National Comprehensive Cancer Network®

NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines™)

Distress Management

Version 1.2011

NCCN.org

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NCCN Guidelines™ Version 1.2011 Panel Members
Distress Management

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Discussion

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Distress Management

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For End of Life Issues, See the NCCN Palliative Care Guidelines

For Cancer Pain, See the NCCN Cancer Pain Guidelines

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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

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NCCN Guidelines™ Version 1.2011 Updates
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Updates in Version 1.2011 of the NCCN Guidelines from Version 1.2010 include:

DIS-4
- **Under Evaluation: "Social problems" was added.**
- **"Social Work Services" changed to "Social Work and Counseling Services" throughout the guidelines.**

DIS-A
- **Practical Problems: "Treatment decisions" was added.**
- **Family Problems: "Family health issues" was added.**

DIS-B
- **Patients at increased risk for distress: "Uncontrolled symptoms" was added.**

DIS-10
- **Second column: "Suicidal risk" changed to "Danger to self or others". (Also for DIS-12)**
- **Treatment: "Antidepressant ± anxiolytic + psychotherapy" changed so that "Psychotherapy" is now listed as a separate option.**

DIS-20
- **After "Spiritual assessment": "Reconciliation rituals" changed to "Rituals".**

DIS-21
- **After "Current member of religious community": "Serve as liaison between patient and religious community" was added.**

DIS-22
- **Placement of "Spiritual counseling" was moved for clarity. (Also for DIS-23)**

DIS-27
- **Interventions; Second bullet: Changed to "Screening toll (0-10) in clinics and inpatient setting".**

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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.**

Definition of Distress in Cancer (DIS-2)

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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

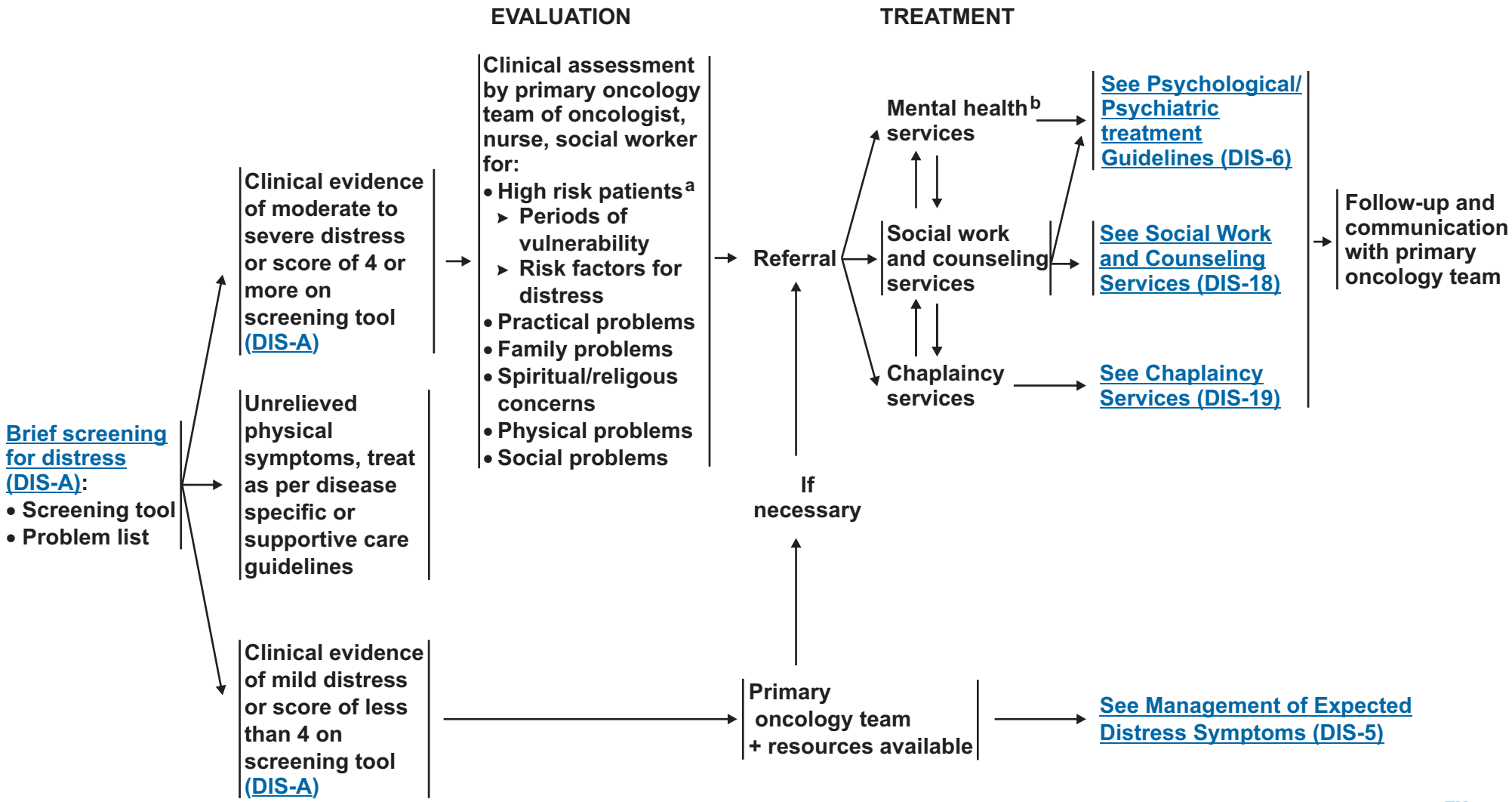
- **Distress should be recognized, monitored, documented, and treated promptly at all stages of disease and in all settings.**
- **Screening should identify the level and nature of the distress.**
- **All patients should be screened for distress at their initial visit, at appropriate intervals, and as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



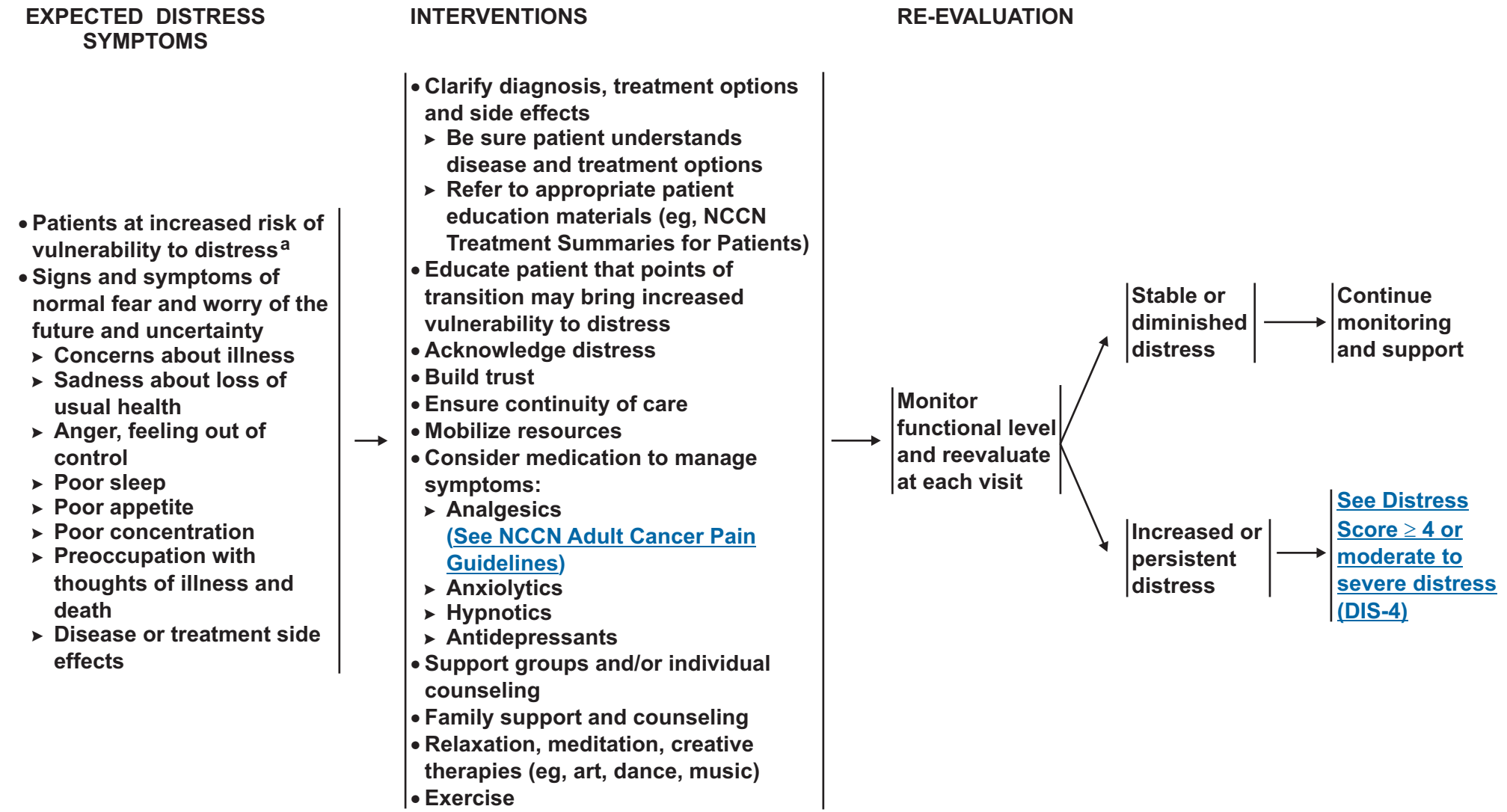
[a] See Psychosocial Distress Patient Characteristics (DIS-B).
[b] Psychiatrist, psychologist, advanced practice clinicians, social worker and certified chaplain.

Refer to NCCN Guidelines™ Table of Contents for Supportive Care Guidelines.

