp~~ dangerous objects”.

[DIS-18](#) (Substance-Related Disorder/Abuse)

- Fourth column: The recommendation changed to “Referral to specialized treatment programs”.

[DIS-19](#) (Personality Disorder)

- Evaluation: The following bullets were clarified as follows, “Threatening behavior; Dramatic/histrionic behavior; Demanding behavior”.

[DIS-24](#) (Chaplaincy Services: Guilt)

- Footnote “h”: “Referral to clergy of person’s faith” changed to “Consider referral to community religious resource”.

“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.**

[Definition of Distress in Cancer \(DIS-2\)](#)

Note: All recommendations are category 2A unless otherwise indicated.

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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.

[Standard of Care for Distress Management \(DIS-3\)](#)

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STANDARDS OF CARE FOR DISTRESS MANAGEMENT

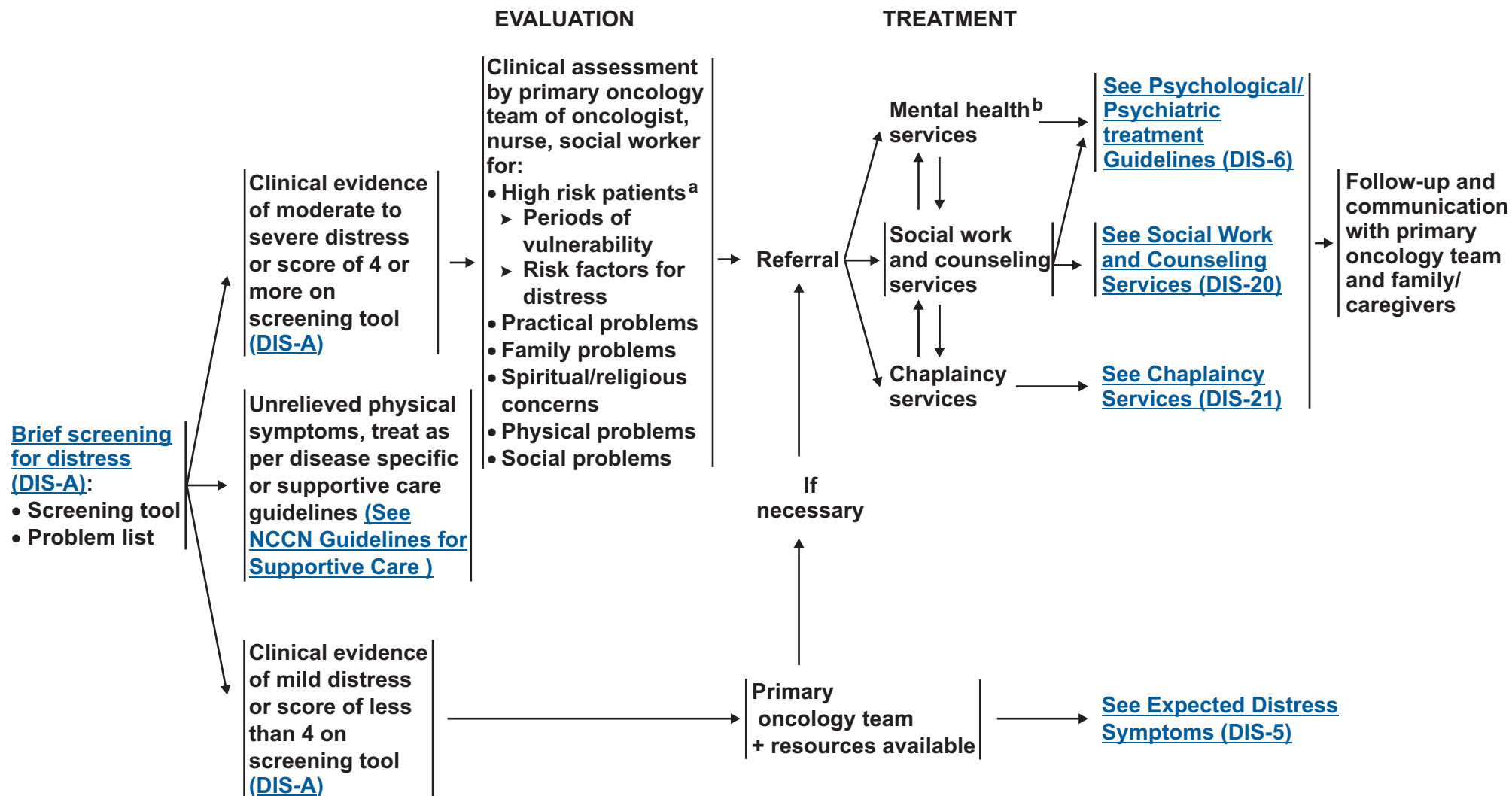
- **Distress should be recognized, monitored, documented, and treated promptly at all stages of disease and in all settings.**
- **Screening should identify the level and nature of the distress.**
- **All patients should be screened for distress at their initial visit, at appropriate intervals, and as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

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OVERVIEW OF EVALUATION AND TREATMENT PROCESS



^a[See Psychosocial Distress Patient Characteristics \(DIS-B\).](#)

^bPsychiatrist, psychologist, advanced practice clinicians, and/or social worker.

[Refer to NCCN Guidelines Table of Contents for Supportive Care Guidelines.](#)

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Distress Management

EXPECTED DISTRESS SYMPTOMS

INTERVENTIONS

RE-EVALUATION

- Patients at increased risk of vulnerability to distress^a
- Signs and symptoms of fear and worry about the future and uncertainty
 - Concerns about illness
 - Sadness about loss of usual health
 - Anger, feeling out of control
 - Poor sleep
 - Poor appetite
 - Poor concentration
 - Preoccupation with thoughts of illness and death
 - Disease or treatment side effects
 - Concerns about social role (ie, as father, mother)



- Clarify diagnosis, treatment options and side effects
 - Be sure patient understands disease and treatment options
 - Refer to appropriate patient education materials (eg, NCCN Treatment Summaries for Patients)
- Educate patient that points of transition may bring increased vulnerability to distress
- Acknowledge distress
- Build trust
- Ensure continuity of care
- Mobilize resources
- Consider medication to manage symptoms:
 - Analgesics
([See NCCN Adult Cancer Pain Guidelines](#))
 - Anxiolytics
 - Hypnotics
 - Antidepressants
- Support groups and/or individual counseling
- Family support and counseling
- Relaxation, meditation, creative therapies (eg, art, dance, music)
- Spiritual support
- Exercise



Monitor functional level and reevaluate at each visit

Stable or diminished distress



Continue monitoring and support

Increased or persistent distress



[See Distress Score ≥ 4 or moderate to severe distress \(DIS-4\)](#)

^a[See Psychosocial Distress Patient Characteristics \(DIS-B\).](#)

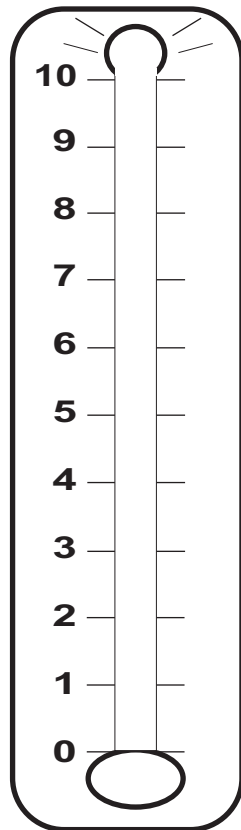
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SCREENING TOOLS FOR MEASURING DISTRESS

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

Extreme distress



No distress

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 Practical Problems

- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school
- Treatment decisions

Family Problems

- Dealing with children
- Dealing with partner
- Ability to have children
- Family health issues

Emotional Problems

- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

- Spiritual/religious concerns**

YES NO Physical Problems

- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhea
- Eating
- Fatigue
- Feeling Swollen
- Fevers
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Substance abuse
- Tingling in hands/feet

Other Problems: _____



PSYCHOSOCIAL DISTRESS PATIENT CHARACTERISTICS^c

PATIENTS AT INCREASED RISK FOR DISTRESS^d

- History of psychiatric disorder/substance abuse
- History of depression/suicide attempt
- Cognitive impairment
- Communication barriers^e
- 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 diagnostic 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

^cFor 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. (Based on the NCCN Distress Management Guidelines). IPOS Press, 2006. Available at www.apos-society.org.

^dFrom the NCCN Palliative Care Clinical Practice Guidelines in Oncology. Available at www.nccn.org.

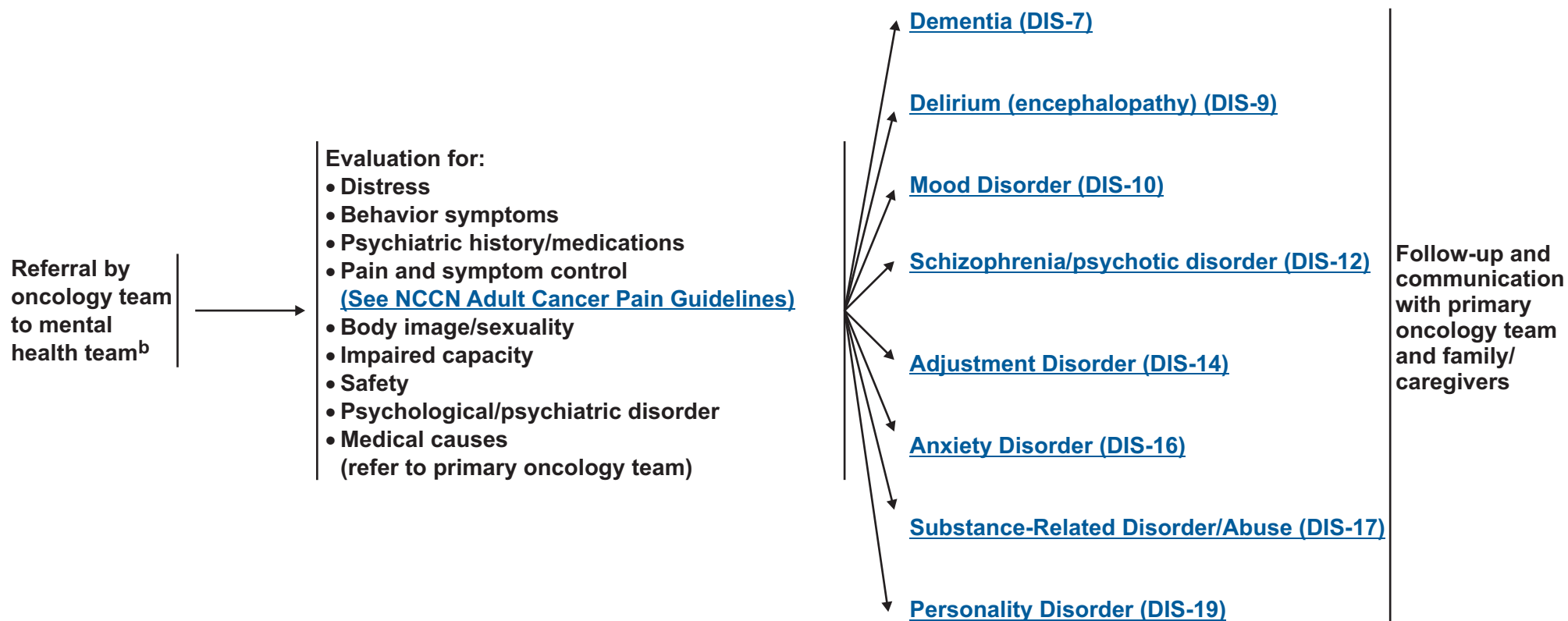
^eCommunication barriers include language, literacy, and physical barriers.

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PSYCHOLOGICAL/PSYCHIATRIC TREATMENT GUIDELINES



^bPsychiatrist, psychologist, advanced practice clinicians, and/or social worker.

