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Clinical practice guidelines for the management of psychosocial distress at the end of life

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> *". . . We are not ourselves when nature, being oppressed,*
> *commands the mind to suffer with the body."*
> King Lear, Act II, Sc. IV, Li. 116–119

INTRODUCTION

After years of neglect, care at the end of life is receiving increasing attention and concern. It is then that the body is consumed by a progressive and mortal illness, and the person must cope not only with the bodily symptoms, but also with the existential crisis of the end of life and approaching death. As the body suffers, the mind is indeed "commanded . . . to suffer with the body," as Shakespeare so well described. Thus, suffering near the end of life encompasses both the mind and the body. Providing optimal symptom relief and alleviation of suffering is the highest priority. However, evidence suggests that we continue to fall far short of this ideal (American Society of Clinical Oncology, 1996; Cassem, 1997; Cassel & Foley, 1999; Carver & Foley, 2000). Although pain management guidelines have been the most widely disseminated, we know that many patients continue to suffer not only from pain, but other troubling physical symptoms in their final days (American Nursing Association, 1991; Carr et al., 1994; American Pain Society, 1995; American Academy of Neurology, 1996; American Board of Internal Medicine, 1996; Ahmedzai, 1998). Despite clear advances in the identification and treatment of psychiatric disorders, we continue to underdiagnose and undertreat the debilitating symptoms of depression, anxiety, and delirium in the final stages of life (Carroll et al., 1993; Hirschfeld et al., 1997; Holland, 1997, 1998, 1999; Breitbart et al., 2000; Chochinov & Breitbart, 2000). And, beyond these physical and psychological symptoms, we fall even shorter of our goals of alleviating the spiritual, psychosocial, and existential suffering of the dying patient and family (Cherny & Portenoy, 1994; Cherny et al., 1996; Fitchett & Handzo, 1998; Karasu, 2000). And this is in spite of the ethical imperative "to comfort always" (Pellegrino, 2000).

Clinical practice guidelines have proven to be highly effective in many areas of clinical care and especially cancer. They have served to establish a benchmark of quality care based on the delivery of evidence-based medicine (Field & Lohr, 1990, 1992; Field & Cassel, 1997; Chassin & Gavin, 1998). There is every reason to believe that guidelines should be equally effective in improving care at the end of life.

However, ensuring full application of practice guidelines poses special issues when it applies to end-of-life care. The comfort care that can be implemented is affected by a range of cultural factors: the customs and ethnicity of the patients and their families, community norms and expectations, religious and philosophical belief systems, and physicians' personal attitudes and beliefs about death. Development and evaluation of clinical practice guidelines for end-of-life care must take into account these unique aspects as well as combining medical and psychological guidelines in an inte-

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grated model that physicians find acceptable to use.

CLINICAL PRACTICE GUIDELINES FOR END-OF-LIFE CARE

The World Health Organization (WHO) Expert Committee on Cancer and Palliative Care (1996, 1998) defined end-of-life care as the active, total care of patients whose disease is not responsive to curative treatment; it seeks to attain maximal quality of life through control of physical, psychological, social, and spiritual distress of the patient and family. Hospice philosophy has long supported this integrated approach. The range of these issues, covering as they do the major components of quality of life, makes the task of developing clinical practice guidelines more formidable, but at the same time, more crucial. In its landmark report of 1997, the Institute of Medicine stated that quality care at the end of life requires the following: recommendations made by experienced professionals; clear goals; access to clinical trials, if desired; services provided in a coordinated manner; clear treatment options; availability of psychosocial services; compassionate care; integrated physical and psychosocial care (Institute of Medicine, 1997). These statements speak to the need for setting a benchmark for quality care in these areas through the establishment of clinical practice guidelines.

The call for such guidelines has been voiced also by policy analysts, health care professionals, patients, families, and third party payers. In 1996, the Task Force on Cancer Care at the End of Life, the American Society of Clinical Oncology (ASCO), set out principles for end of life care of “optimizing quality of life . . . with attention to the myriad physical, spiritual and psychosocial needs of the patient and family” (p. 671).

A multidisciplinary panel on Palliative Care Guidelines, chaired by Michael Levy, M.D., was organized by the National Comprehensive Cancer Network (NCCN) and has completed the first end of life clinical practice guidelines (Table 1).

Table 1 sets out the current status of the major clinical practice guidelines for overall end of life care, doctor–patient communication, and psychosocial distress.