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

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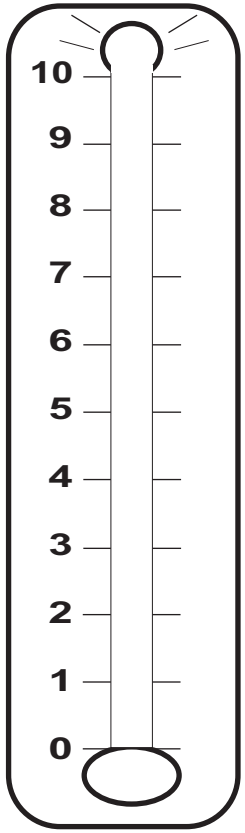
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SCREENING TOOLS FOR MEASURING DISTRESS

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

YES	NO	Family Problems
❑	❑	Dealing with children
❑	❑	Dealing with partner
❑	❑	Ability to have children
❑	❑	Family health issues

YES	NO	Emotional Problems
❑	❑	Depression
❑	❑	Fears
❑	❑	Nervousness
❑	❑	Sadness
❑	❑	Worry
❑	❑	Loss of interest in usual activities

YES	NO	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
❑	❑	Tingling in hands/feet

Other Problems: _____

_____

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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 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
- Uncontrolled symptoms

PERIODS OF INCREASED VULNERABILITY

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

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

[d] From the NCCN Palliative Care Clinical Practice Guidelines in Oncology. Available at www.nccn.org.

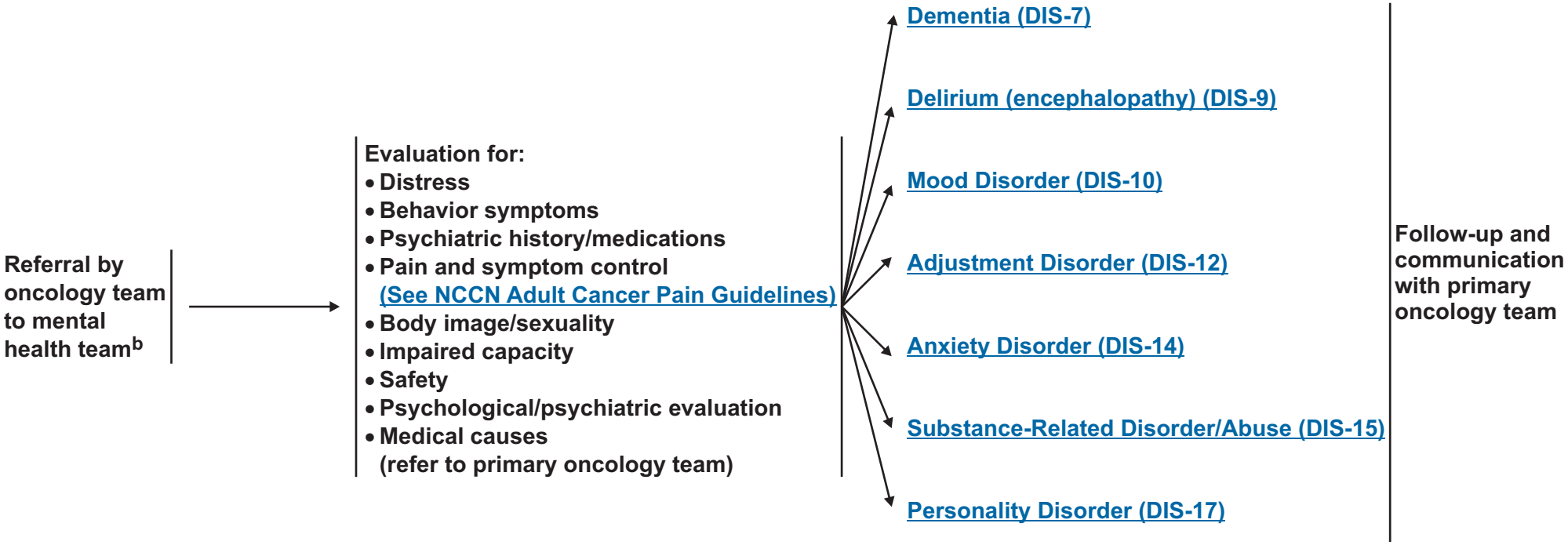
[e] Communication barriers include language, literacy, and physical barriers.

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PSYCHOLOGICAL/PSYCHIATRIC TREATMENT GUIDELINES



[b] Psychiatrist, psychologist, advanced practice clinicians, social worker and certified chaplain.

For End of Life Issues, See NCCN Palliative Care Guidelnes

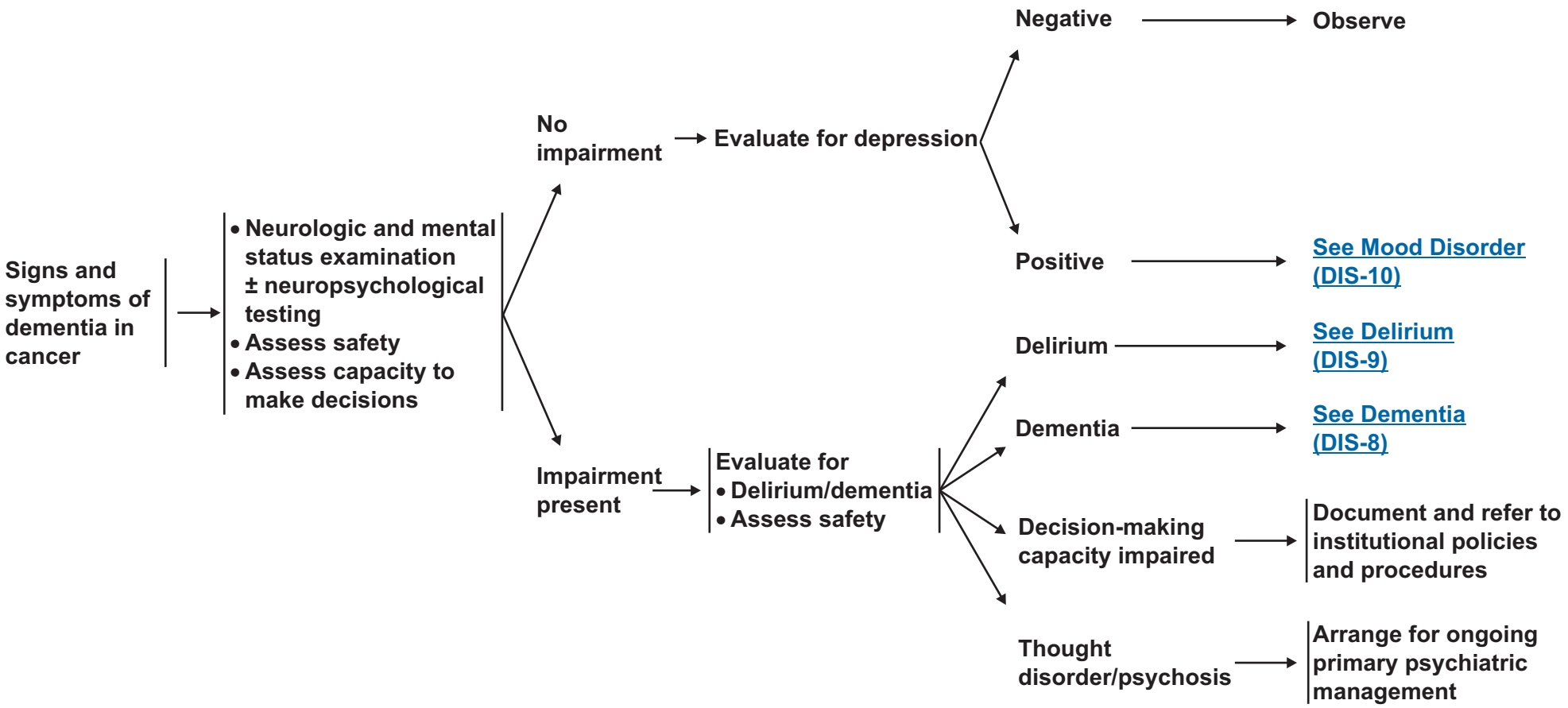
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DEMENTIA
(ICD-10 codes: F00-F03)

EVALUATION



Return to Psychological/Psychiatric Guidelines (DIS-6)

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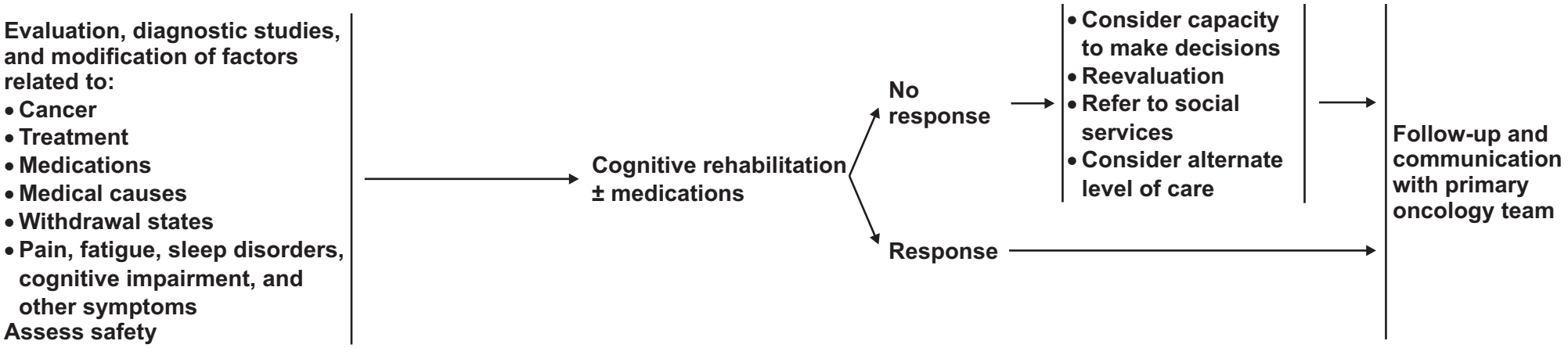
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DEMENTIA (continued)
(ICD-10 codes: F00-F03)