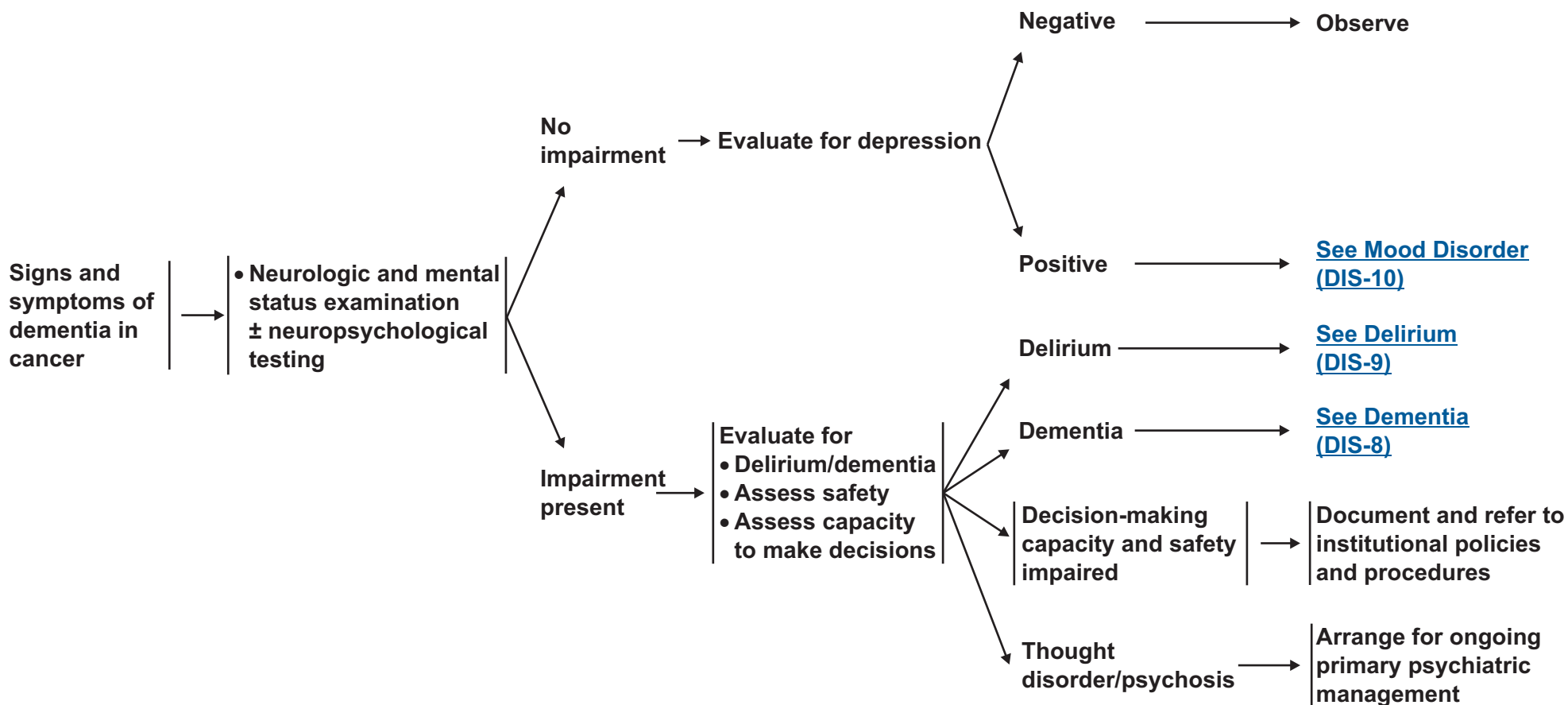
[For End of Life Issues, See NCCN Palliative Care Guidelines](#)

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DEMENTIA
(ICD-10 codes: F00-F03)

EVALUATION



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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

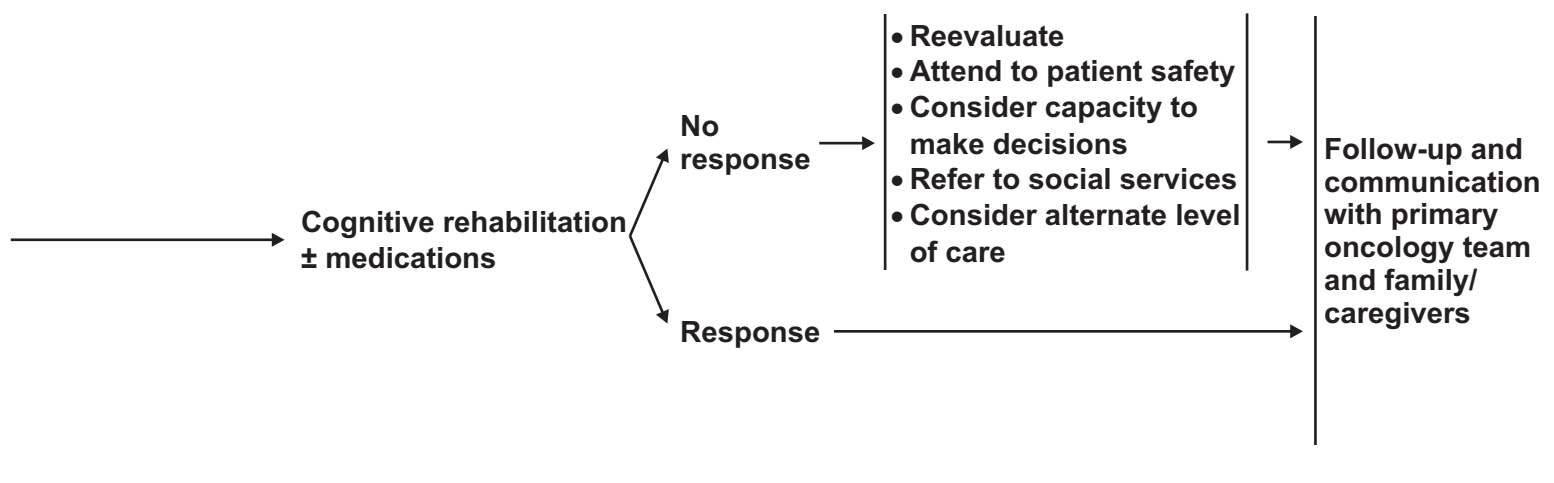
TREATMENT

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
Assess family/caregiver resources



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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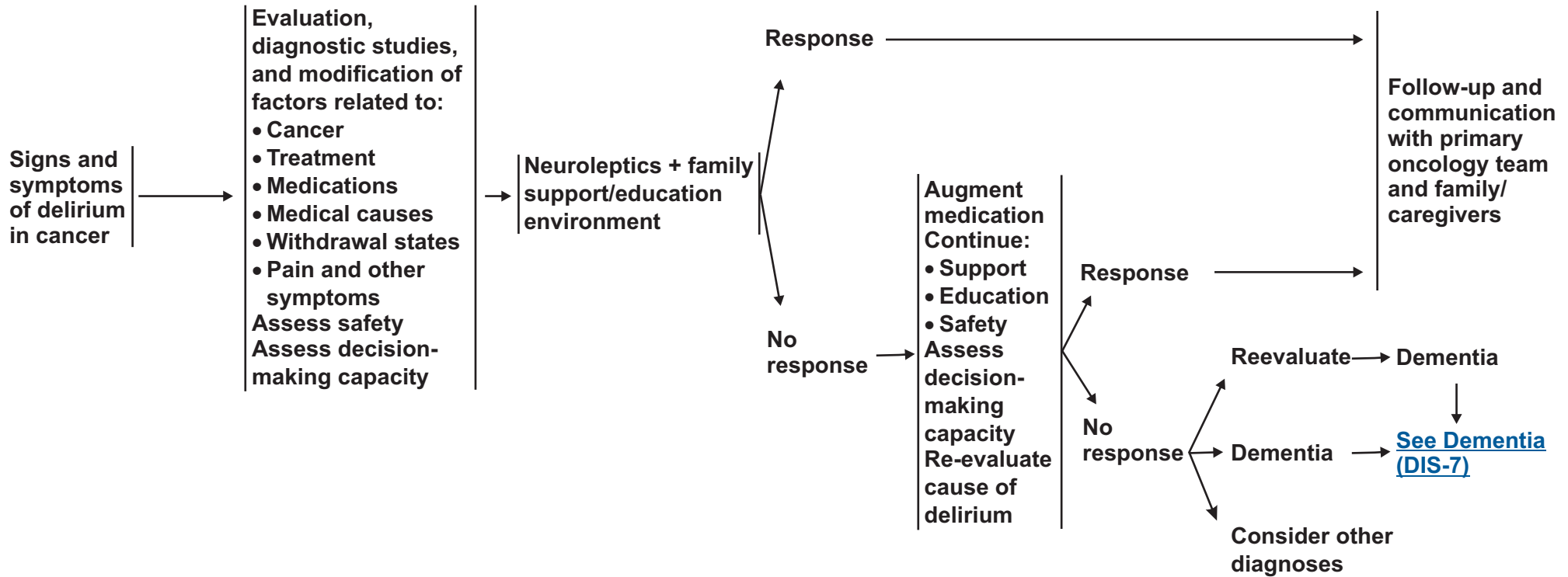
Distress Management

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

EVALUATION

TREATMENT

FOLLOW-UP



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

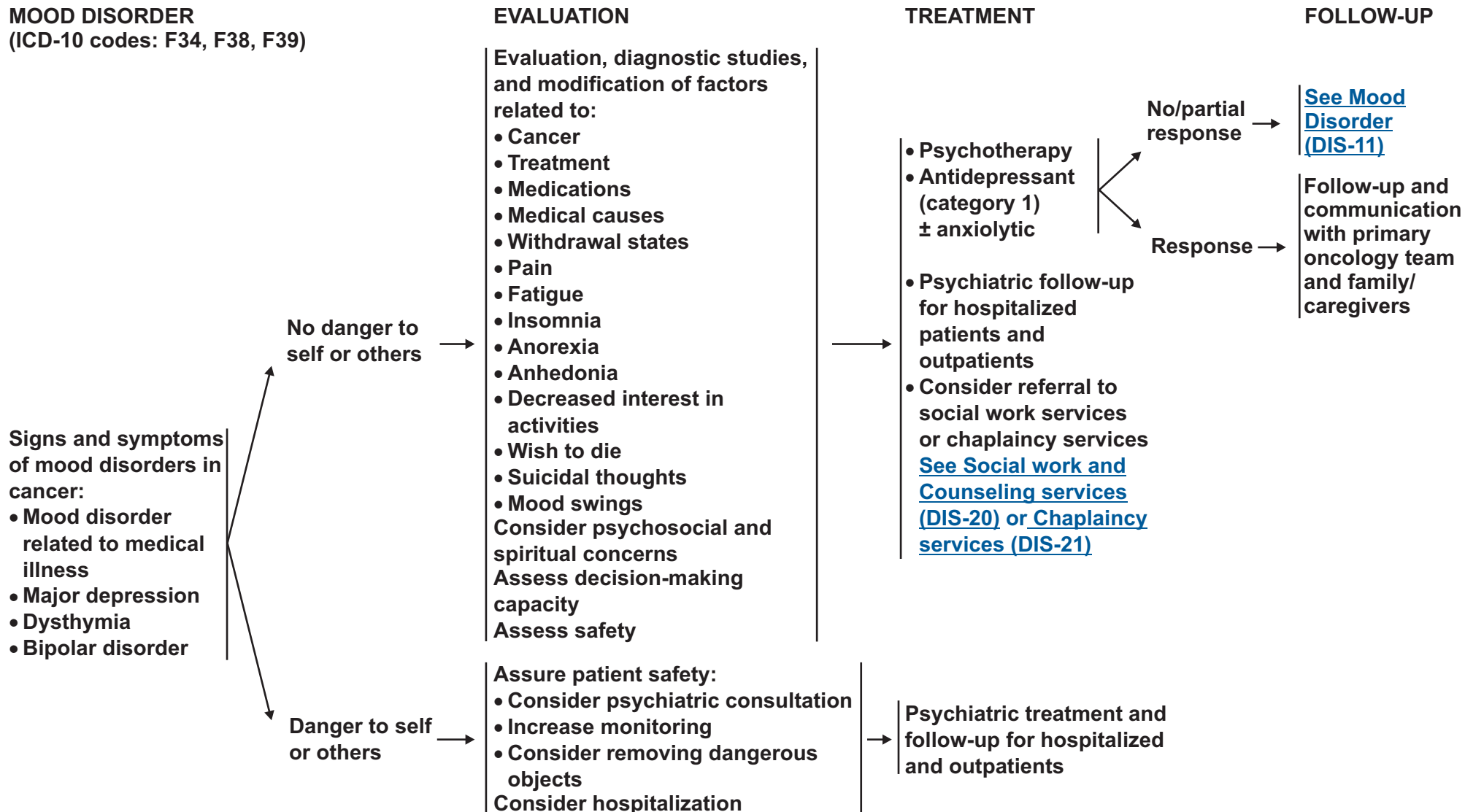
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Distress Management

MOOD DISORDER (ICD-10 codes: F34, F38, F39)