The focus of this article is the management of psychosocial distress and psychiatric disorders in palliative care, especially depression, anxiety, and delirium, and the need to fully integrate their treatment into total care (Wanzer et al., 1989; Twycross & Lichter, 1998).

COMMUNICATION WITH PATIENT AND FAMILY

Central to ensuring quality of *all* care at the end of life is communication between the doctor, patient, and family (Girgis & Sanson-Fisher, 1995; Ptacek & Eberhardt, 1996). Identification and management of symptoms—physical and psychological—hinge upon this interaction. Buckman, an oncologist who teaches communication, noted, “Almost invariably, the act of communication is an important part of therapy: occasionally it is the only constituent. It usually requires greater thought and planning than a drug prescription, and unfortunately it is commonly administered in subtherapeutic doses” (Buckman, 1998, p. 141). Many physicians find communication around end of life particularly difficult because of questions related to prognosis and death.

Teaching how to break bad news is the most studied aspect of doctor–patient communication. An NCCN Panel, chaired by Baile, has developed algorithm-based guidelines for delivering bad news and they are being revised for application to end of life care (Baile et al., 1999; Holland, 1999; see also Table 1). A review of the literature from 1975 to 1999 revealed that of the 166 articles published on doctor–patient communication, the majority were written in the past 5 years, reflecting the greater attention being given to communication recently (Holland & Almanza, 1999). Most publications were based on consensus opinions or clinical experience; only 14% of the studies were based on controlled trials.

Communication guidelines must be directed to finding out what the patient understands and how much information the patient actually wants; being empathic with emotions expressed by the patient; allowing time for tears and emotions to be expressed without signs of being rushed; taking into account the family and its ethnic, cultural, and religious roots, especially the traditionally uderserved with language barriers (Hastings Center, 1987; Braun et al., 2000).

Family members face similar challenges in expressing their feelings and asking questions about prognosis. In a cooperative group study of eight cancer centers, doctors said they had more trouble communicating with families than with patients (Speice et al., 2000). Patients in the study noted that their relatives often felt “left out” and “in the way.” These observations are particularly disturbing because the death vigil is a time of terrible distress for family members. They often recall in exquisite detail the sensitivity (or lack of it) of the doctor and staff when their relative was dying. Their grieving is affected by memories of how they

Table 1. *Clinical practice guidelines for management of distress in end-of-life care*

In	Status	Source	Further development
Overall	Descriptive	Literature	Practice guidelines development
Palliative care	*NCCN Practice Guidelines	Evidence/consensus	Pilot testing; additional guidelines in 2002
Doctor–patient communication	Descriptive guides for breaking bad news	Literature	Expand to major communication issues in end of life care
	*NCCN Practice Guidelines: Breaking Bad News	Evidence/consensus	Modify for end of life care
Symptom	Status	Source	Further development
Distress	*NCCN Distress Management Practice Guidelines: Psychosocial, existential/spiritual issues	Definition Variable/consensus	Consensus of NCCN Panel regarding definition; algorithm for recognition/referral; modify for end of life care
Mental health psychiatric disorders (DSM-IV)			
Delirium	*APA Practice Guidelines, 2000	Evidence/consensus	Modify for medically ill/end of life care
	*NCCN Practice Guidelines	Consensus	Modify for end of life care; pilot
Mood Disorders (depression)	*AHCPR Clinical Practice Guidelines	Evidence/consensus	Modify for end of life care
	*APA Practice Guidelines, 2000	Evidence/consensus	Modify for end of life care
	*NCCN Practice Guidelines	Evidence/consensus	Modify for end of life care; pilot
Anxiety disorders	*APA Practice Guidelines	Evidence/consensus	Modify for use with medically ill/end of life care
	*NCCN Practice Guidelines	Evidence/consensus	Modify for end of life care; pilot
Personality disorders	*APA Practice Guidelines	Evidence/consensus	Modify for end of life care
	*NCCN Practice Guidelines	Evidence/consensus	Modify for end of life care; pilot
Social work			
Practical or psychosocial problems	*NCCN Practice Guidelines for Social Work Services in Cancer	Evidence/consensus	Modify for end of life care; pilot
Pastoral counseling			
Spiritual/religious issue	*NCCN Practice Guidelines for Clergy/Pastoral Counselors	Evidence/consensus	Modify for end of life care; pilot

*Algorithm based.

were kept informed of changes in the medical situation, and especially how attentive the doctor and the staff were in controlling the patient's distress and physical symptoms affect (Chochinov et al., 1998; Zisook, 2000).