TREATMENT

FOLLOW-UP



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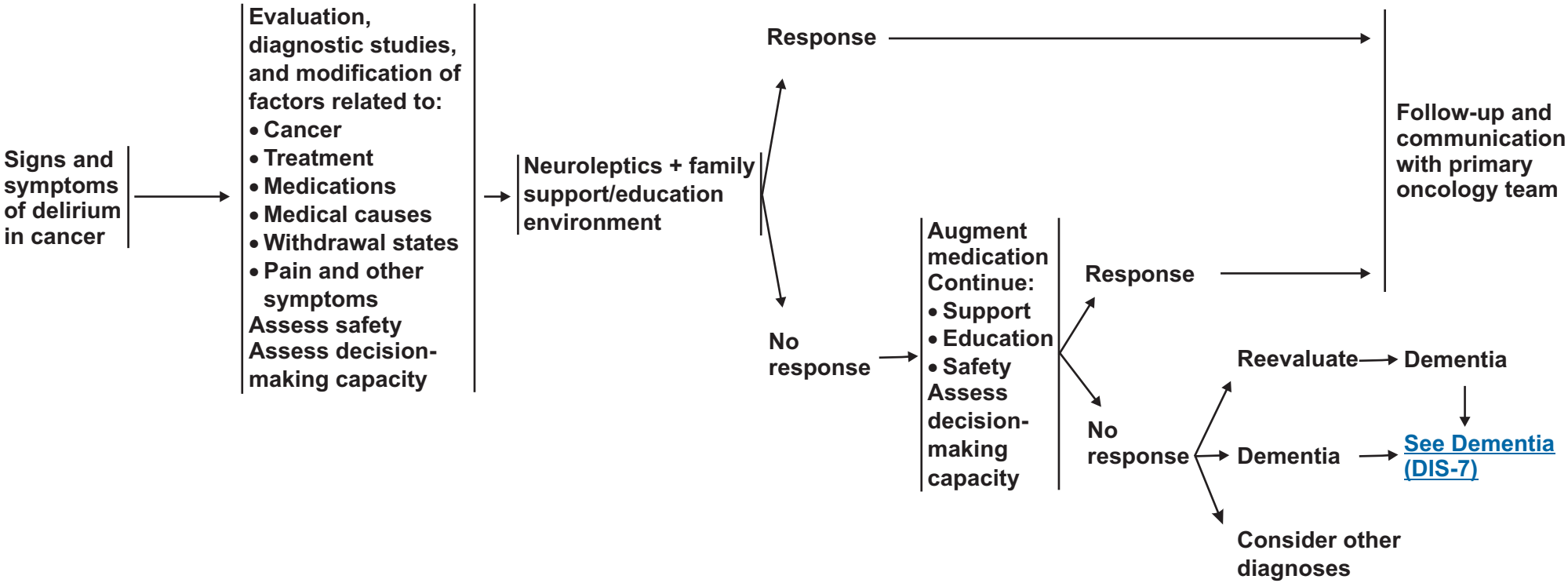
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DELIRIUM (Encephalophathy) (ICD-10 code: F05)

EVALUATION

TREATMENT

FOLLOW-UP



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

Signs and symptoms of mood disorders in cancer:
- Mood disorder related to medical illness
- Major depression
- Dysthymia
- Bipolar disorder

No danger to self or others →

EVALUATION

Evaluation, diagnostic studies, and modification of factors related to:
- Cancer
- Treatment
- Medications
- Medical causes
- Withdrawal states
- Pain
- Fatigue
- Insomnia
- Anorexia
- Anhedonia
- Decreased interest in activities
- Wish to die
- Suicidal thoughts
- Mood swings

Consider psychosocial and spiritual concerns
Assess decision-making capacity
Assess safety

TREATMENT

- Psychotherapy
- Antidepressant (category 1) ± anxiolytic

No/partial response → See Mood Disorder (DIS-11)

Response → Follow-up and communication with primary oncology team

- Psychiatric follow-up for hospitalized patients and outpatients
- Consider referral to social work services or chaplaincy services See Social work and Counseling services (DIS-18) or Chaplaincy services (DIS-19)

Danger to self or others →

Assure patient safety:
- Increase monitoring
- Consider removing sharp objects
- Consider psychiatric consultation

Consider hospitalization

→ Psychiatric treatment and follow-up for hospitalized and outpatients

FOLLOW-UP

Return to Psychological/Psychiatric Guidelines (DIS-6)

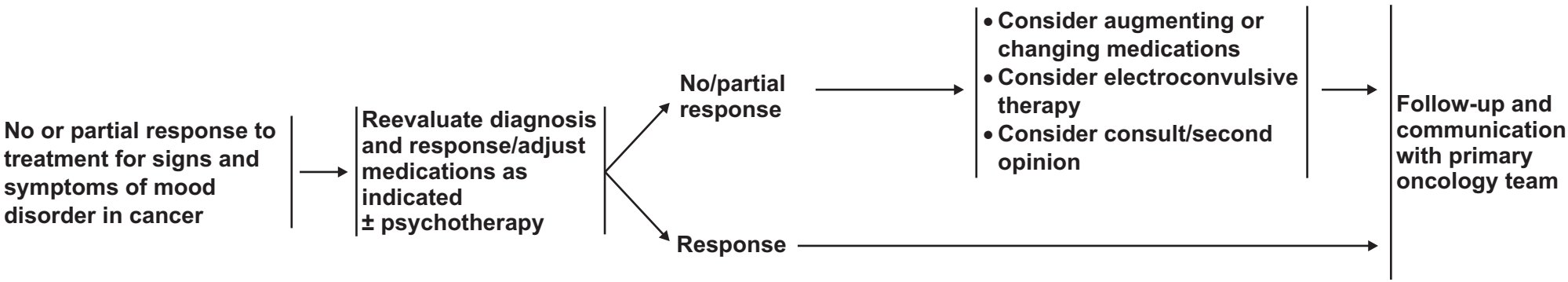
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MOOD DISORDER (continued)
(ICD-10 codes: F34, F38, F39)

EVALUATION | **TREATMENT** | **FOLLOW-UP**



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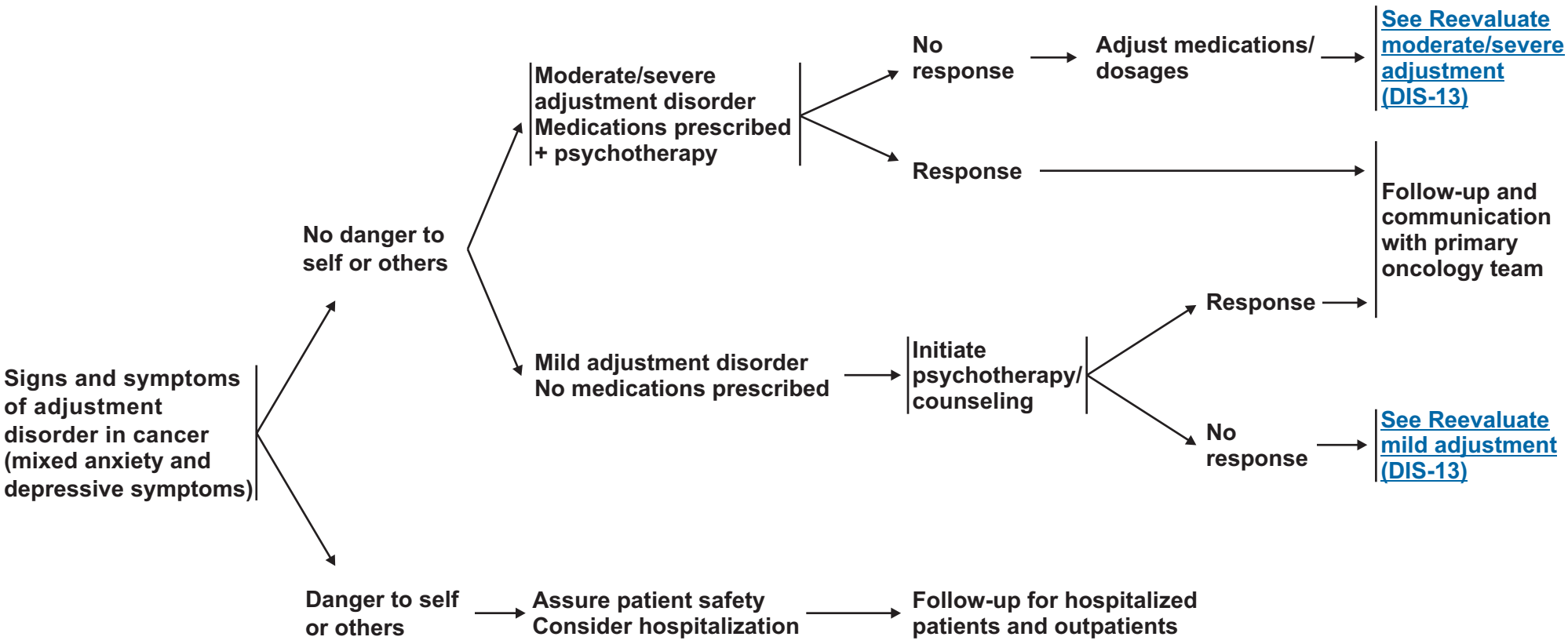
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ADJUSTMENT DISORDER (ICD-10 code: F43.2)

EVALUATION

TREATMENT

FOLLOW-UP



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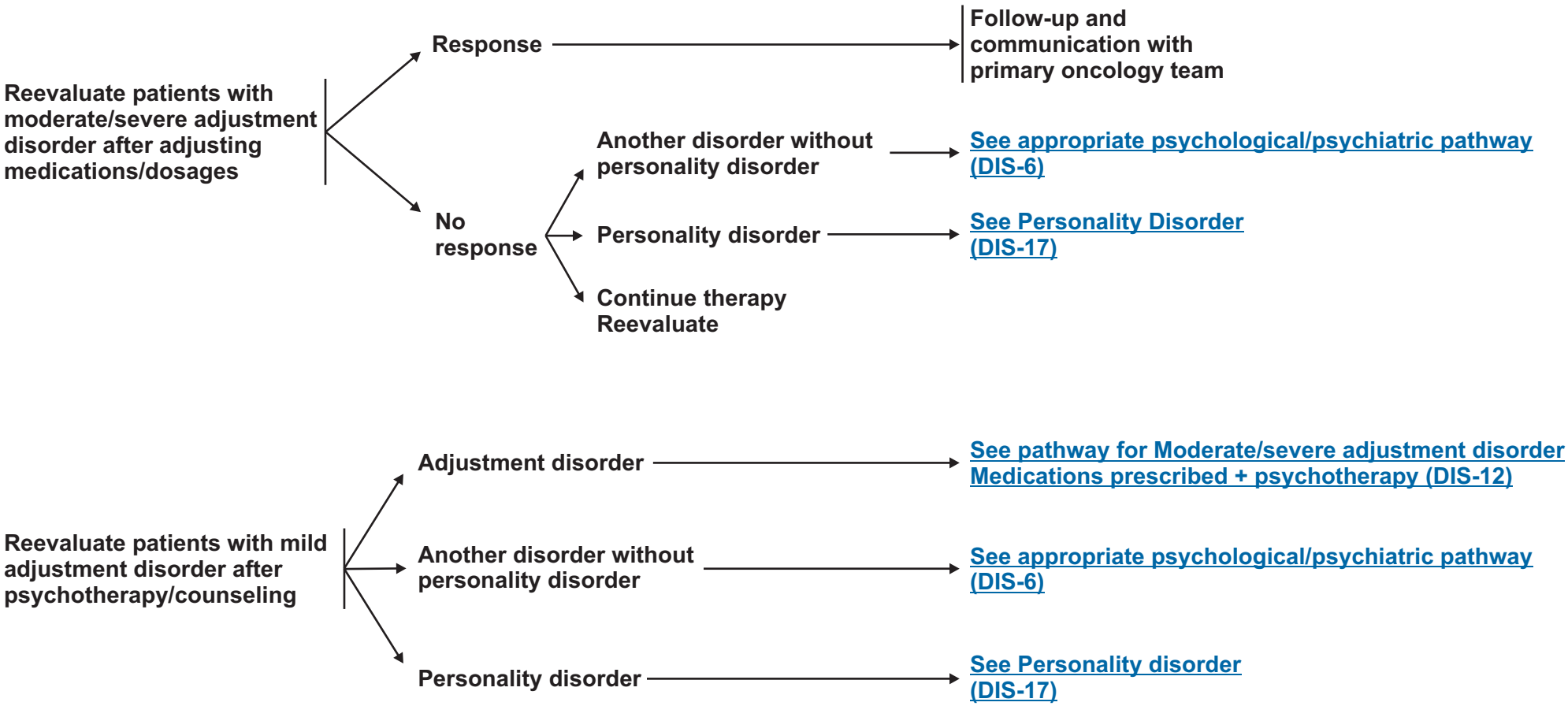
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ADJUSTMENT DISORDER (continued)
(ICD-10 code: F43.2)