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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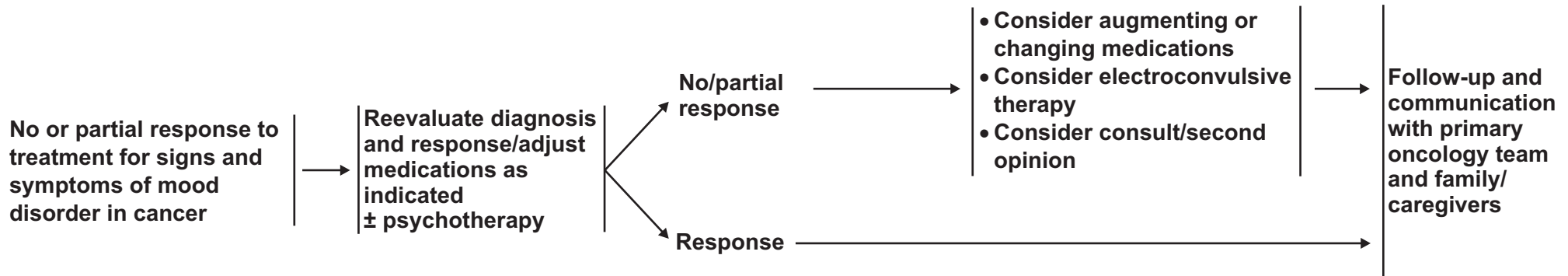


MOOD DISORDER (continued)
(ICD-10 codes: F34, F38, F39)

EVALUATION

TREATMENT

FOLLOW-UP



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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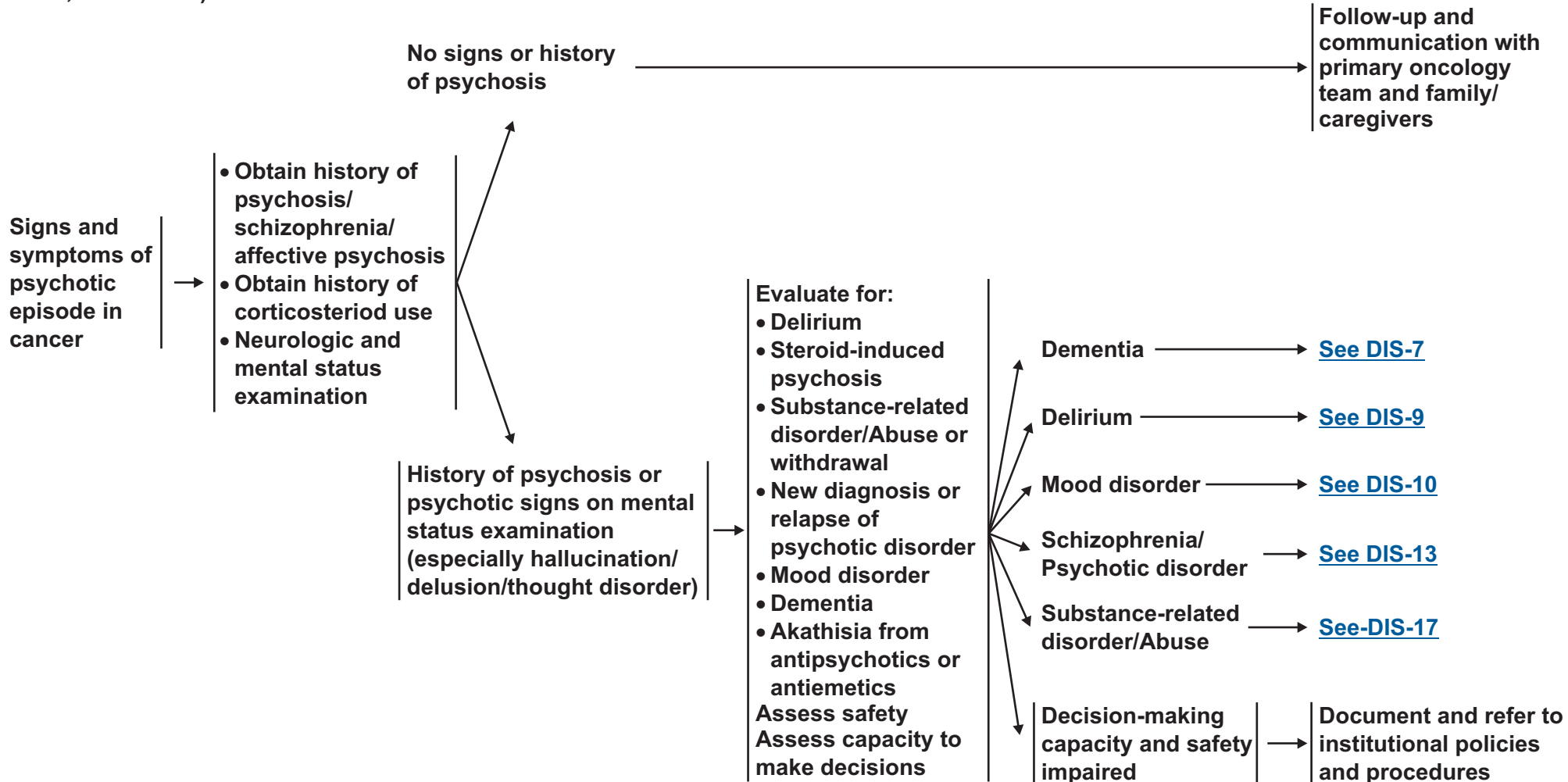


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Distress Management

SCHIZOPHRENIA/PSYCHOTIC DISORDER (ICD-10 codes: 295.0, 296.0, 298.8, 298.9, 295.7, 298.0 298.4)

EVALUATION



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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SCHIZOPHRENIA/PSYCHOTIC DISORDER
(ICD-10 codes: 295.0, 296.0, 298.8, 298.9, 295.7, 298.0 298.4)

TREATMENT

FOLLOW-UP

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

- Cancer
- Treatment
- Medications (particularly steroids)
- Delirium
- Withdrawal states or substance abuse
- New diagnosis of psychotic disorder
- Relapse of psychotic disorder (eg, not taking maintenance anti-psychotic medications)
- Dementia

Assess safety
Assess capacity to make decisions
Assess family/caregiver resources including inpatient psychiatry hospitalization and community mental health team

- Secure safety
- Consider anti-psychotic medications (Urgently administer if necessary.)
- Consider medications for mood
- Consider transfer to psychiatric unit/hospital
- Consider role of electroconvulsive therapy in psychotic depression/mania, catatonia

No response

Response

- Reevaluate
- Attend to patient safety
- Consider capacity to make decisions
- Maintain communication with team for chronic psychotic disorder/psychiatric service
- Consider alternate level of care

Follow-up and communication with primary oncology team and family/caregivers

[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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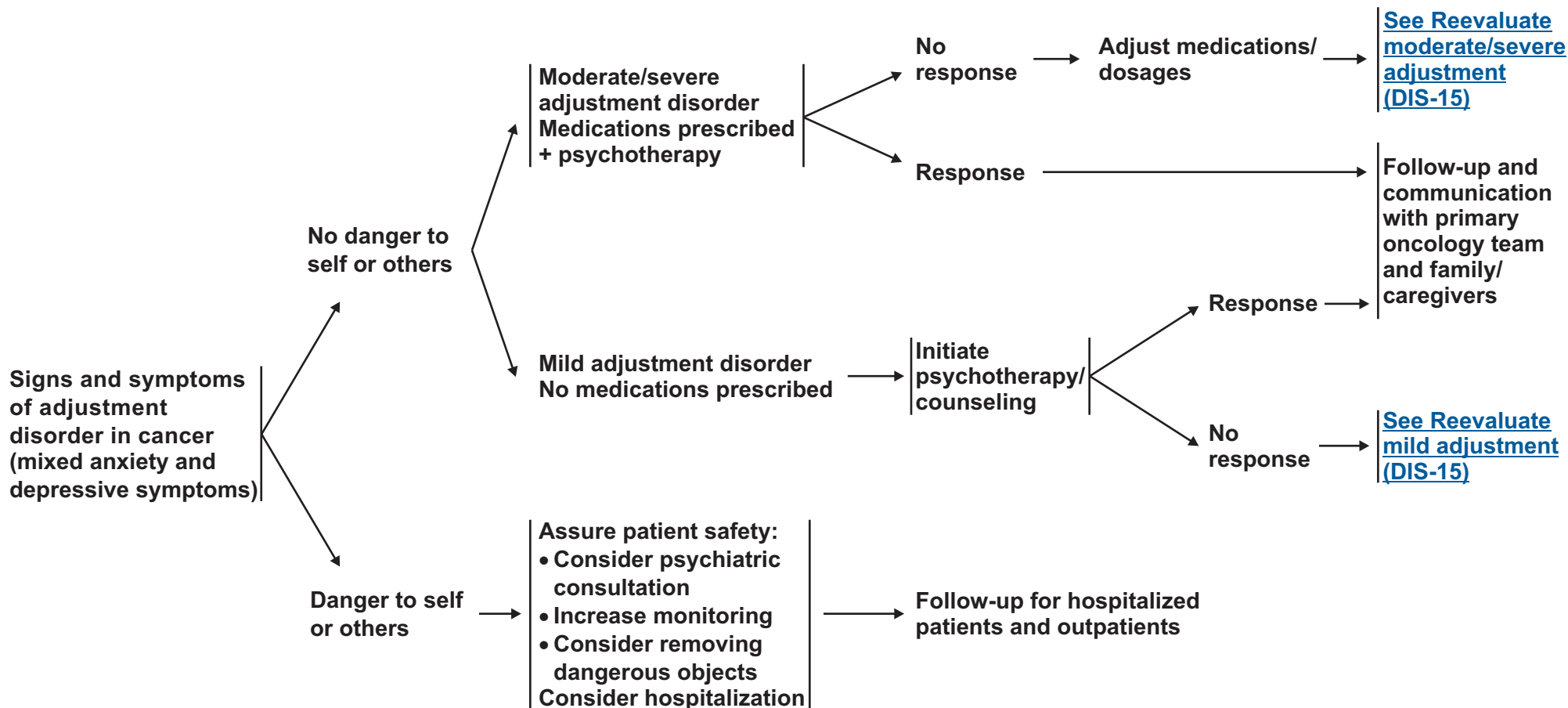
Distress Management

**ADJUSTMENT
DISORDER**
(ICD-10 code: F43.2)

EVALUATION

TREATMENT

FOLLOW-UP



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

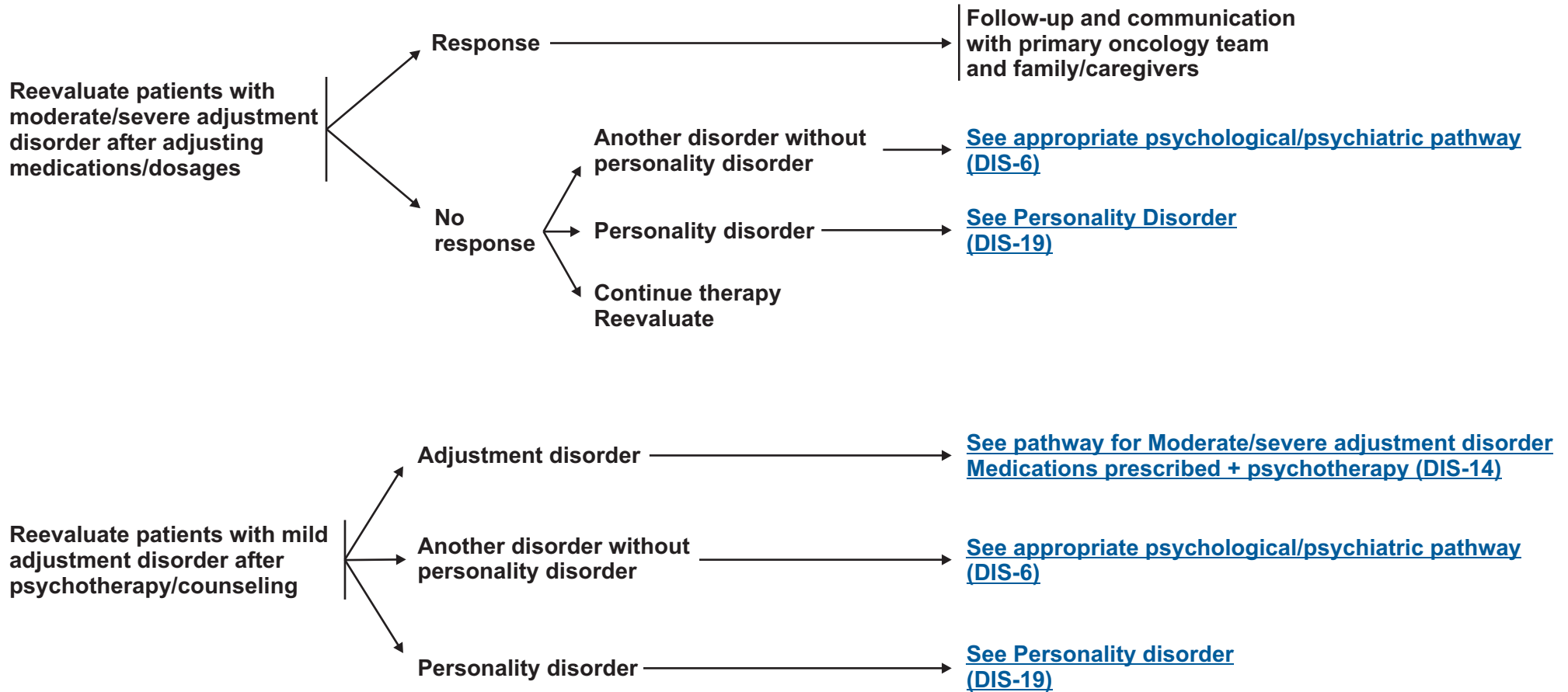
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ADJUSTMENT DISORDER (continued)
(ICD-10 code: F43.2)