MANAGEMENT OF DISTRESS

Diagnosis of untreatable cancer leads to reflection on the meaning one attaches to life and death. For many in America, this may be the first real (unavoidable) confrontation with death because, as a society, we prefer to avoid thoughts of death. In fact, death is the last taboo topic. A Gallup poll in 1995 found that most people in the United States reported that they never thought about death, or almost never. Arnold Toynbee noted in 1883 that "death is considered un-American, an affront to every citizen's right to life, liberty and the pursuit of happiness." Callahan wisely observed that much of the recent public excitement, debate, and furor about physician-assisted suicide and euthanasia is really a societal attempt to "control death" and thereby avoid facing the actual meaning of death in personal terms. (Callahan, 1993) Approaching death brings reconsideration of death/after-life issues; it also becomes a time for identifying values, beliefs, and personal resources. The psychological, social, and existential/religious/spiritual concerns are fully intertwined.

Mental health professionals, social workers, and pastoral counselors must be available to patients at the end of life because of the pronounced, complex distress many experience. However, because of continuing negative attitudes toward psychological problems, medical staff are often reluctant to ask for a mental health or psychiatric consultation, even when it is highly appropriate, out of concern that the patient or family may be offended by such a referral. Indeed, sometimes the family sees it as an affront to the patient at a time of grave illness.

A major neglected problem in palliative care is the underrecognition, underdiagnosis, and thus, undertreatment of patients with significant distress, ranging from existential anguish to anxiety and depression. As Cherny and colleagues noted in 1996, the "suffering" of patients relates to coping with the increasing physical symptoms that, by their own nature, become a major source of distress. This situation continues to exist despite the fact that, when asked, dying patients, themselves, said that maintaining a sense of control, relieving burdens (conflicts), and strengthening ties were central concerns about their care (Singer et al., 1999). Even though patients and families clearly express their wishes for attention to their nonmedical concerns and the inclusion of this domain as a core element in palliative care, there remains significant evidence that inadequate attention is given to these issues, in spite of lip service and good intentions.

DEVELOPMENT OF STANDARDS FOR MANAGEMENT OF DISTRESS

Over a 2-year period beginning in 1998, the NCCN, through a multidisciplinary panel, developed the first set of standards and clinical practice guidelines for psychosocial care in cancer. Full participation of all the supportive care disciplines (psychiatry, psychology, chaplaincy, social work, and nursing) as well as oncology and patient advocacy made this panel both highly effective and practical in its approach to improving care (Holland, 1999). The panel focused on the ambulatory setting, but the basic principles apply to and need only some modification for palliative care.

The NCCN panel chose the term "distress" (Table 1) to describe the psychological/social/spiritual domains of care because it carries no stigmatizing connotations and is inclusive in its meaning. Clinically, distress can increase along a continuum from common normal feelings of vulnerability, sadness, and fear to problems that are disabling, such as true depression, generalized anxiety, panic, and feeling isolated or in a spiritual crisis. Sadness of separation and anticipatory grief may increase to severe distress in the patient and family. The normal search for meaning may increase to become an existential crisis with spiritual or religious meanings and require the advice of a pastoral counselor (Rousseau, 2000).

Level of distress should be assessed at each visit, whether this occurs at home, in the clinic or office, or at the hospital or hospice. The NCCN practice guidelines give an algorithm (Fig. 1) for rapid identification of patients with significant distress and the trigger for referral to supportive services. A rapid visual analog approach is used by a verbal question: "How is your distress today on a scale of 0–10?" or by making a hatch mark on the Distress Thermometer (Fig. 2). The Distress Thermometer is similar to the pain scale of 0–10 severity and allows a patient to mark their level of "distress." A score of 5 or more is the algorithm for referral to a supportive service. The Thermometer is accompanied by the Problem List (Fig. 2) on which the patient marks the nature and source of the distress (physical, social, psychological, or spiritual) and thereby identifies the discipline to which referral is to be made (e.g., mental health, social work, pastoral counseling). Patients have found this acceptable and physicians have found that it serves as a check list to guide questions. Several other screening methods are available and should be studied and compared in a research mode (Razavi et al., 1990; Hopwood et al., 1991; Ibbotson et al., 1994; Zabora et al., 2001).

Physicians and nurses must be trained to use rapid screening methods to ensure that patients are asked at each visit, at all stages of illness, about their level of distress. Staff must be able to use the algorithm to refer patients to community resources for psychosocial services. Ready access to community resources is important (e.g., a phone referral list). They must be trained in how to communicate with patients and families in an empathic, compassionate, and supportive manner (Maguire & Faulkner, 1988; Fallowfield et al., 1998; Holland & Almanza, 1999; Maguire, 2000).