FOLLOW-UP

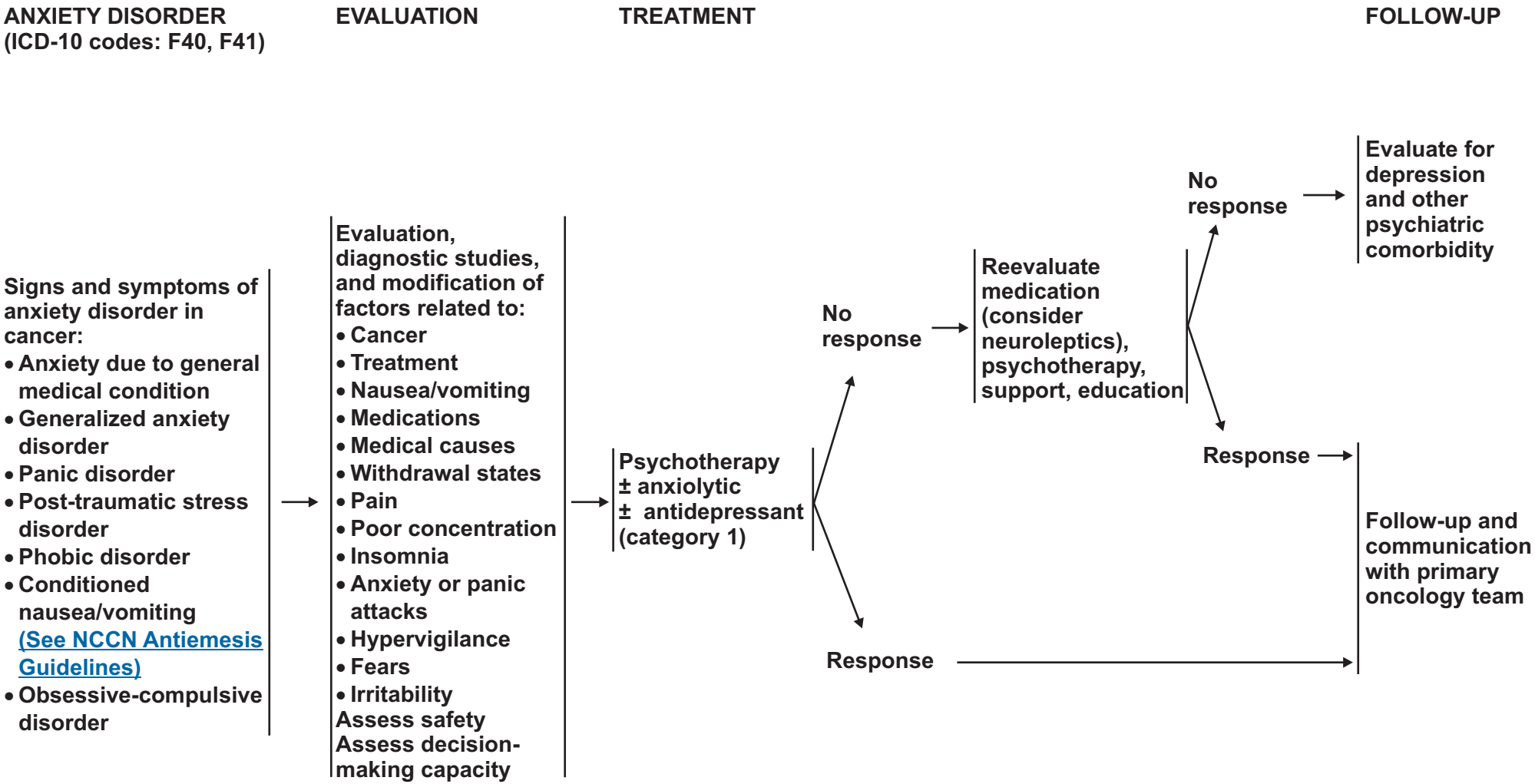


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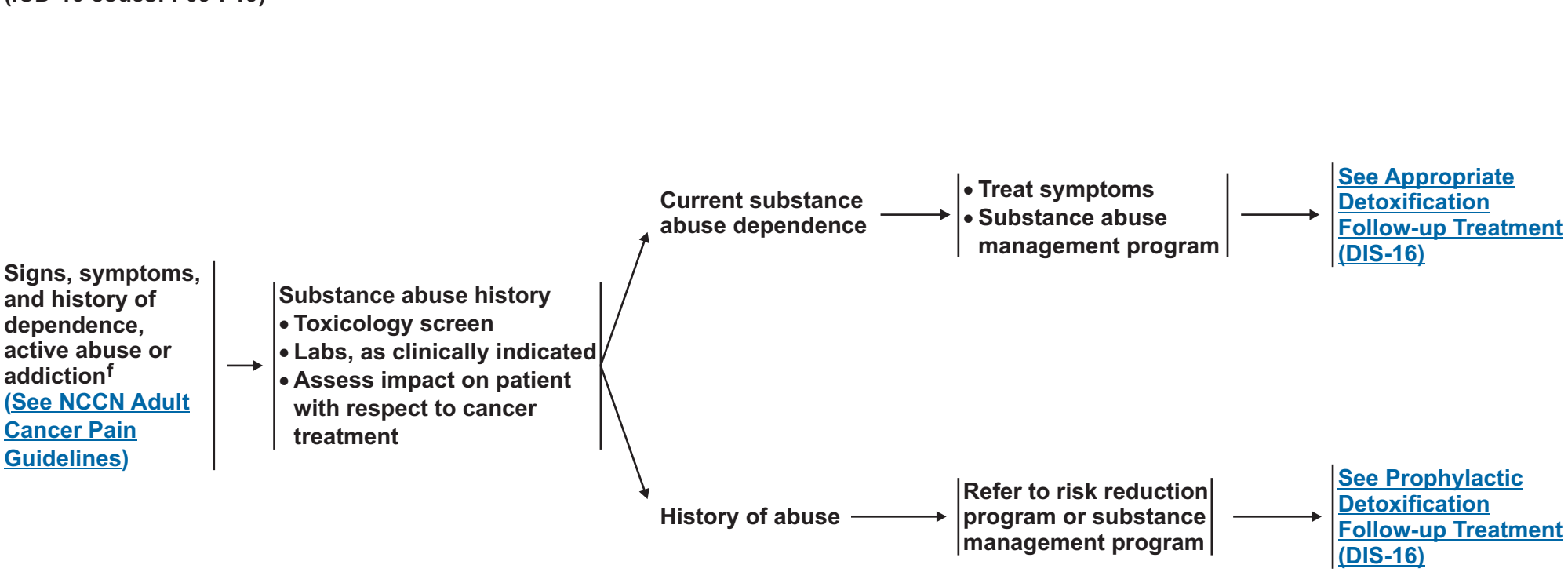


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Return to Psychological/Psychiatric Guidelines (DIS-6)

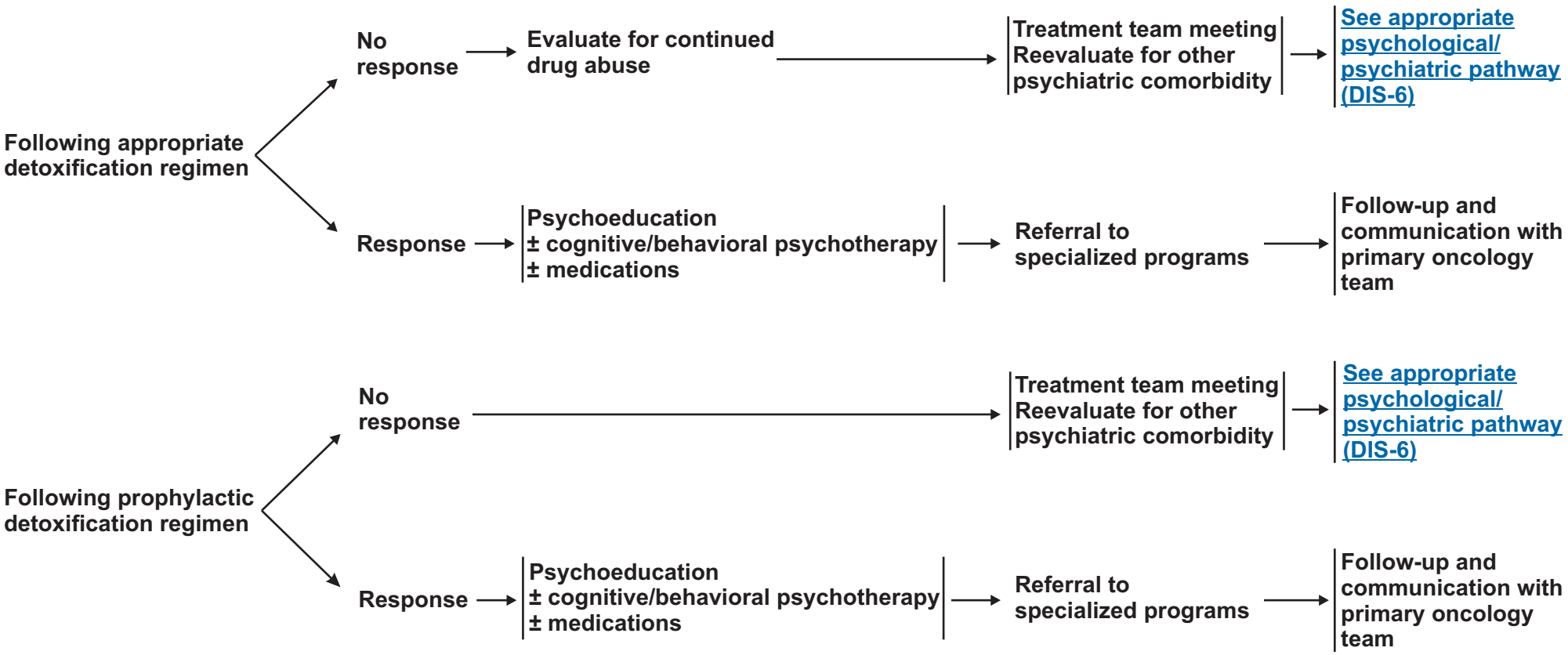
Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