FOLLOW-UP



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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Distress Management

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

EVALUATION

TREATMENT

FOLLOW-UP

Signs and symptoms of anxiety disorder in cancer:

- Anxiety due to general medical condition
- Generalized anxiety disorder
- Panic disorder
- Post-traumatic stress disorder
- Phobic disorder
- Conditioned nausea/vomiting ([See NCCN Guidelines for 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)

No response

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

No response

Evaluate for depression and other psychiatric comorbidity

Response

Follow-up and communication with primary oncology team and family/caregivers

Response

[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

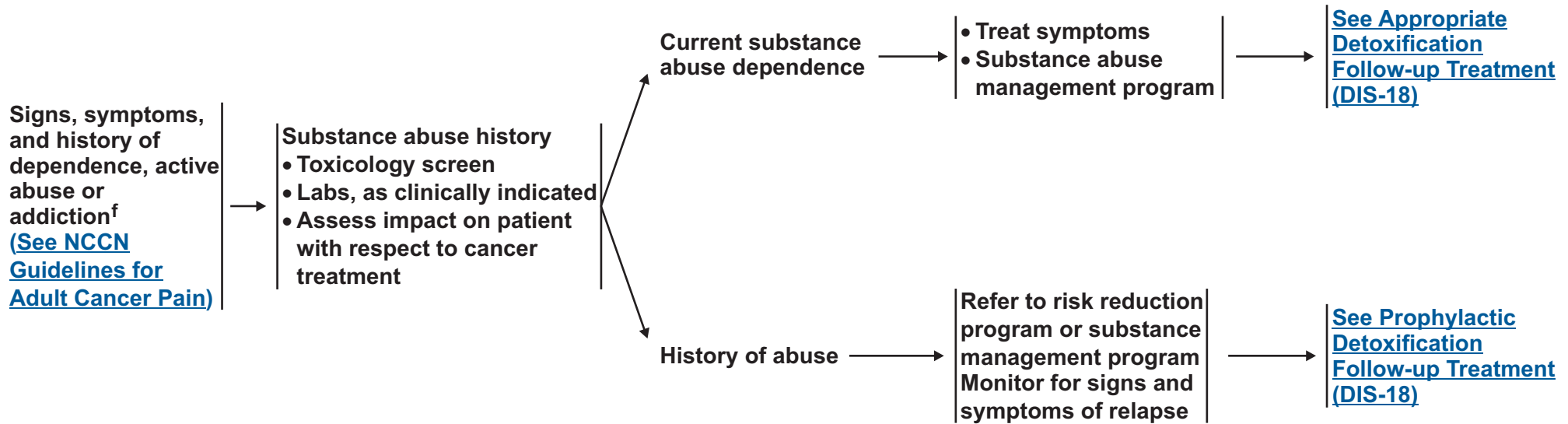
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SUBSTANCE-RELATED EVALUATION
DISORDER/ABUSE
(ICD-10 codes: F09-F19)

TREATMENT



^fOpioids, alcohol, tobacco, or other.

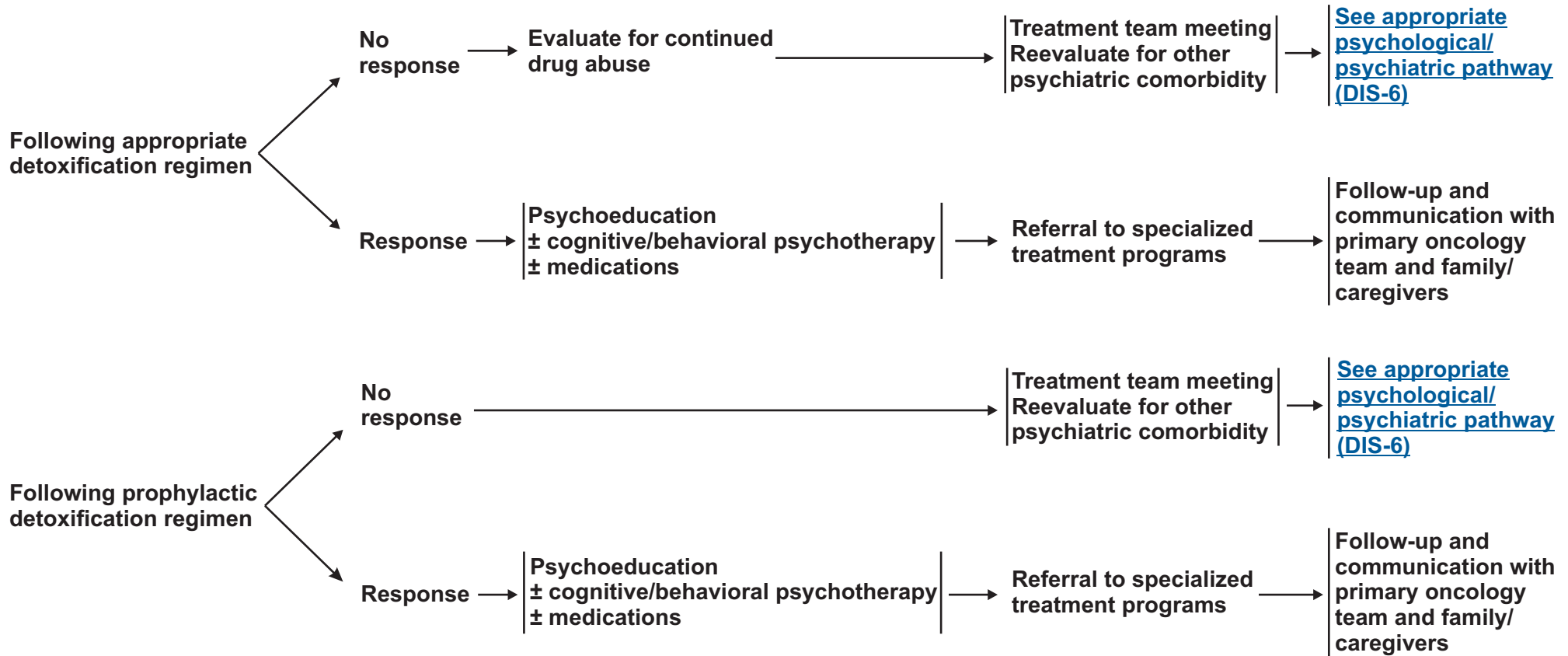
[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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

FOLLOW-UP



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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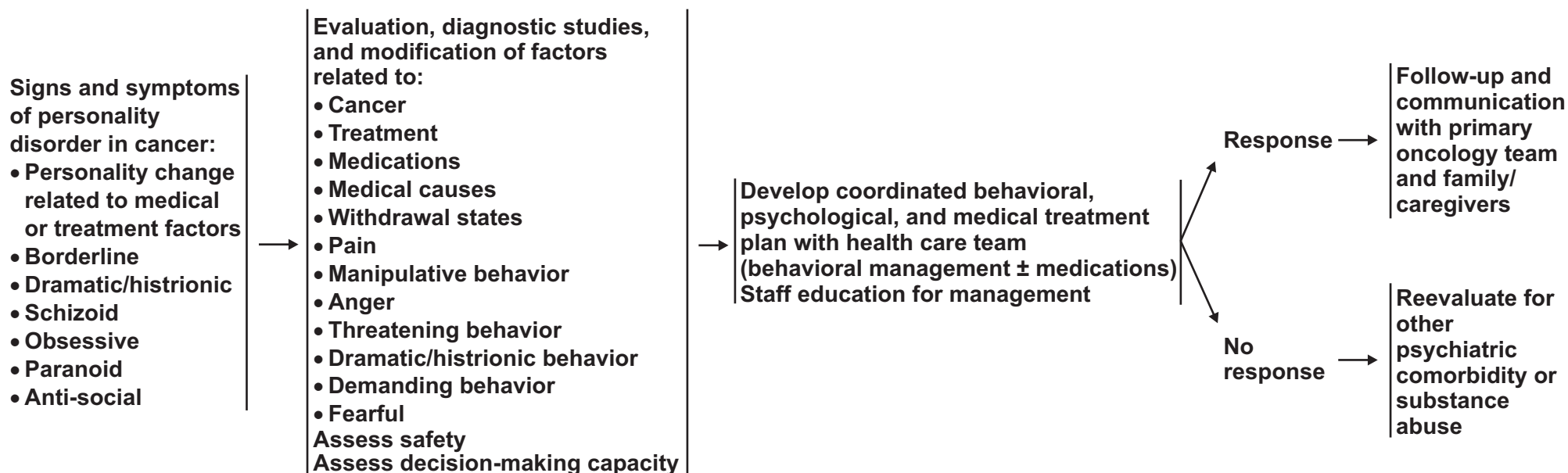
Distress Management

PERSONALITY DISORDER (ICD-10 code: F60)

EVALUATION

TREATMENT

FOLLOW-UP



[Return to Psychological/Psychiatric Guidelines \(DIS-6\)](#)

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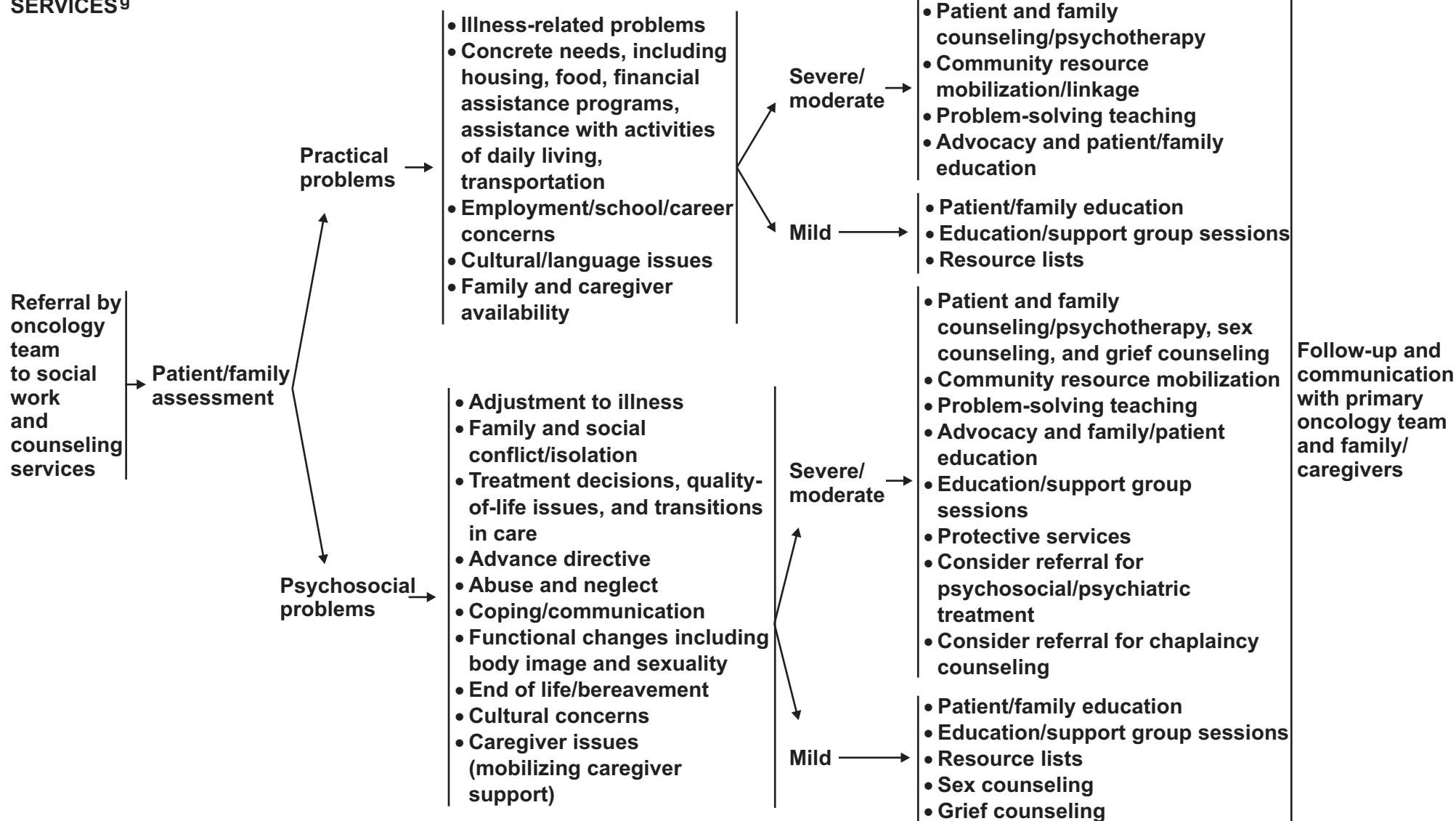
Distress Management