CLINICAL PRACTICE GUIDELINES

Management of Common Psychiatric Disorders

There are several common psychiatric symptoms/disorders (DSM-IV classification) that are encountered during end of life care (Table 1). Mental health professionals with expertise in end-of-life problems can substantially diminish the distress of patients, which is most frequently related to anxiety, depression (mood disorder), and delirium. The American Psychiatric Association Clinical Practice Guidelines are useful for modification to end-of-life care, as are the NCCN guidelines for the management of these disorders specifically in cancer patients (Fig. 3) (Holland 1999; Holland & Almanza, 1999; American Psychiatric Association, 2000*a*).

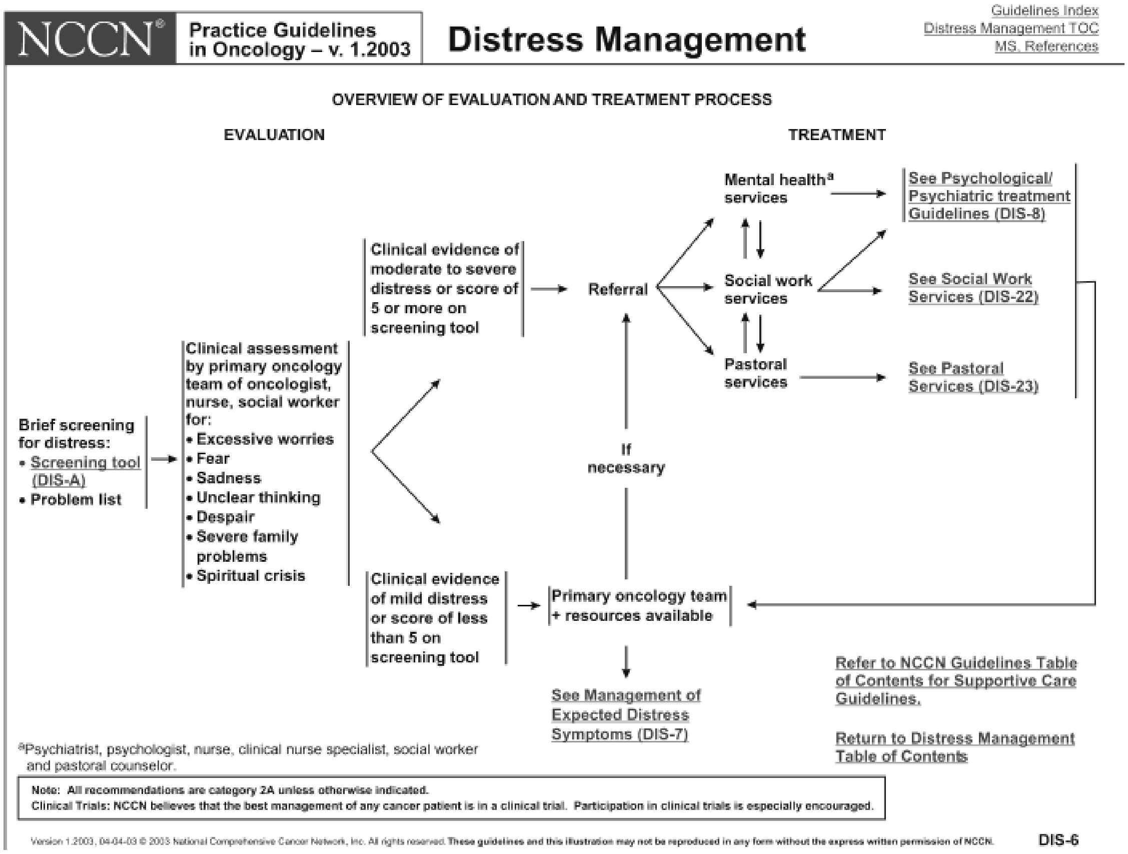
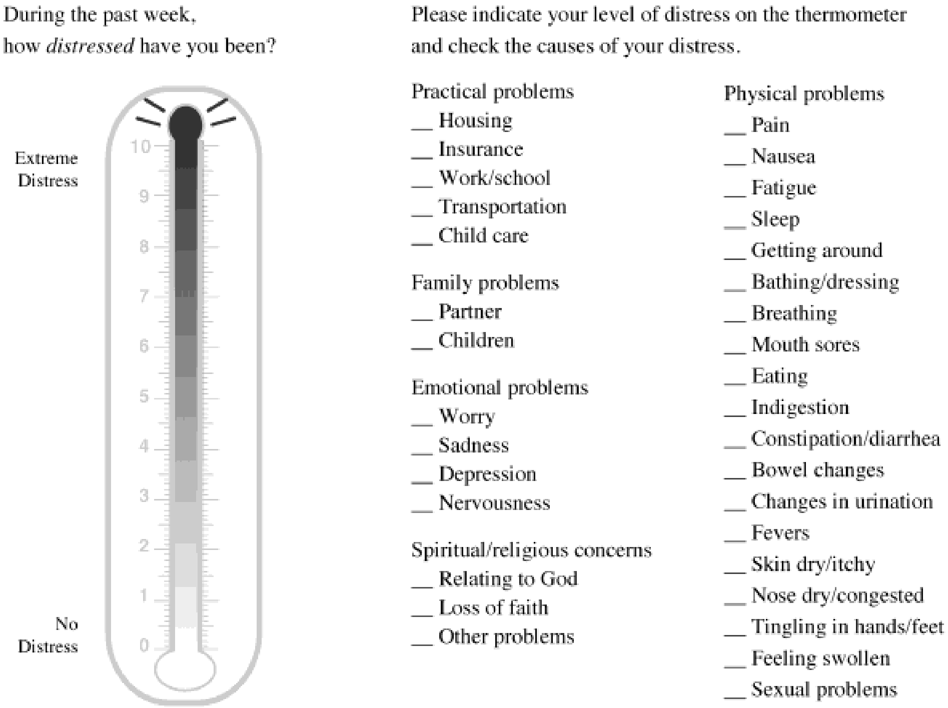