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

FOLLOW-UP



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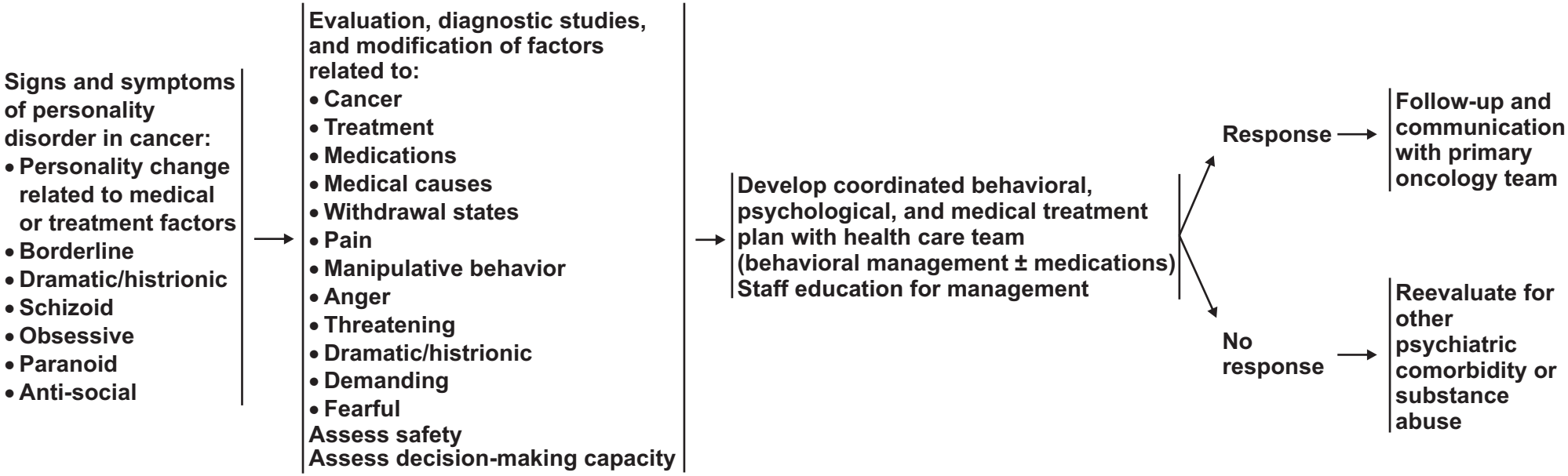
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PERSONALITY DISORDER (ICD-10 code: F60)

EVALUATION

TREATMENT

FOLLOW-UP

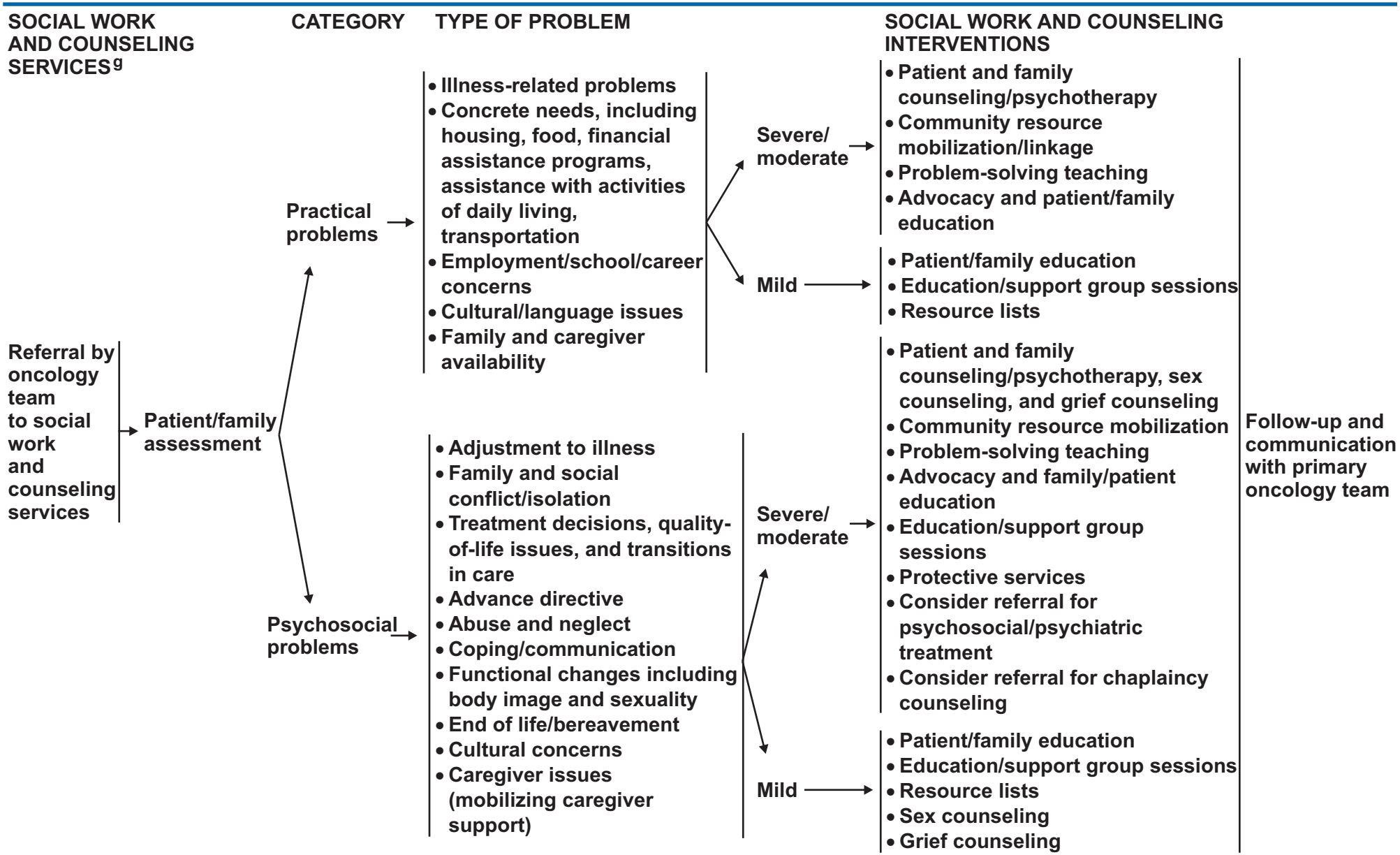


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[g] Social work and counseling services include mental health services using psychological/psychiatric treatment guidelines.

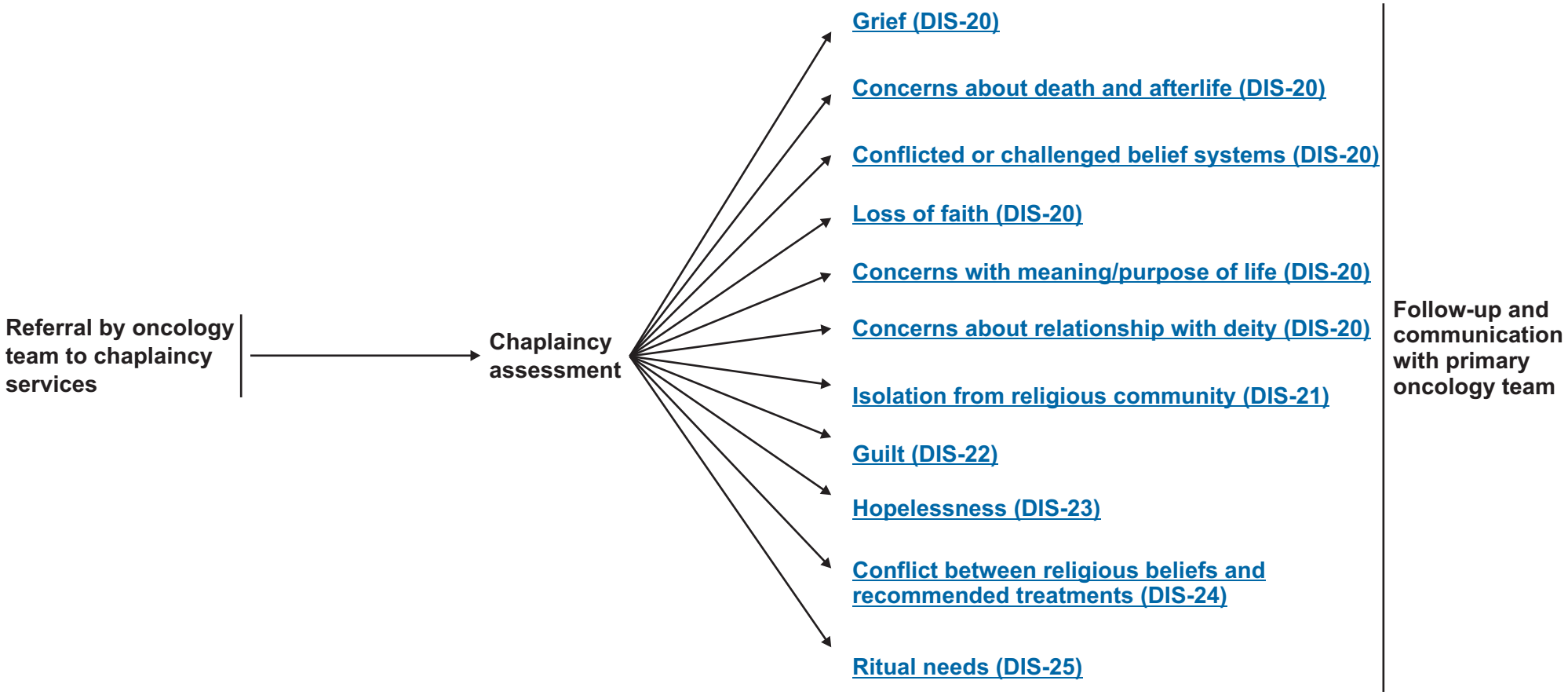
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See NCCN Palliative Care Guidelines