SOCIAL WORK AND COUNSELING SERVICES⁹

CATEGORY

TYPE OF PROBLEM

SOCIAL WORK AND COUNSELING INTERVENTIONS



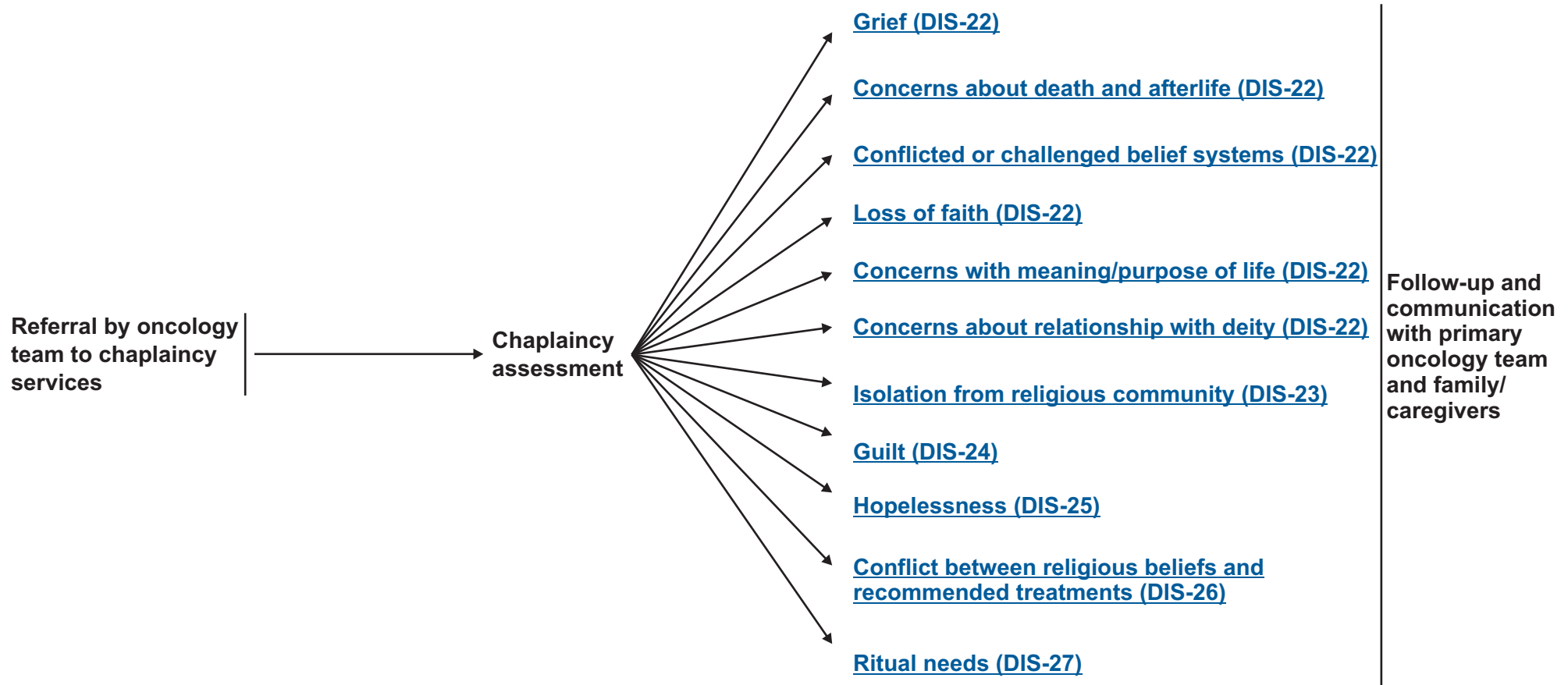
⁹Social work and counseling services include mental health services using psychological/psychiatric treatment guidelines.

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[See NCCN Guidelines for Palliative Care](#)



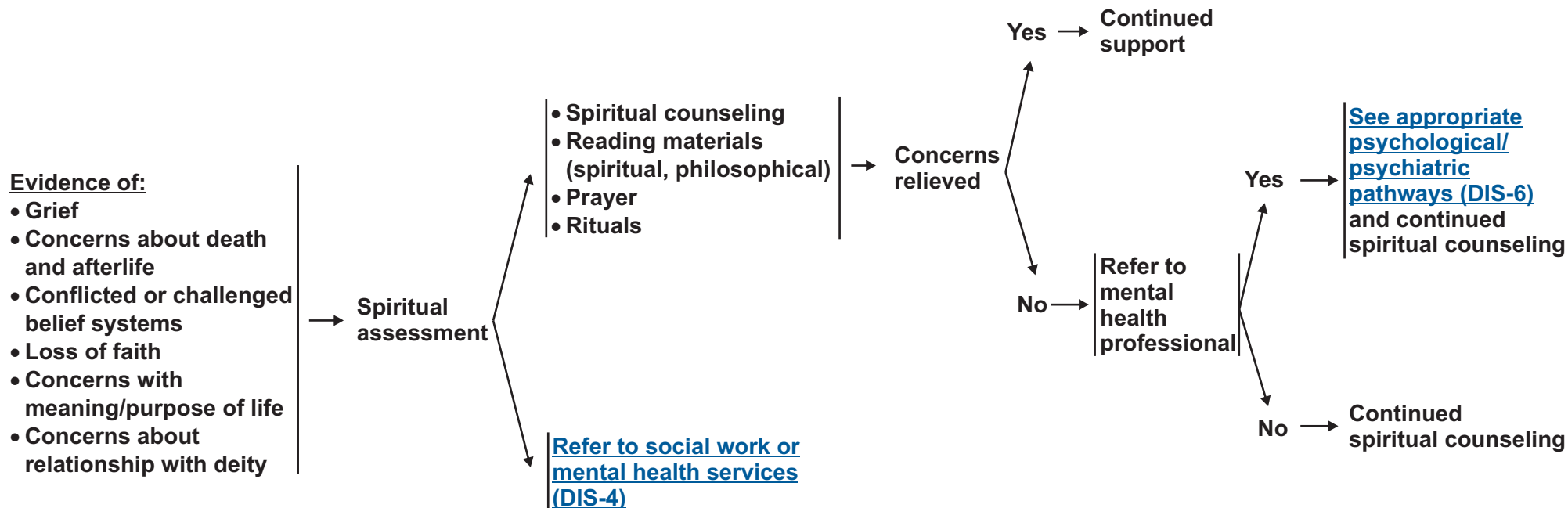
CHAPLAINCY SERVICES



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CHAPLAINCY SERVICES

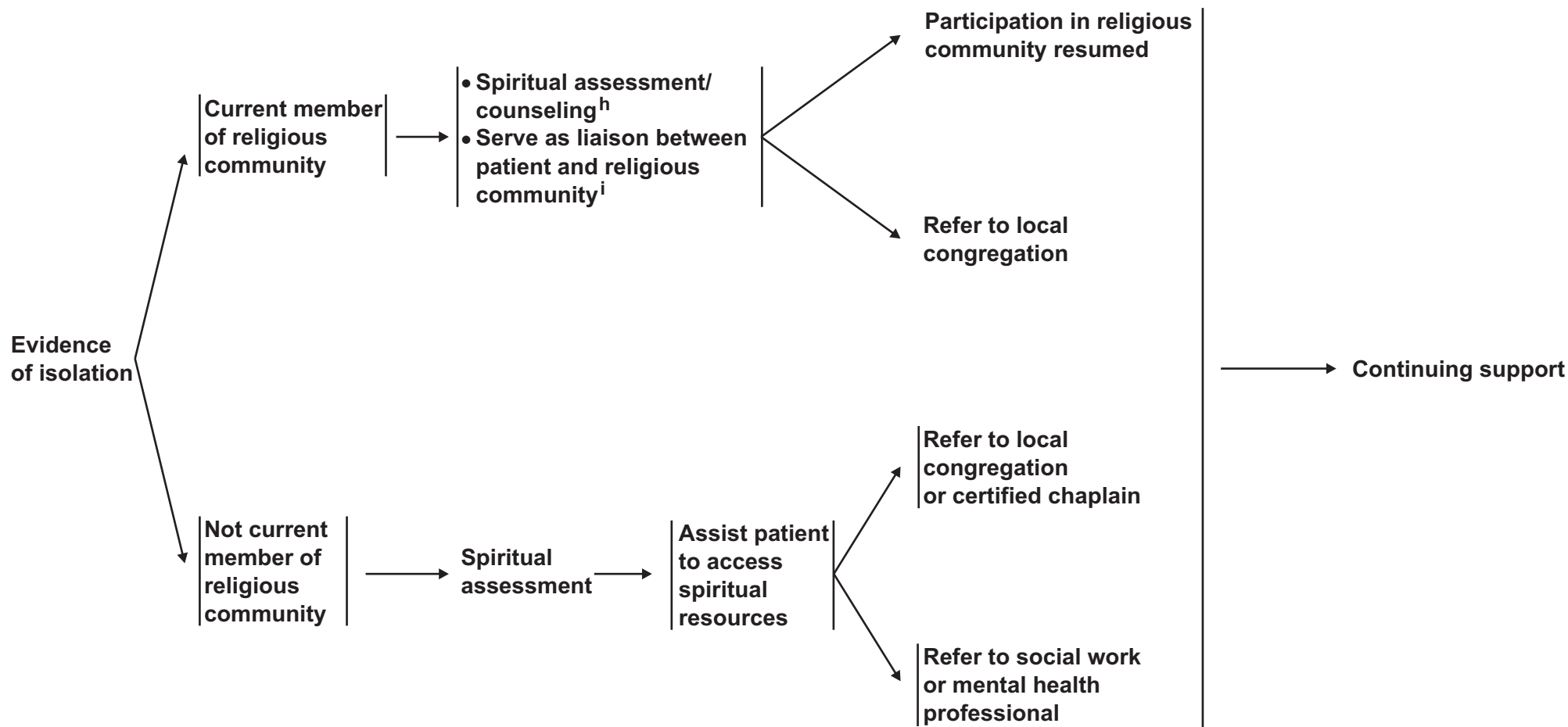


[Return to Chaplaincy Services \(DIS-21\)](#) [See NCCN Palliative Care Guidelines](#)

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CHAPLAINCY SERVICES: ISOLATION FROM RELIGIOUS COMMUNITY



^hReferral to clergy of person's faith.

ⁱPuchalski C; Ferrell B; Birani Ret al. Special Report: Improving the Quality of Spiritual Care as a dimension of Palliative Care: The Report of the Consensus Conference. Journal of Palliative Medicine 2009; 12:885-905.