Fig. 1. Overview of evaluation and treatment process. (Reproduced with permission of NCCN.)



During the past week,
how *distressed* have you been?

Please indicate your level of distress on the thermometer and check the causes of your distress.

Practical problems
__ Housing
__ Insurance
__ Work/school
__ Transportation
__ Child care

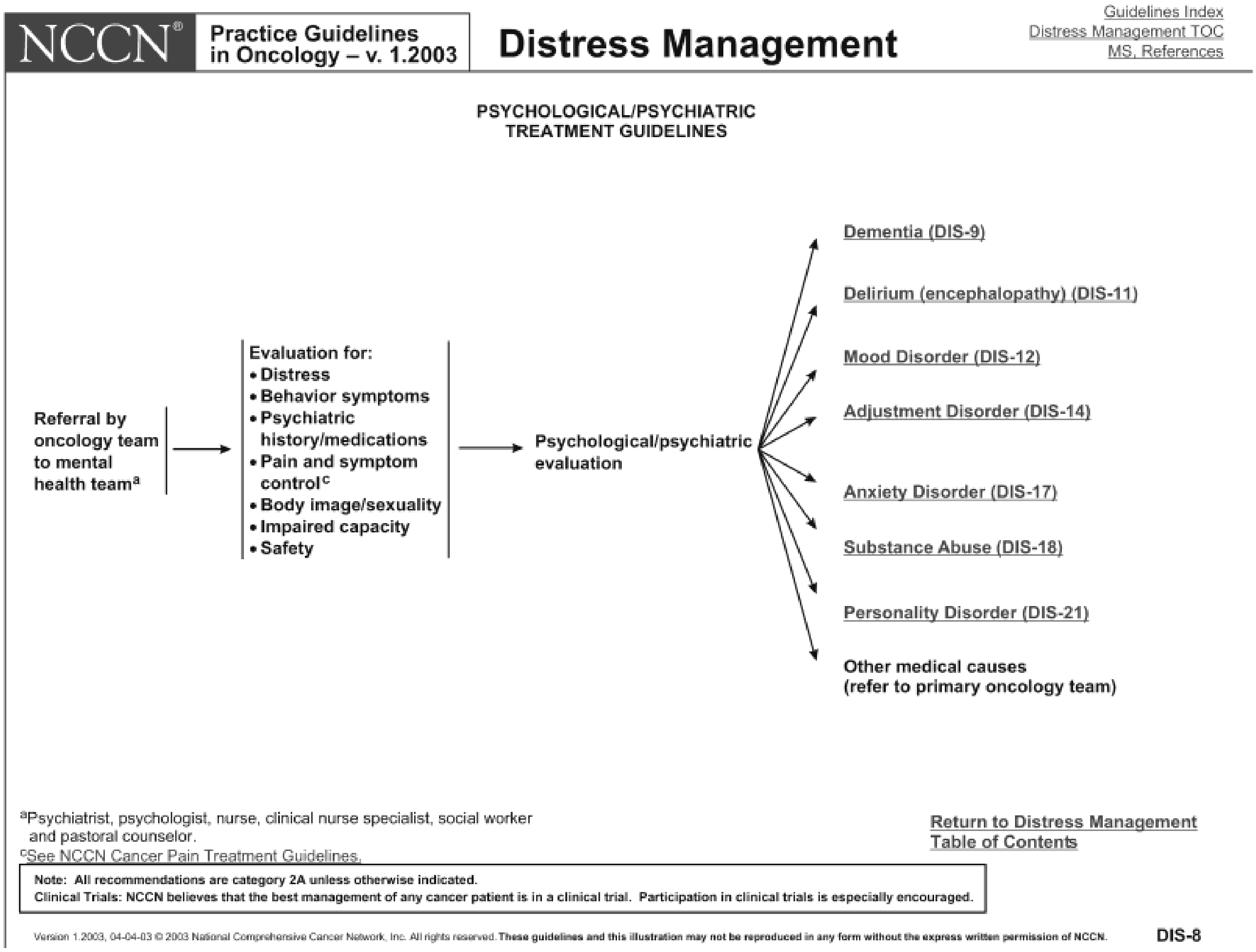
Family problems
__ Partner
__ Children

Emotional problems
__ Worry
__ Sadness
__ Depression
__ Nervousness

Spiritual/religious concerns
__ Relating to God
__ Loss of faith
__ Other problems

Physical problems
__ Pain
__ Nausea
__ Fatigue
__ Sleep
__ Getting around
__ Bathing/dressing
__ Breathing
__ Mouth sores
__ Eating
__ Indigestion
__ Constipation/diarrhea
__ Bowel changes
__ Changes in urination
__ Fevers
__ Skin dry/itchy
__ Nose dry/congested
__ Tingling in hands/feet
__ Feeling swollen
__ Sexual problems

Fig. 2. The Distress Thermometer. (Reproduced with permission of NCCN.)



[a] Psychiatrist, psychologist, nurse, clinical nurse specialist, social worker and pastoral counselor.

[c] See NCCN Cancer Pain Treatment Guidelines.

Note: All recommendations are category 2A unless otherwise indicated.
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Fig. 3. Psychological/psychiatric treatment guidelines. (Reproduced with permission of NCCN.)

Delirium