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CHAPLAINCY SERVICES

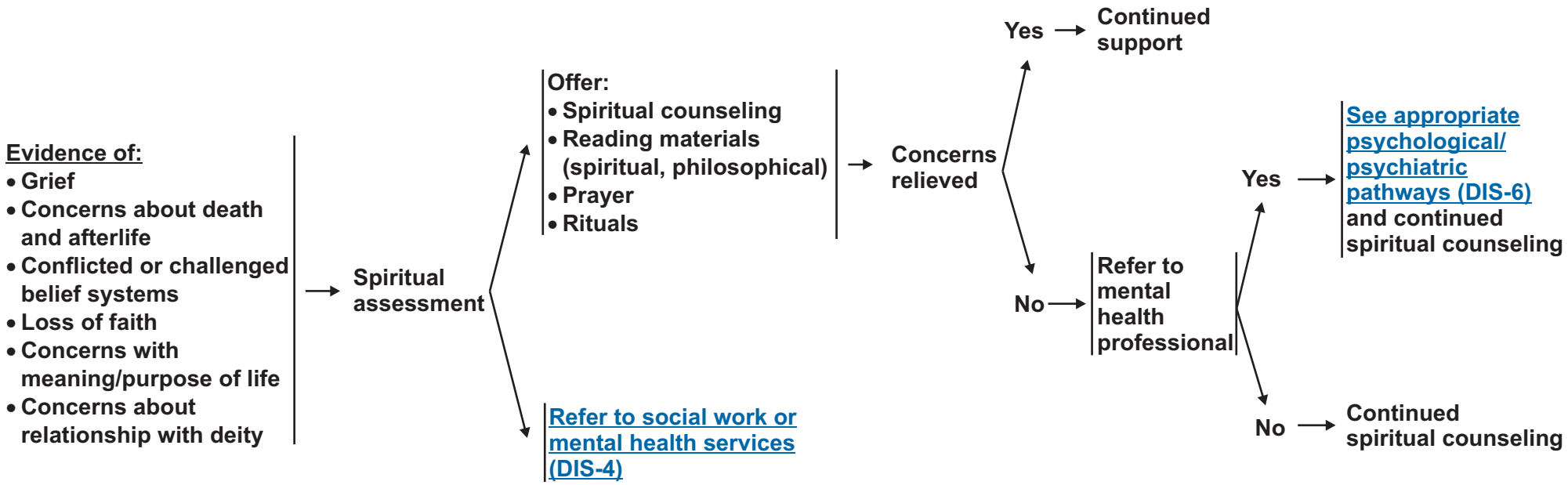


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CHAPLAINCY SERVICES



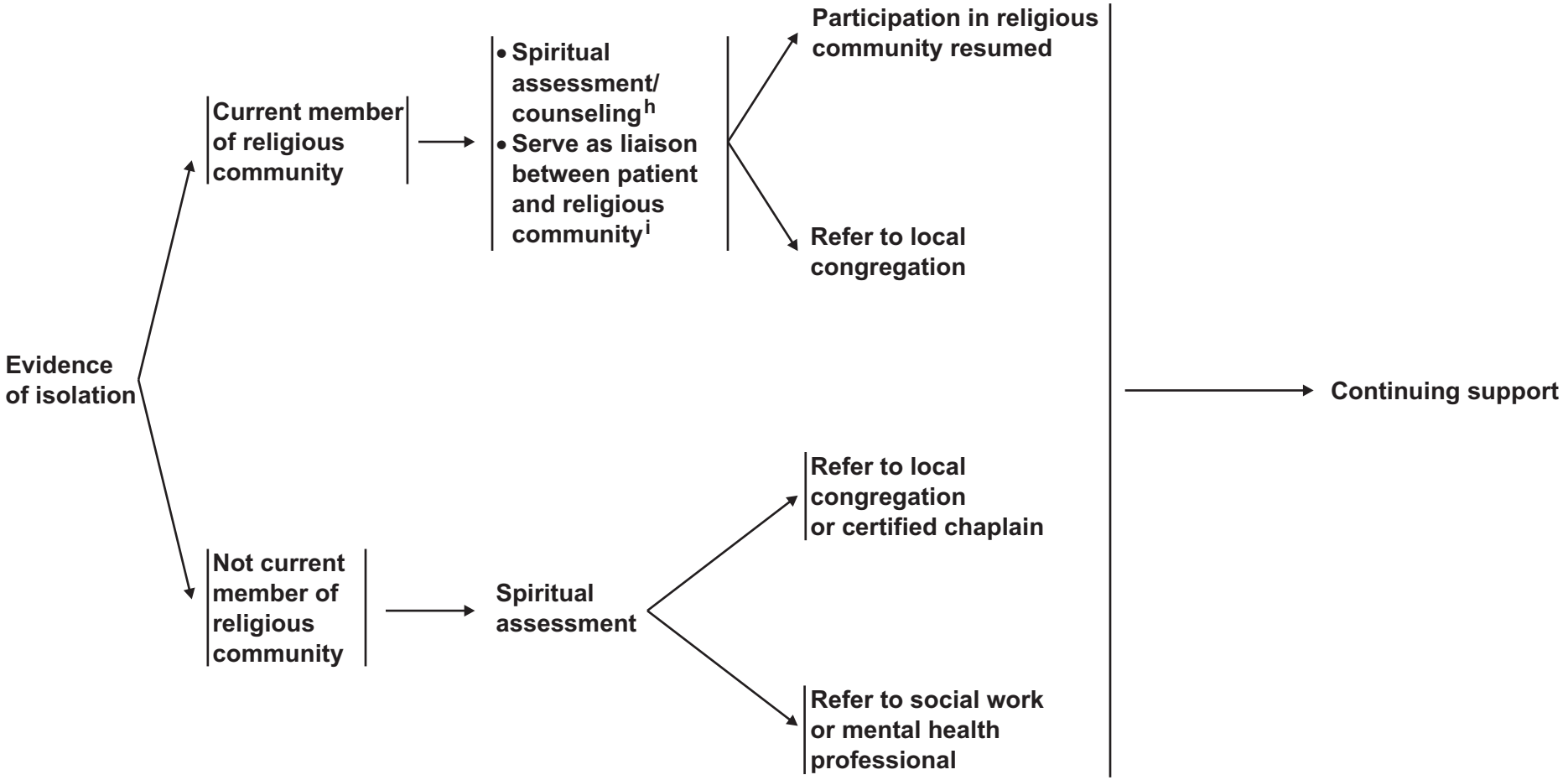
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CHAPLAINCY SERVICES: ISOLATION FROM RELIGIOUS COMMUNITY



[h]Referral to clergy of person's faith.

[i]Puchalski 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.

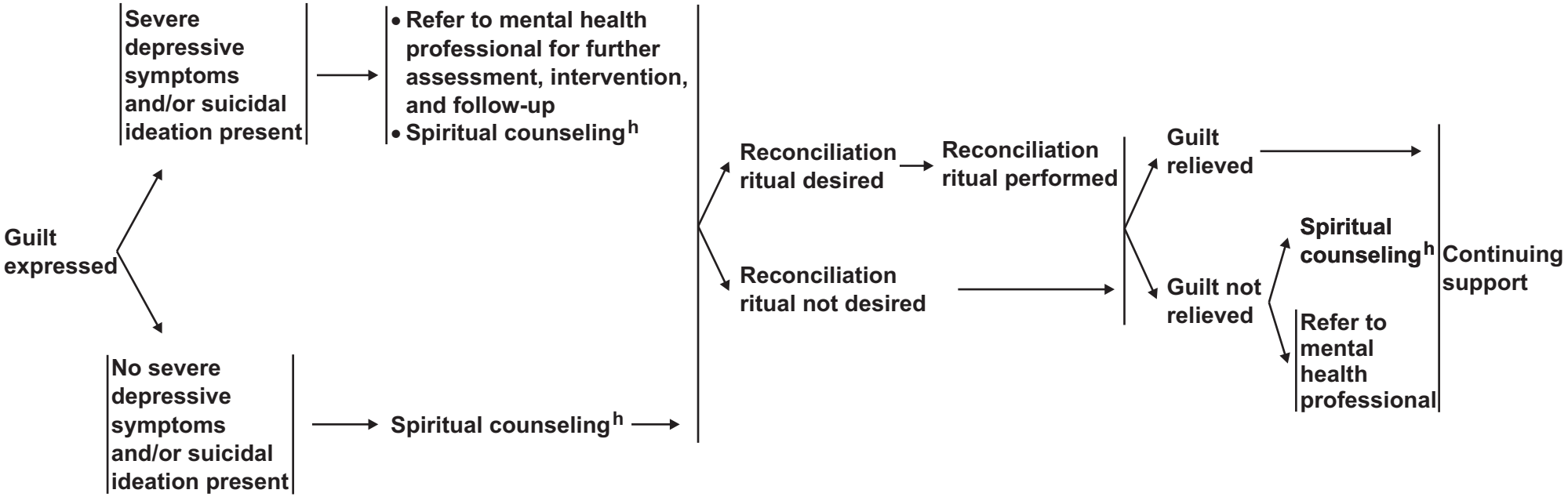
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CHAPLAINCY SERVICES: GUILT



[h]Referral to clergy of person's faith.