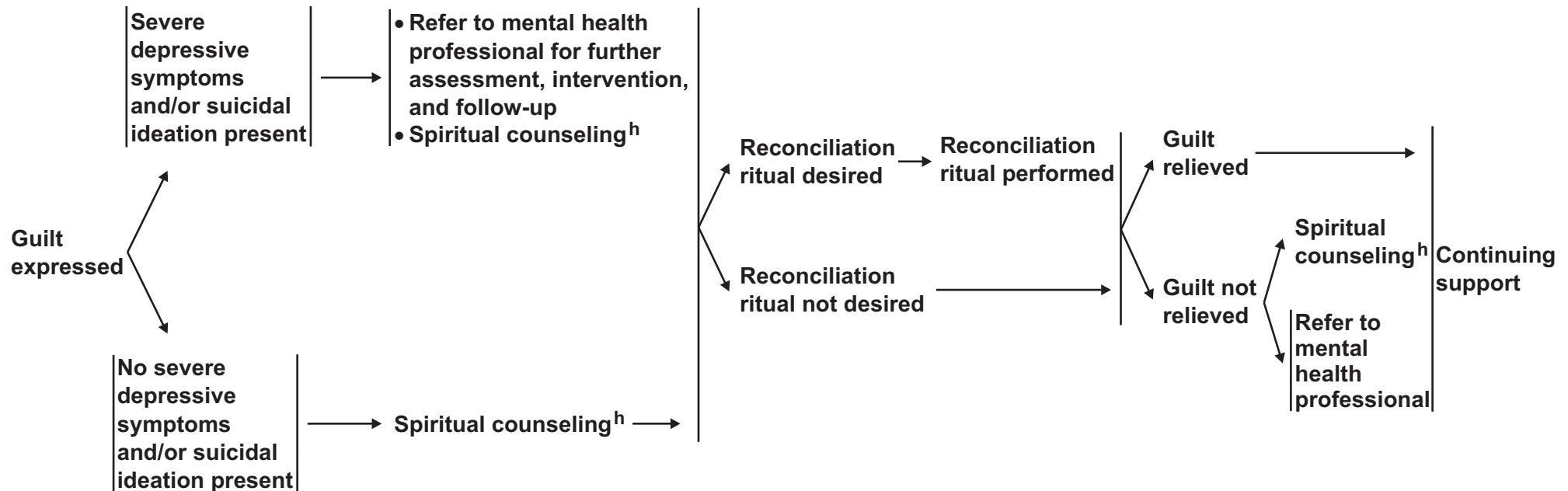
[Return to Chaplaincy Services \(DIS-21\)](#)

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CHAPLAINCY SERVICES: GUILT



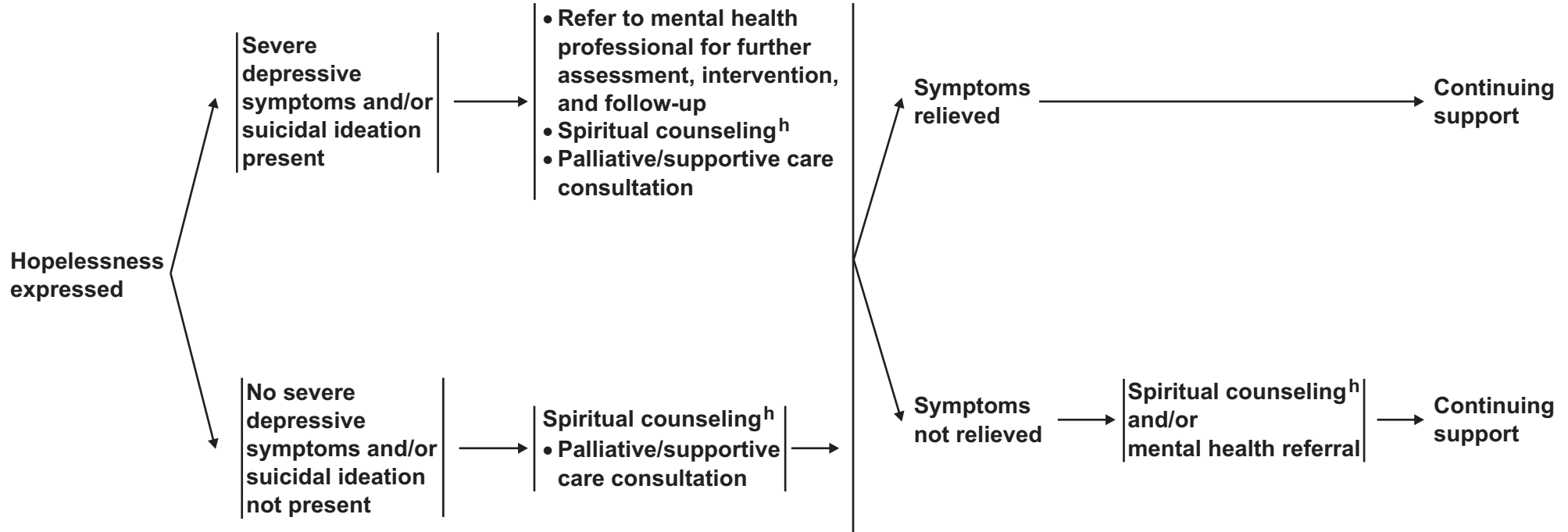
^hConsider referral to community religious resource.

[Return to Chaplaincy Services \(DIS-21\)](#)

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



CHAPLAINCY SERVICES: HOPELESSNESS



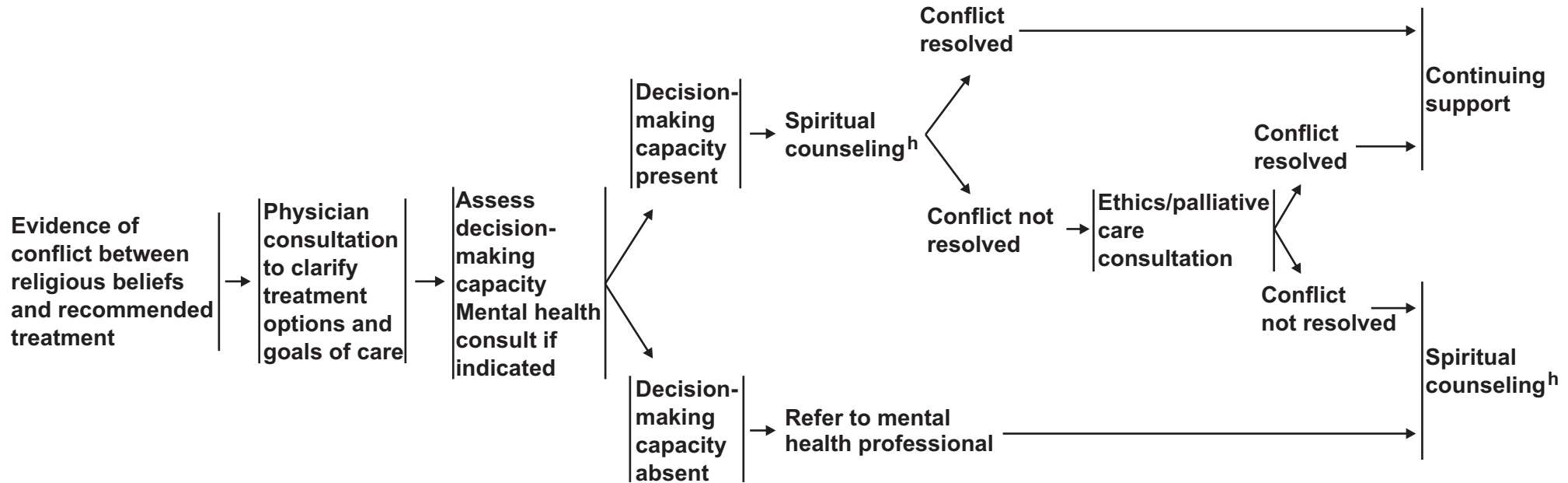
^hConsider referral to community religious resource.

[Return to Chaplaincy Services \(DIS-21\)](#)

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CHAPLAINCY SERVICES: CONFLICT BETWEEN RELIGIOUS BELIEFS AND RECOMMENDED TREATMENTS



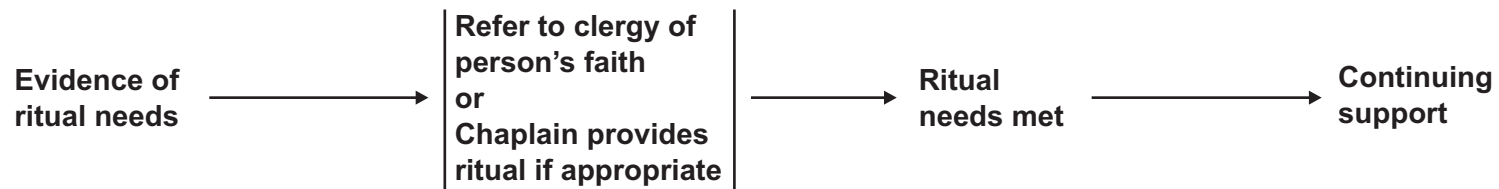
^hConsider referral to community religious resource.

[Return to Chaplaincy Services \(DIS-21\)](#)

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



CHAPLAINCY SERVICES: RITUAL NEEDS



Note: All recommendations are category 2A unless otherwise indicated.

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

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 (continuous quality improvement) 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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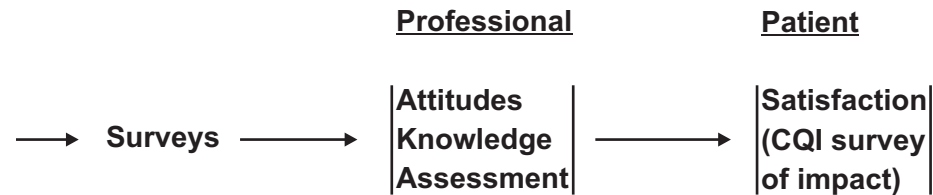


INSTITUTIONAL EVALUATION OF STANDARDS OF CAREⁱ

INTERVENTIONS

- Interdisciplinary committee tailors standards to institutional setting
- Screening tool (0-10) in clinics and inpatient setting
- Problem list
- Education of primary oncology teams via rounds and liaison with nurses and social workers
- Clarification of resources access (psychological, social, religious)
- CQI studies

OUTCOMES



ⁱBased on implementation/evaluation of pain management guidelines.

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NCCN Guidelines Version 2.2013 Distress Management

Discussion

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.

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Overview

In the United States, it is estimated that a total of 1,638,910 new cancer cases and 577,190 deaths from cancer will occur in 2012.¹ All patients experience some level of distress associated with the diagnosis of cancer and the effects of the disease and its 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 Distress Management guidelines 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. These guidelines also provide guidance for social workers, certified chaplains, and mental health professionals that describe treatments and interventions for various psychosocial problems as they relate to patients with cancer.

Psychosocial Problems in Patients with Cancer

In the past two 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.² In addition, the physiologic effects of cancer itself and certain anti-cancer drugs can also be non-psychological contributors to distress symptoms.³⁻⁶ Furthermore, cancer patients may

have pre-existing 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 as well as by patient age. In a study of 4496 cancer patients, Zabora and colleagues reported that the overall prevalence of distress was 35.1%, which varied from 29.6% for patients with gynecological cancers to 43.4% for patients with lung cancer.⁷ The prevalence of distress, depression, and psychiatric disorders has been studied in many sites and stages of cancer.⁸⁻¹⁴ Overall, surveys have found that 20-47% of newly diagnosed and recurrent cancer patients show a significant level of distress. A recent metaanalysis reported that 30-40% of patients with various types of cancer have some combination of mood disorders.¹⁵

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; living alone, having young children, and prior physical or sexual abuse.

Distress is a risk factor for non-adherence to treatment, especially with oral medications. In women with primary breast cancer, Partridge and colleagues 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 due to poor adherence.¹⁶ In a meta-analysis, DiMatteo and colleagues found that noncompliance was 3 times greater in depressed patients as compared to non-depressed patients.¹⁷ 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.^{18,19} Distress in patients with cancer also leads to poorer quality of life and can even negatively impact survival.^{14,20,21} Furthermore, cancer survivors with untreated distress have poorer compliance with surveillance screenings and are less likely to exercise and quit smoking.²²

Early evaluation and screening for distress leads to early and timely management of psychological distress, which in turn improves medical management.^{23,24} 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 month than did screening without personalized triage for referrals.²⁵ Those with the highest level of initial distress benefitted the most. In addition, there is evidence from randomized trials that psychologically effective interventions may lead to a survival advantage in patients with cancer.²⁶ 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

Less than half of distressed patients with cancer are actually identified and referred for psychosocial help.^{27,28} Many patients with cancer 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.²⁹ The need is particularly acute in community oncologists'

practices where there are few to no psychosocial resources, and cancer care is often provided by 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 their diagnosis of cancer due to the stigma attached to the disease. Since the 1970s, this situation has changed and patients are well aware of their diagnosis and treatment options.³⁰ 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 was made by the NCCN when it established a panel to develop clinical practice guidelines, 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 guideline panels,

but the NCCN recognized that many distressed patients prefer a certified chaplain.³¹

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 non-stigmatizing. This led to the first published guidelines in 1999 for the management of *distress* in cancer patients. 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).³²

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).³³

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*.³⁴ The IOM report is based on the pioneering work of the NCCN panel, which recommends screening for distress and the development of a treatment plan with referrals as needed to psychosocial resources.³³ Psychosocial care is now a part of the new standard for quality cancer care and should be integrated into routine care.^{34,35} 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.^{18,36}

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 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.³⁷ The standards of care developed by the NCCN Distress Management panel, which can also be found in the guidelines, are:

- 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 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 whose goal is to advance the recommendations from the IOM report. Their website has hundreds of psychosocial resources for health care professionals, patients, and caregivers, searchable by state.