Delirium is a common psychiatric disorder toward the end of life, found to affect, according to one study, as many as 85% of patients in their final days (Massie & Holland, 1983). The etiology of delirium in the terminally ill cancer patient is often multifactorial due to medication side effects, infection, organ failure, metabolic derangement, and direct CNS involvement. Older individuals who have mild impairment of cognition are especially susceptible to delirium. In the final stages of life, it is unlikely that the cause of the delirium can be resolved, and attention should focus on comfort. All too often, "quiet delirium" is ignored, but patients may be distressed by frightening delusions. Patients' capacity to make health care decisions must be assessed at times and the health care proxy identified. Considerable psychopharmacologic research has gone into management of delirium (usually antipsychotics; Kress et al., 2000; see also Table 1).

Delirium is sometimes accompanied by agitation with self-injurious behavior (pulling out lines), or less likely, the risk of injuring others (Johanson, 1993). Sometimes, poor impulse control, confusion, and depression combine to result in poorly planned, impulsive suicide attempts. Loved ones are frightened by a sudden change in behavior and they need explanation as to the origin—be it related to disease or medication effects or both. Patients need explanation because they fear, "I'm losing my mind" (Chochinov & Breitbart, 2000).

Thus, appropriate treatment of delirium includes steps to ensure early identification, safety of the patient, interventions (both to treat the delirium and its underlying cause, if possible), and education of patient and family to decrease distress associated with this disturbing symptom (see Fig. 4).