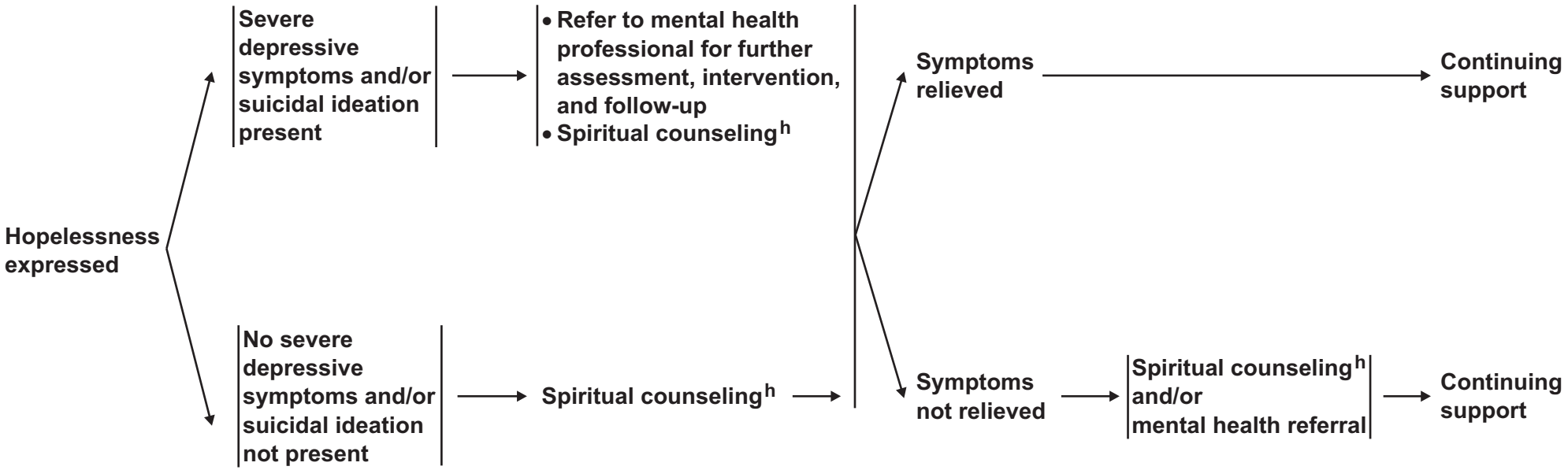
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CHAPLAINCY SERVICES: HOPELESSNESS



[h]Referral to clergy of person's faith.

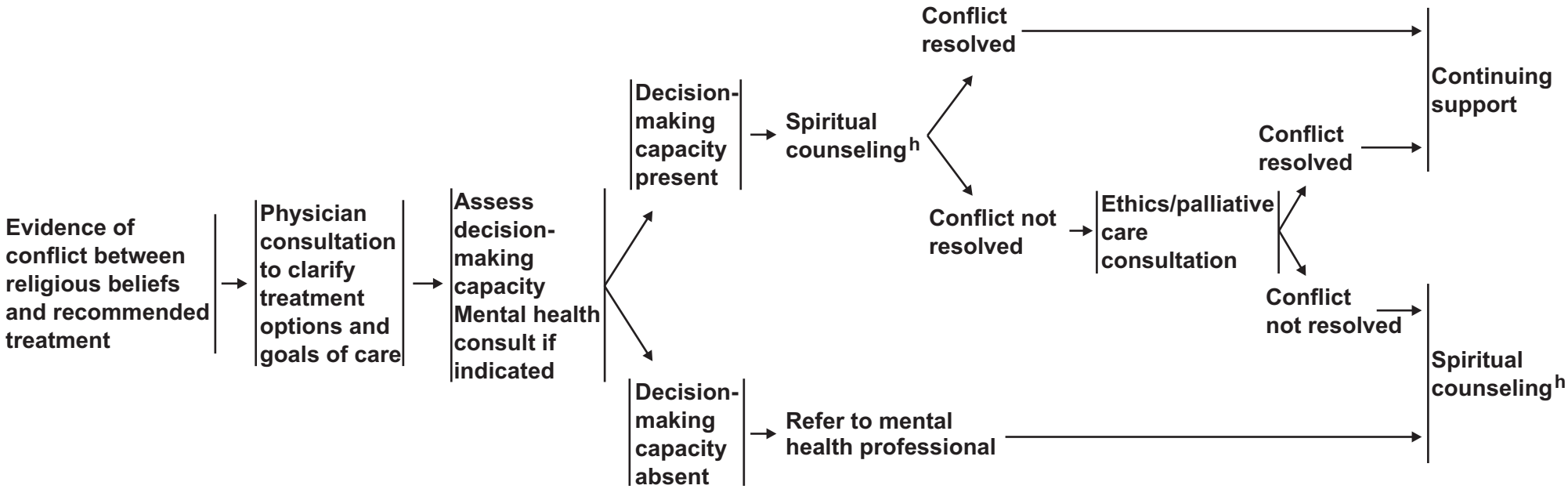
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CHAPLAINCY SERVICES: CONFLICT BETWEEN RELIGIOUS BELIEFS AND RECOMMENDED TREATMENTS



[h]Referral to clergy of person's faith.

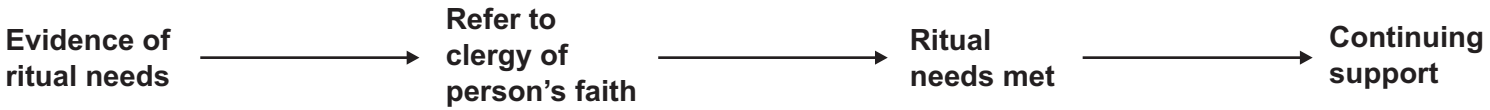
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CHAPLAINCY SERVICES: RITUAL NEEDS



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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**

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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

→ **Surveys** →

Professional

Attitudes
Knowledge
Assessment

→

Patient

Satisfaction (CQI survey of impact)

[i] Based on implementation/evaluation of pain management guidelines.

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Discussion

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.

Overview

In the United States, a total of 1,529,560 new cancer cases and 569,490 deaths from cancer are estimated to occur in 2010.[1] All patients experience some level of distress associated with diagnosis and treatment of cancer at all stages of the disease. Surveys have found that 20-40% of newly diagnosed and recurrent cancer patients show a significant level of distress.[2] However, less than 10% of patients are actually identified and referred for psychosocial help.[3] 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 oncologists' practices where there are few to no psychosocial resources and cancer care is often provided by short visits.[4]

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. However, patients are reluctant to reveal emotional problems to the oncologist. The words "psychological," "psychiatric," and "emotional" are as stigmatizing as the word "cancer." Psychological issues remain stigmatized even in the context of coping with cancer. Consequently, they 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.

Failure to recognize and treat distress leads to several problems: trouble making decisions about treatment 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.[5,6]

The Patients' Bill of Rights does not address psychosocial concerns within total health care. While regulatory bodies such as the Joint Commission on Accreditation of Healthcare Organizations have included concerns for decision making and the ethical aspects of care, psychosocial care has not been considered as an aspect of quality care until the 2007 Institute of Medicine (IOM) report.[7] Psychosocial care is now a part of the new standard for quality cancer care, which states

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that it must be integrated into routine care.[7,8-10] In Canada, emotional distress is the sixth vital sign which is checked routinely along with pulse, respiration, blood pressure, temperature and pain (the five vital signs).[11] Patients and families should be made aware that this new standard exists and that they should expect it in their oncologist's practice.[12]

Psychosocial Problems in Cancer Patients

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.[13] The prevalence of psychological distress in individuals varies by the type of cancer. In a study of 4,496 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 lung cancer patients.[14] The prevalence of distress, depression and psychiatric disorders has also been studied in all sites and stages of cancer.[15-17,18,19]

Cognitive impairment related to chemotherapy (sometimes known as "chemobrain") has also been described in patients with advanced cancer.[20,21,22] 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.[20,21] Although subtle, chemotherapy-related cognitive impairment 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.[23] A detailed understanding of the mechanisms that cause chemobrain is crucial for the development of more specific treatments to improve cognitive functioning and overall quality of life in patients with cancer.[24]

Non-adherence to treatment occurs, 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.[25] Depression and anxiety are risk factors for noncompliance. In a meta-analysis, DiMatteo and colleagues found that noncompliance was 3 times greater in depressed cancer patients as compared to non depressed patients.[26]

Psychosocial Interventions

Psychosocial interventions have been effective in reducing distress and improving overall quality of life among cancer patients.[7,10,27] The 2007 IOM report noted that there is a strong evidence base that supports the value of psychosocial interventions in cancer care.[7] Their review examined the range of interventions (psychological, social and pharmacological) and their impact on any aspect of quality of life, symptoms or survival.[7] The extensive review found randomized clinical trials, systematic reviews and meta-analyses which supported the conclusion that to give quality cancer care today, psychosocial aspects must be integrated into routine 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.[7]

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Cognitive-behavioral Therapy

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)[28] as well as physical symptoms (pain and fatigue)[29] in patients with cancer.

There is no standard treatment 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 in patients with cancer.[30-32] 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.[33] Further placebo controlled trials are needed to confirm these preliminary findings.

Ferguson and colleagues have developed a brief CBT [Memory and Attention Adaptation Training (MAAT)] aimed at helping breast cancer survivors manage cognitive dysfunction associated with adjuvant chemotherapy.[34] 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) comprising 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.[35] ICCTF is also creating 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.

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 especially in patients with metastatic breast cancer. [36,37] Cognitive existential group therapy was found to be useful in women with early stage breast cancer receiving adjuvant chemotherapy.[38] 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 their life) has also been proved to reduce psychological distress among patients with advanced cancer.[39]

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 with terminally ill cancer patients.[40] 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 compared to demand-withdraw communication.[41]

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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 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.[42-44] Mitchell and colleagues recently reported that ultra-short methods (PHQ2 or the Distress Thermometer) were acceptable to about three quarters of clinicians.[45,46, 47]

The IOM report supported the work of the NCCN Guidelines for Distress Management by proposing a model that could be implemented in any community oncology practice.[7] 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
- Reevaluation as appropriate.