Recommendations for Implementation of Standards and Guidelines

Jacobsen and colleagues conducted a study in 2005 evaluating the implementation of NCCN Guidelines for Distress Management by 15 NCCN member institutions.³⁸ Eight institutions (53%) conducted routine distress screening of some patient populations and an additional 4 institutions (27%) also preformed pilot testing of screening strategies. However, concordance to 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 and colleagues. They developed a patient chart audit which permits an oncologists' office or clinic to evaluate the quality of their psychosocial care.³⁹ The survey queries whether there is documentation that the patient's current emotional well-being was assessed and if there is



documentation that 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 the American Society of Clinical Oncology (ASCO) as a pilot project (<http://qopi.asco.org/program.html>).⁴⁰ This program became available to all ASCO member medical oncologists in 2006. Jacobson's psychosocial quality indicators were added as part of the core measures in the QOPI quality measures in 2008.⁴¹ In a recent analysis, Jacobson and colleagues reported that practices participating in QOPI demonstrated improved performance, with initially low-performing practices showing the greatest improvement.⁴¹ Blayney and colleagues 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.⁴² The American Psychosocial Oncology Society (APOS) has also adopted these quality indicators.⁴³

The panel encourages the establishment of institutional interdisciplinary committees to implement and monitor distress management. The interdisciplinary committee should be responsible for evaluation of standard care in distress management with continuous quality improvement (CQI) studies. The panel encourages interdisciplinary CQI studies to assess the quality of distress management programs as well as the efficacy of standards of care and implementation of these NCCN Guidelines for Distress Management and the new quality standard established by the IOM report.³⁴ The new CoC accreditation standards for hospital cancer programs include screening all patients with cancer for psychosocial distress, so 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 implement the integration of psychosocial care into clinical care.⁴⁴ The authors outline strategies they used to accomplish the required cultural shift and describe the results of their efforts. Other groups have also described their efforts towards implementing psychosocial screening in various outpatient settings.⁴⁵⁻⁴⁹ Additional guidance for the implementation of the new IOM standards has been published.⁵⁰⁻⁵² In Canada, a national approach has been used to implement screening for distress. Their strategies have been described.⁵³ Groups in Italy and France have also described results of their preliminary efforts toward the implementation of psychosocial distress screening.^{54,55} A reading list for implementation of programs that integrate psychosocial care into the routine care of patients with cancer is provided in these guidelines.

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.⁵² The NCCN Distress Management panel developed such a rapid screening tool, as discussed below.

Screening Tools for Distress and Meeting Psychosocial Needs

Identification of 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

them. 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.⁵⁶⁻⁵⁸ Mitchell and colleagues recently reported that ultra-short methods (PHQ2 or the Distress Thermometer) were acceptable to about three quarters of clinicians.^{59,60} Automated touch-screen technologies have also been used for psychosocial screening of patients with cancer.^{61,62} Recently, an internet-based program that includes distress screening, reporting, referrals, and followup components has been developed. The screening component was validated in a trial of 319 community-based cancer survivors and showed good psychometric properties.⁶³

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

The Distress Thermometer (DT)

The NCCN Distress Management panel developed the distress thermometer (DT), a now well known tool for initial screening, 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 word “distress” was chosen as described above, because it is less stigmatizing and more acceptable to patients and oncologists than other terms such as psychiatric, psychosocial, or emotional. Using this

non-stigmatizing 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 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. If the patient's distress level is mild (score is less than 4 on the DT), the primary oncology team may choose to manage the concerns by usual clinical supportive care management. If the patient's distress level is 4 or higher, the nurse looks at the problem list (see below) 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 DT 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).^{56,65-71} The DT has shown good sensitivity and specificity. The needs assessment surveys performed in ambulatory clinics using these screens show 20-40% of patients have significant levels of distress. Two studies validated a version of the DT with an expanded problems list.^{72,73} Tuinman and colleagues validated the DT with the 46-item problem list in a cross-sectional group of 227 cancer patients.⁷³ Graves and colleagues validated the DT with an adapted problems list with two new problem categories (information concerns and cognitive problems) in lung cancer patients.⁷² The DT is also a useful tool for screening distress among bone marrow transplant patients.^{74,75} The DT had acceptable overall accuracy and greater

sensitivity and specificity when compared to the Center for Epidemiological Studies-Depression Scale (CES-D) in the assessment of depression in patients undergoing bone marrow transplants.⁷⁴

The Problem List

The screening tool developed by the NCCN Distress Management panel includes a 39-item Problem List, which is on the same page with the DT. The Problem List asks patients to identify their problems in five different categories: practical, family, emotional, spiritual/religious, and physical (see Screening Tools for Measuring Distress in the guidelines). The completed list is reviewed by the nurse, because he/she is present at all visits and is the likely person 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, due to both the effects of brain tumors themselves and the effects of treatment targeted to the brain.^{76,77} Recent evidence has shown that chemotherapy-related cognitive dysfunction is also prevalent in patients with non-CNS cancers and without brain metastases.⁷⁸⁻⁸¹ Chemotherapy can cause subtle cognitive changes, studied primarily in breast and lymphoma patients. It can continue over years and at times, 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.⁸² In addition, evidence suggests that cancer itself and therapies other than chemotherapy, such as hormone therapy, can cause cognitive impairments in patients with cancer.⁸³⁻⁸⁶ 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.⁸⁷ 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.^{76,77,88}

There is no standard treatment 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.^{89,90} In addition, some studies have shown that the use of psychostimulants such as methylphenidate and modafinil improved cognitive function in patients with cancer.⁹¹⁻⁹³ Donepezil, a reversible acetylcholinesterase inhibitor (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.⁹⁴ Further placebo controlled trials are needed to confirm these preliminary findings.

In October 2006 the International Cognition and Cancer Task Force (ICCTF), comprised of a multidisciplinary group of health professionals and health advocates, was formed. The mission of ICCTF is to advance understanding of the impact of treatment-related cognitive and behavioral functioning in patients with non-CNS cancers.⁹⁵ ICCTF also has a web site (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.

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.⁹⁶ 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 below in Substance-Related Disorder/Abuse.

Initial Evaluation and Treatment by Oncology Team

The panel recommends that all patients be assessed in the waiting room using a simple screening tool. While there are several types of screening tools, the DT and the accompanying Problem List are recommended to assess the level of distress and to identify causes of distress. If the patient's distress is moderate or severe (thermometer score of 4 or more), the oncology team must recognize that score as a trigger to a second level of questions should prompt referral to a mental health professional, social worker, or spiritual counselor, depending on the problems identified in the Problem List. Common symptoms that require further evaluation are: excessive worries and fears, excessive sadness, unclear thinking, despair and hopelessness, severe family problems, social problems, and spiritual or religious concerns.

Mild distress (DT score of less than 4) is routinely managed by the primary oncology team and represents what the panel terms "expected distress" symptoms. The symptoms that the team manages are fear, 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, poor appetite, and poor concentration; preoccupation with thoughts of illness, death, treatment, and side effects; and concerns about social roles (eg, as mother, father). Most patients experience these symptoms at the time of diagnosis and during arduous treatment cycles. They might persist long after the completion of treatment. For instance, 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 as well as understand the treatment options and side effects.^{97,98} Adequate time should be provided for the patient to ask questions and for the physician to put the patient at ease. When communication is done well at diagnosis, the stage is set for future positive trusting encounters. It is important to ensure that the patient mentally grasps what has been said. Information may be reinforced with drawings or by taping the session and giving the tape to the patient. Communication skills training for oncology professionals who teach, for example, how to discuss prognosis and unanticipated adverse events and how to reach a shared treatment decision may be very helpful. Communication skills training was recently reviewed by Kissane et al.⁹⁹

It is important for the oncology team to acknowledge that this is a difficult experience for the patient and that distress is normal and expected. Being able to express distress to the staff helps provide relief to the patient and builds trust. The team needs to ensure that social supports are in place for the patient and that he or she knows about community resources such as support groups, teleconferences, and



help lines. The IOM report contains a list of national organizations and their toll-free numbers.³⁴ Some selected organizations that provide free information services to cancer patients are:

- American Cancer Society (www.cancer.org)
- American Institute for Cancer Research (www.aicr.org)
- American Psychosocial Oncology Society (www.apos-society.org)
(APOS provides a toll-free Help Line [1-866-276-7443] to which patients and their caregivers can be referred to help them find psychological resources in their community.)
- CancerCare (www.cancer.org)
- National Cancer Institute (www.cancer.gov)
- Cancer.net, sponsored by ASCO (www.cancer.net).
- Cancer Support Community
(<http://www.cancersupportcommunity.org>)

Clinicians should be aware of the evidence-supported interventions available for the management of distress. In addition to these NCCN Guidelines for Distress Management (www.nccn.org), the following clinical practice guidelines will be useful to clinicians, including the oncology team:

- Clinical practice guidelines for the psychosocial care of adults with cancer have been developed by the Australian National Breast Cancer Centre and the National Cancer Control Initiative (<http://www.nhmrc.gov.au/guidelines/publications/cp90>).
- National Cancer Institute and several partners have developed a web site that provides information about research-tested intervention programs (<http://rtips.cancer.gov/rtips/index.do>).

Follow-up at regular intervals or at transition points in illness is an essential part of the NCCN Guidelines for Distress Management and the IOM model for care of the whole patient. This reassessment is particularly important in elderly cancer patients.¹⁰⁰

Psychological/Psychiatric Treatment by Mental Health Professionals

Psychosocial Interventions

Psychosocial interventions have been effective in reducing distress and improving overall quality of life among cancer patients.^{34,35} The 2007 IOM report noted that there is a strong evidence base that supports the value of psychosocial interventions in cancer care.³⁴ The review examined the range of interventions (psychological, social, and pharmacologic) and their impact on any aspect of quality of life, symptoms, or survival. The extensive review found randomized clinical trials, systematic reviews, and meta-analyses supporting the conclusion that psychosocial aspects must be integrated into routine cancer care in order to give quality cancer care. Cognitive-behavioral therapy (CBT), supportive psychotherapy, and family and couples therapy are the three key types of psychotherapies discussed in the IOM report.³⁴

Cognitive-Behavioral Therapy

CBT involves relaxation, enhancing problem-solving skills, and the identification and correction of inaccurate thoughts associated with depressed feelings. In randomized clinical trials, CBT has been shown to effectively reduce psychological symptoms (anxiety and depression)^{101,102} as well as physical symptoms (pain and fatigue)¹⁰³ in patients with cancer. A recent systematic review, however, concluded that data on the efficacy of CBT in patients with advanced cancer is lacking.¹⁰⁴



Ferguson and colleagues have developed a brief CBT intervention (Memory and Attention Adaptation Training [MAAT]) aimed at helping breast cancer survivors manage cognitive dysfunction associated with adjuvant chemotherapy.¹⁰⁵ In this single-arm pilot study, improvements in self reporting 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 since performed a randomized study to evaluate the efficacy of MAAT.⁸⁹ They found that patients in the intervention arm had improved verbal memory performance and spiritual well-being.

Supportive Psychotherapy

Supportive psychotherapy, aimed at flexibly meeting patients' changing needs, is most widely used. Different types of group psychotherapy have been evaluated in clinical trials among cancer patients.

Supportive-expressive group therapy has been shown to improve quality of life and psychological symptoms, especially improvements in mood and pain control in patients with metastatic breast cancer.^{106,107}

Cognitive-existential group therapy has been found to be useful in women with early-stage breast cancer receiving adjuvant chemotherapy.¹⁰⁸ Meaning-centered group psychotherapy, designed to help patients with advanced cancer sustain or enhance a sense of meaning, peace, and purpose in their lives (even as they approach the end of life), has also been shown to reduce psychological distress among patients with advanced cancer.^{109,110} Recently, dignity therapy has been assessed in a randomized controlled trial of patients with a terminal diagnosis (not limited to cancer).¹¹¹ Although there was no significant improvement in levels of distress in patients receiving dignity therapy as measured by several scales, significant improvements,

specifically for depression and self-reported aspects of quality-of-life, were seen.

Family and Couples Therapy

A cancer diagnosis causes distress in partners and family as well as the patient. Psychosocial interventions aimed at patients and their families together might lessen distress more effectively than individual interventions. In a longitudinal study of couples coping with early-stage breast cancer, mutual constructive communication was associated with less distress and more relationship satisfaction for both the patients and partners compared to demand/withdraw communication or mutual avoidance, suggesting that training in constructive communication would be an effective intervention.¹¹²

Family and couples therapy has not been widely studied in controlled trials. A small randomized trial was recently reported in which patients and their caregivers received 8 emotionally focused therapy sessions or standard care.¹¹³ Significant improvements in marital functioning and patient experience of empathetic care by the caregiver were seen. These effects were maintained 3 months after the intervention. In addition, a randomized controlled trial showed that family-focused grief therapy can reduce the morbid effects of grief in families with terminally ill cancer patients.¹¹⁴ A recent systematic review of 23 studies that assessed the efficacy of psychosocial interventions for couples affected by cancer found evidence that couples therapy might be at least as effective as individual therapy.¹¹⁵

Pharmacologic Interventions

Research suggests that antidepressants and anti-anxiety drugs are beneficial in the treatment of depression and anxiety in adult cancer patients.¹¹⁶⁻¹²² In randomized controlled trials, alprazolam^{123,124} (a benzodiazepine) and fluoxetine^{125,126} (a selective serotonin reuptake



inhibitor [SSRI]) have been effective in improving depressive symptoms in cancer patients. SSRIs are widely used for depression and anxiety symptoms.

Psychostimulant drugs help in the management of fatigue.¹²⁷⁻¹²⁹ Methylphenidate is likely effective for the treatment of cancer-related fatigue, but additional trials are needed. Wakefulness-promoting agents such as modafinil are also commonly used to treat fatigue in patients with cancer, but their efficacy remains to be shown conclusively.¹²⁷

Psychological/Psychiatric Treatment Guidelines

Patients scoring 4 or higher on the DT during any visit to the oncologist are referred to the appropriate supportive service (mental health, social work and counseling, or chaplaincy services) based on the identified problem.

Mental health professionals are expected to conduct a psychological or psychiatric evaluation that includes an assessment of the nature of the distress, behavior and psychological symptoms, psychiatric history, use of medications, pain, fatigue, sleep disturbances, other physical symptoms, cognitive impairment, body image and sexuality, and capacity for decision making and physical safety. 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 has developed evaluation and treatment guidelines for the most commonly encountered psychiatric disorders: dementia, delirium (encephalopathy), mood disorder, adjustment disorder, anxiety

disorder, substance abuse-related disorder, and personality disorder. For the 2012 guidelines, the panel developed new guidelines to address psychotic disorder and schizophrenia. Psychotropic drugs are recommended throughout the guidelines to treat psychiatric disorders. It is important to note that these drugs can sometimes interact with anticancer therapies and cause adverse effects. A recent article reviews some of these interactions and discusses other challenges in treating cancer in patients with severe mental illness.¹³⁰

Dementia and Delirium

Dementia and delirium are cognitive impairments that can severely impair the patient's decision-making capacity. Dementia is a permanent cognitive impairment. It is not a common complication of cancer treatment, but is often present in elderly patients as a comorbid condition.^{131,132} Dementia can be treated with cognitive rehabilitation, with or without medications, though treatment is largely management of behavior. Delirium is a short-term cognitive impairment. It is usually reversible and occurs in cancer treatment related to any toxic state, and it often related to medication, particularly opioids.¹³³ Delirium is managed by attention to safety, modification of opioids or other medications, neuroleptics, and family support and education.¹³⁴ The United Kingdom's National Institute for Health and Clinical Excellence (NICE) issued detailed guidelines for the diagnosis, prevention, and management of delirium.¹³⁵ In addition, a recent comprehensive review in *The Journal of Clinical Oncology* Special Series on Psychosocial Care in Cancer by Breitbart and Alici¹³⁶ describes the evidence base for recommended pharmacologic and non-pharmacologic treatments for delirium in patients with cancer.



Mood and Adjustment Disorders

Mood disorders such as depression and adjustment disorder (mixed anxiety and depressive symptoms) are common in patients with cancer and can be debilitating. Patients with uncontrolled mood and adjustment disorders can develop suicidal tendencies. The incidence of suicide among cancer patients in the United States is twice that of the general population.¹³⁷⁻¹³⁹ Older patients and men with head and neck cancer or myeloma seem to have a higher risk of suicide.¹⁴⁰

Mood disorder is usually managed with psychotherapy or an antidepressant with or without anxiolytics. The evidence for these treatments has been described.^{35,141-143} In particular, a recent review by Li et al¹⁴⁴ in *The Journal of Clinical Oncology* Special Series on Psychosocial Care in Cancer comprehensively describes the evidence for recommended pharmacologic and psychosocial interventions for treating depression in patients with cancer. Referral to social work and counseling services and chaplaincy services may also be considered. Patients considered a danger to themselves or others should be considered for psychiatric consultation. Increased monitoring is also warranted, and the removal of dangerous objects should be considered. Psychiatric treatment and hospitalization may sometimes be necessary.

Anxiety Disorder

Anxiety occurs at times in most patients with cancer.¹⁴⁵ The diagnosis of cancer and the effects of the disease and its treatment are obvious sources of unease; however, anxiety may also be related to physiological aspects of the medical condition (eg, hormone-secreting tumors; effects of certain types of medications [bronchodilators]; withdrawal from alcohol or narcotics; pain or some other distressing physical symptom). Anxiety may not be severe or problematic, but

needs to be addressed when it becomes disruptive. After ruling out medical causes, the clinician should assess symptoms to determine the particular nature of the anxiety disorder(s). Generalized anxiety disorder is usually pre-existing and may be exacerbated by illness. Panic disorder may recur during illness in a person with previous panic symptoms. Post-traumatic stress disorder may develop after arduous cancer treatments or during a cancer treatment that triggers a traumatic memory of a past frightening event. Obsessive-compulsive disorder is a pre-existing disorder that results in difficulty in making decisions, ruminative thoughts about illness, and fearfulness to take medication. Some patients develop phobias of needles, hospitals, and blood or conditioned nausea/vomiting related to chemotherapy. Chemotherapy-induced nausea and vomiting should be managed according to the NCCN Guidelines for Antiemesis.

The NCCN Distress Management Panel recommends psychotherapy with or without an anxiolytic and/or an antidepressant for the treatment of anxiety (category 1), after eliminating medical causes. If the anxiety responds to initial treatment, follow-up should occur with the primary oncology team and family/caregivers. If no response is noted, the patient should be re-evaluated and treated with different medications (a neuroleptic should be considered) with continued psychotherapy, support, and education. If there is still no response, then the patient should be evaluated for depression and other psychiatric comorbidity.

The evidence for the effectiveness of these treatments has been reviewed.^{34,35} In a recent review in *The Journal of Clinical Oncology* Special Series on Psychosocial Care in Cancer, Traeger et al¹⁴⁶ give a comprehensive description of the evidence for recommended pharmacologic and non-pharmacologic treatments for anxiety in patients with cancer.

Substance-Related Disorder/Abuse

Substance abuse is rare among cancer patients who do not have a history of active abuse or addiction to opioids, alcohol, or tobacco. Substance abuse or dependence developing during the course of the treatment may be due to insufficient symptom control and can be treated by improving symptom control. In patients with a history of substance abuse, its impact on cancer treatment should be assessed. After appropriate detoxification regimens, psychoeducation should be provided with or without cognitive-behavioral psychotherapy and with or without medication. Referral should be made to risk reduction, substance abuse management, or specialized treatment programs as needed. Patients with a history of substance abuse should be monitored for signs and symptoms of relapse.

Personality Disorder

Patients with cancer may have a pre-existing personality disorder, which can be exacerbated by the stress of cancer and its treatment.¹⁴⁷ When a personality disorder is suspected, the patient should be evaluated by a mental health professional, and safety and decision-making capacity should be assessed. If possible, any medication or other factors that could be aggravating the condition should be modified. A coordinated behavioral, psychological, and medical treatment plan, with or without medication, should be developed with the health care team.

Psychotic Disorder and Schizophrenia

Psychotic disorder includes hallucinations, delusions, and/or thought disorders; patients with recurrent psychotic episodes have schizophrenia. Psychotic disorder and schizophrenia can exist as comorbidities in patients with cancer and can also be caused or exacerbated by cancer and its associated stress and treatment. In

particular, steroids or steroid withdrawal can induce psychosis, which may be relieved by modifying dose or changing steroid choice.^{148,149} When a patient in a long-term psychiatric facility develops cancer, there is a need for coordination of care between the psychiatric facility and the inpatient cancer facility. Special attention should be paid to the transition of a psychiatric patient who needs inpatient oncology care. The issues around continuation of psychotropic medications, when they must be stopped for surgery or chemotherapy and when they should be restarted, are important issues in total care.

When a psychotic episode occurs in a patient with cancer, differential diagnoses must be ruled out. Delirium is often confused with psychotic disorder and is much more common; dementia, mood disorder, and substance abuse/withdrawal should also be considered. When psychotic disorder or schizophrenia is diagnosed, several interventions can be considered: 1) anti-psychotic medication, 2) medication for mood, 3) transfer to a psychiatric unit/hospital, and 4) electroconvulsive therapy (ECT) for psychotic depression/mania or catatonia.

In ECT, electrical currents are passed through the brain in a controlled fashion, inducing a brief seizure. ECT appears to be an effective treatment of psychotic depression, mania, catatonia, and other psychiatric disorders.¹⁵⁰⁻¹⁵⁴ Although the use of ECT in cancer has not been well studied, several case studies suggest that it can be safe and effective.¹⁵⁵⁻¹⁵⁹

Social Work and Counseling Services

Social work and counseling services are recommended when a patient has a psychosocial or practical problem. Practical problems are illness-related concerns; concrete needs (eg, 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; concerns about advance directives; domestic abuse and neglect; poor coping or communication skills; concerns about functional changes (eg, body image, sexuality); and issues pertaining to end of life and bereavement (including cultural and caregiver concerns).

Social workers intervene in mild psychosocial problems by using patient and family education, support groups, and/or sex or grief counseling and by 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 and Chaplaincy Services

Many patients use their religious and spiritual resources to cope with illness¹⁶⁰; many cite prayer as a major help. In addition, the diagnosis of cancer can cause an existential crisis, making spiritual support of critical importance. Balboni et al¹⁶¹ surveyed 230 patients with advanced cancer treated at multiple institutions who had failed to respond to first-line chemotherapy. The majority of patients (88%) considered religion as 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.¹⁶¹ Importantly, patients receiving spiritual support reported a higher quality of life. Religiousness and spiritual support have also been associated with improved satisfaction with medical care. Astrow et al¹⁶² found that 73% of patients with

cancer had spiritual needs, and that patients whose spiritual needs were not met reported lower quality of care and lower satisfaction with their care. A recent multi-institution study of 75 patients with cancer and 339 oncologists and nurses (the Religion and Spirituality in Cancer Care Study) found that spiritual care had a positive effect on patient-provider relationships and the emotional well-being of patients.¹⁶³

The panel has included chaplaincy services as part of psychosocial services. 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. 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, conflict between beliefs and recommended treatments, and ritual needs.

The certified chaplain evaluates the problem and may offer spiritual or philosophical reading materials, spiritual advice and guidance, prayer, and/or rituals. For patients who are members of a religious community, the certified chaplain could also serve as a liaison between the patient and the religious community or assist the patient to access spiritual resources. Some patients may be referred for social work and counseling or mental health services if the problems indicate a need for more than spiritual counseling. In addition, patients whose concerns are not allayed may be referred for mental health evaluation while continuing to receive spiritual counseling if they wish. In particular, patients who experience guilt or hopelessness should also be evaluated by mental health professionals for further assessment since they may also have severe depressive symptoms or suicidal ideations.

A palliative/supportive care consultation can also be important in patients who express hopelessness.

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 the integration of spiritual care into the patient's overall treatment plan.¹⁶⁴ The inclusion of a certified chaplain in the interdisciplinary team is critical for the implementation of spiritual care into routine clinical practice.

The following guidelines on religion and spirituality in cancer care may 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. Spiritual, Religious, and Existential Aspects of Care are included as 1 of the 8 clinical practice domains in these guidelines: <http://www.nationalconsensusproject.org/guideline.pdf>.
- The National Cancer Institute's comprehensive cancer information database (PDQ) has information on "Spirituality in Cancer Care" for patients (<http://www.cancer.gov/cancertopics/pdq/supportivecare/spirituality/Patient>) and for health care professionals (<http://www.cancer.gov/cancertopics/pdq/supportivecare/spirituality/HealthProfessional>).

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.¹⁶⁵ 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 of 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://jco.ascopubs.org/content/30/11.toc>), demonstrating that this topic is now getting the attention it has so long deserved. The Special Series includes a review by Jacobsen and Wagner 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.¹⁶⁶ Integral to the successful integration of psychosocial care into routine cancer care is a distress screening program. In the Special Series, Carlson et al⁵⁰ present their recommendations for implementing such a program, and Fann et al⁵¹ 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, both by health care professionals and by the public.¹⁶⁷ The Special Series includes reviews of evidence-based

interventions for 3 common psychosocial problems in patients with cancer: depression, anxiety, and delirium.^{136,144,146}

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 (AYA) and adult cancer survivors.^{168,169} An article on the psychosocial needs of care givers is also included.¹⁷⁰

In addition, an article was included on ‘oncologist burnout,’ a problem with an estimated prevalence of 28% to 38%, depending on medical specialty.¹⁶⁵ 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.⁹⁹ Patient benefit from such training (ex, 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 cancer patients. Treating distress in cancer benefits the patients and their families/caregiver as well as the treating staff and helps improve the efficiency of clinic operations. For patients with cancer, integration 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.¹⁷¹ 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 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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