NCCN Guidelines™ for Distress Management

A major milestone in the improvement of psychosocial care 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 but the panel recognized that many patients prefer a certified chaplain.[48]

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.[49]

The IOM report on Cancer Care for the Whole Patient is based on the pioneering work of the NCCN panel, which recommend screening for distress, and development of a treatment plan with referrals as needed to psychosocial resources.[50] NCCN has developed several cancer treatment and supportive care guidelines for the management of cancer-related symptoms, including pain and fatigue. Recommendations in the guidelines are based on evidence and 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).[50]

Definition of Distress

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

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a scale of 0 to10?" opens a dialogue with the oncologist or nurse for a discussion of emotions that is more acceptable.

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. Early detection and treatment of distress leads to

- better adherence to treatment
- better communication
- fewer calls and visits based on anxiety
- avoidance of patients' anger and developing severe anxiety or depression

The Distress Thermometer

A well known tool for initial screening is the distress thermometer (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 38-item Problem List, which is on the page with the DT, 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 look at the DT and the Problem List and to ask clarifying questions. Social workers are often not immediately available in busy clinics.

Chemotherapy and radiation therapy also have an impact on the on the fertility of patients, especially in those who are of child-bearing age.[51] 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.

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 four or higher suggest a level of distress that has clinical significance. If the patient's distress level is four or higher, the nurse looks at the problem list to identify key issues of concern and asks further questions to determine to which resource the patient should be referred. 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.

DT has been validated by several studies in patients with different types of cancer and has revealed concordance with Hospital Anxiety and Distress Scale (HADS).[42,52-57,58] 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 recent studies have validated the DT with an expanded problems list.[59, 60] Tuinman and colleagues validated the DT with the 46-item problem list in a cross-sectional group of 227 cancer patients.[60] 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.[59] The DT is also a useful tool for screening distress among bone marrow transplant patients.[61, 62] The DT had acceptable overall accuracy and greater sensitivity and specificity when compared to the Center for

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Epidemiological Studies-Depression Scale (CES-D) in the assessment of depression.[61]

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 the 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.[63,64]

- 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 by 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 (ie, 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 in the community. This is now an added indicator of quality cancer care by the IOM report 2007.[7]
- 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 the evaluation of patients' needs and the identification of system changes, required to increase the recognition and treatment of distress. Jacobsen and colleagues have developed a patient chart audit which permits an oncologists' office or clinic to evaluate the quality of their psychosocial care.[65] 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 given by a clinic or office.

Quality Oncology Practice Initiative (QOPI) was started in 2002 by American Society of Clinical Oncology (ASCO) as a pilot project (http://qopi.asco.org/program.html).[66] This program became available to all ASCO member medical oncologists in 2006. Jacobson's psychosocial quality indicators are now included in the QOPI initiative

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and may become part of the core measures.[67] In a recent analysis, Jacobson and colleagues reported that practices that participated in QOPI demonstrated improved performance and initially low-performing practices showed the greatest improvement.[67] 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.[68]

Initial Evaluation and Treatment

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,” is recommended to assess the level of distress and to identify causes for 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 which 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, social problems and spiritual or religious concerns.

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. There are several risk factors for greater distress: past psychiatric disorder; alcohol or substance abuse; younger age; female; living alone, having young children, prior physical or sexual abuse. Patients are referred to the appropriate supportive service (mental health, social work and counseling or chaplaincy services) based on the identified problem. Patients with moderate to severe distress who score of 4 or more on the screening tool must then 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: mental health, social work and counseling, or chaplaincy services.

Mild distress (a score of less than 4) is routinely managed by the primary oncology team and represents what the panel termed "expected distress" symptoms. The “normal” symptoms that the team manages are the 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 and death and treatment effects and side effects. Most patients experience these symptoms at the time of diagnosis and during arduous treatment cycles. They might persist long after the 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 as well as understand the treatment options and side effects.[69] Enough time is needed for asking questions and for putting the patient at ease.[70] When communication is done well at diagnosis, the stage is set for future positive trusting encounters. It is important to ensure that the

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patient mentally grasps what has been said, and this may be reinforced with drawings or taping the session and giving the tape to the patient.

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 relieves it somewhat and builds trust. The team needs to ensure that social supports are in place for the patient and that they know about community resources, such as support groups, teleconferences, and help lines. The IOM report contains the list of national organizations and their toll free numbers.[7] Some of the selected organizations that provide free information services to cancer patients are listed below:

- American Cancer Society (www.cancer.org)
- American Institute of Cancer Research (www.aicr.org)
- American Psychosocial Oncology Society (www.apos-society.org) 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.cancercare.org)
- National Cancer Institute (www.cancer.gov)
- Cancer.net sponsored by American Society of Clinical Oncology (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 Guidelines for Distress Management (www.nccn.org)
- ACCC (Association of Community Cancer Centers) Cancer Program Guidelines (www.accc-cancer.org).
- 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/publications/synopses/cp90syn.htm).
- 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).

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 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. A psychiatrist, psychologist, nurse, advanced practice clinician and 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, 4th 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 seven most commonly encountered psychiatric disorders: dementia, delirium (encephalopathy), mood disorder, adjustment disorder, anxiety disorder, substance abuse-related disorder, and personality disorder.

Dementia and delirium are cognitive impairments that may develop during the course of cancer treatment, and can severely impair the patient's decision making capacity.[71] Dementia is a permanent

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cognitive impairment and it is not a common complication of cancer treatment but is often present in elderly patients as a comorbid condition. 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 often related to medication particularly opioids. Delirium is managed by attention to safety, neuroleptics along with family support and education.

The incidence of suicide among cancer patients in the United States is twice that of the general population.[72,73] Older patients and men with head and neck cancer or myeloma seem to have a higher risk of suicide.[74, 75] Patients with mood and adjustment disorders can develop suicidal tendencies. In patients with no danger to self or others, mood disorder is usually managed with psychotherapy or an antidepressant along with or without anxiolytics. Referral to social work and counseling services and chaplaincy services may be considered. No medications are prescribed for those with mild adjustment disorder. Moderate to severe adjustment disorder is treated with medication and psychotherapy. Patients at danger to self or others should have safety measures implemented by the removal of sharp objects and psychiatric consultation. Psychiatric treatment and hospitalization may sometimes be necessary.

Anxiety occurs at all times in all cancer patients.[76] However, it may be related to the general medical condition [eg, hormone-secreting tumor, effects of certain types of medications (bronchodilators), withdrawal from alcohol or narcotics, pain, or some other distressing physical symptom]. 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, which 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, hospital, and blood or conditioned nausea/vomiting related to chemotherapy. Chemotherapy-induced nausea and vomiting should be managed according to the NCCN Guidelines for Antiemesis.

Research suggests that antidepressants and antianxiety drugs are beneficial in the treatment of depression and anxiety in adult cancer patients.[77-79] In randomized controlled trials, alprazolam (a benzodiazepine)[80] and fluoxetine (a selective serotonin reuptake inhibitor [SSRI])[81,82] have been effective in improving depressive symptoms in cancer patients. The SSRIs are widely used for depression and anxiety symptoms. Psychostimulant drugs help in the management of fatigue.

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

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 developed during the course of the

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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 and referral should be made to risk reduction or substance abuse management program.

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, advance directives, domestic abuse and neglect, coping or communication skills, 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

Many patients use their religious and spiritual resources to cope with illness, citing prayer as a major help. Balboni et al surveyed 230 patients with advanced cancer treated at Yale University Cancer Center and Memorial Sloan-Kettering Cancer Center and who had failed to respond to first-line chemotherapy.[83] 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.[83] Religiousness and spiritual support have also been associated with improved coping and quality of life in patients with advanced cancer. Astrow et al found that most cancer patients had spiritual needs but only a slight majority thought that it was appropriate to ask about their spiritual needs and that patients whose spiritual needs were not met reported lower quality and satisfaction with their care.[84] 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 healthcare professionals on the integration of spiritual care into the patient's overall treatment plan.[85] 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 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 one of the eight clinical practice domains in these guidelines. http://www.nationalconsensusproject.org/guideline.pdf

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- The National Cancer Institute's (NCI's) comprehensive cancer information database (PDQ) has information on "Spirituality in Cancer Care" patients (www.cancer.gov/spiritualityincancer/patients) and healthcare professionals (www.cancer.gov/spiritualityincancer/healthprofessional).

Chaplaincy Services

The panel has included chaplaincy services as part of psychosocial services, because the diagnosis of cancer is 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. 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.

The certified chaplain evaluates the problem and may offer spiritual or philosophical reading materials, spiritual advice and guidance, prayer, and rituals. For patients who are members of the religious community, the certified chaplain could also serve as a liaison between the patient and religious community. 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. 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 conflict, referral to social work and counseling services may be advisable in addition to chaplaincy services. Spiritual counseling should be provided for patients who experience guilt or hopelessness. In addition, such patients should also be evaluated by mental health professionals for further assessment since they may also have severe depressive symptoms or suicidal ideations.

Recommendations for Implementation of Standards and Guidelines

Jacobsen and colleagues recently conducted a study to evaluate the implementation of NCCN Guidelines for Distress Management by NCCN member institutions.[86] Eight institutions (53%) conducted routine distress screening and an additional 4 institutions (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 institutional interdisciplinary committees in NCCN institutions to implement and monitor distress management. The interdisciplinary committee must 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.[7]

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 their families to increase their awareness of prevalence of distress and psychological interventions.

Follow-up at regular intervals or at transition points in illness is an essential part of the NCCN Guidelines for Distress management and

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the IOM model for care of the whole patient. This is particularly important in elderly cancer patients.[87, 88]

Presently, the quality of the psychological care that 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 on our institution's report cards.

Summary

Psychosocial care is increasingly being recognized as an integral component of clinical management of cancer patients. 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 DT and Problem List as an initial rough screen.[89] 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 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 who include 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 with further questions as a second stage of screening. 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 updated frequently.

The standard of care should be revised and modified so that they are compatible with the clinical care offered at each institution. The medical staff as well as the patients should be made aware of the resources available to treat distress. It is important to 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 and their families, the treating staff, and improve efficiencies in clinic operations. 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, integration of mental health and medical services is critically important. Outcomes research studies that include quality-of-life assessment and analysis of cost-effectiveness are also needed.

Education of patients and families is equally important to encourage them to recognize that control of their distress is an integral part of their cancer care. Patients and families should be informed that management of distress is part of their total medical care. Spirituality and religion also play an important role for many patients with cancer in coping with the diagnosis and the illness. Chaplaincy services should be an integral part of psychosocial services for such patients.

The NCCN Guidelines for Distress Management are assessed annually and evidence-based interventions are added. This process highlights the critical role of feedback for implementing, assessing, and improving standards of care and guidelines.

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