Depression (Mood Disorder)

Depression is a common mood disorder at the end of life (Wilson et al., 2000; see also Table 1). The

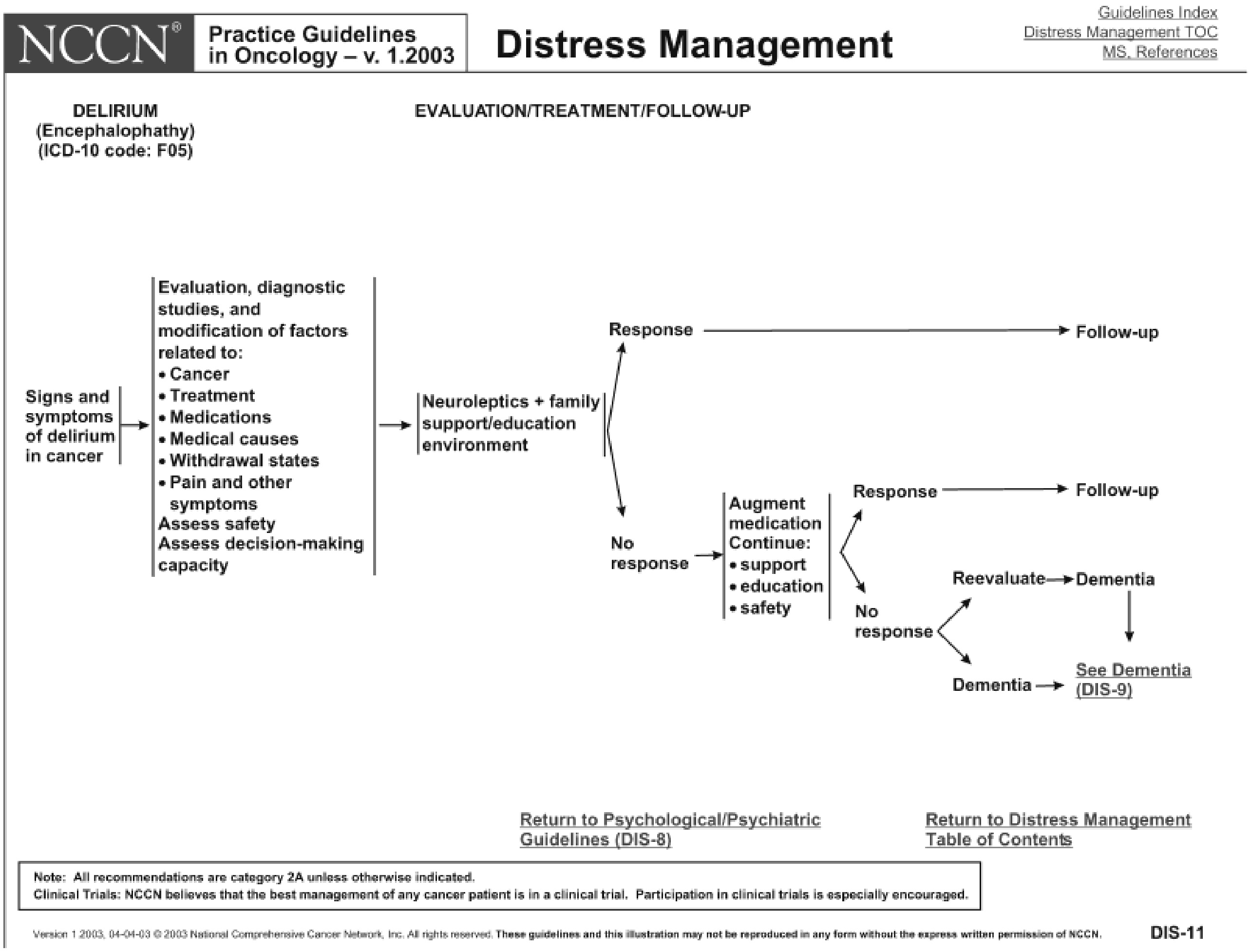


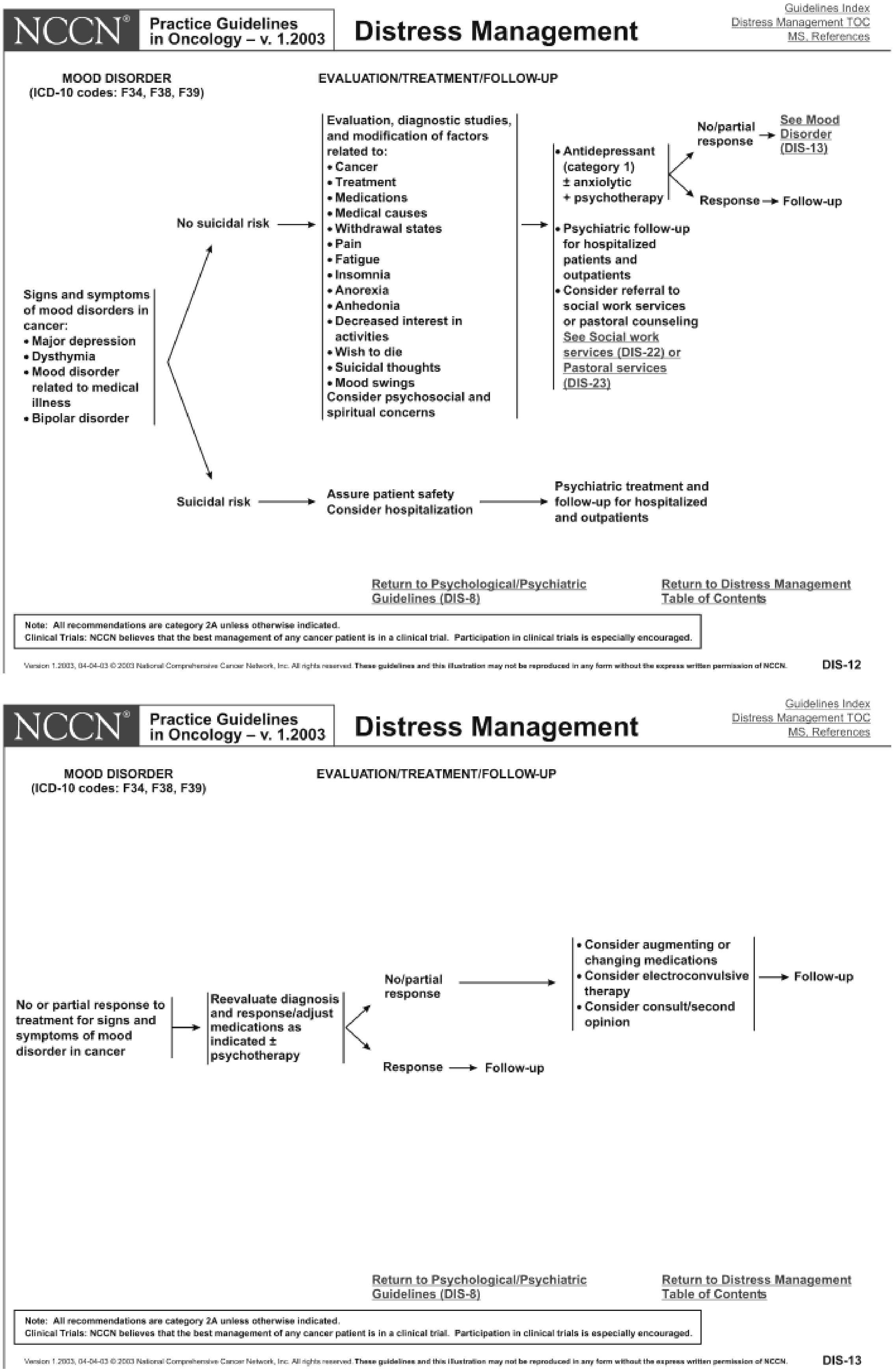
Fig. 4. Delirium (encephalophathy)—evaluation/treatment/follow-up. (Reproduced with permission of NCCN.)

etiology must first be determined, ruling out metabolic, illness, or drug-related causes (Fig. 5). Irrespective of the etiology, depressive symptoms should be addressed and treated. Evaluation of suicidal ideation and risk is essential. It is critically important to evaluate and treat depression because of its role in requests for physician-assisted suicide. The presence of hopelessness appears to be a separate but related factor, along with depression, in suicidal wishes (Breitbart et al., 2000). The notion that depression is an ordinary occurrence at the end of life has been dispelled by careful longitudinal studies by Chochinov et al., who found a high level of fluctuation in suicidal wishes day to day, suggesting caution in assuming a patient's stated wish at a particular time will continue to be the same (Razavi et al., 1990; Passik et al., 1998; Chochinov & Breitbart, 2000).

Meeting criteria for true major depression (DSM-IV criteria) is *not* common, but when major depression is present, it should be treated as aggressively as any physical symptom, with psychological support, psychotherapy, and medication. Antidepressants and psychostimulants are of proven value. Existential forms of psychotherapy using Frankl's concepts and cognitive meaning-seeking psychotherapy are under development by our group (W. Breitbart, pers. comm.). The NCCN guideline for depression is given in Figure 5. Also useful are the clinical practice guidelines developed by the American Psychiatric Association and the Agency for Health Care Policy and Research (see Table 1).

Anxiety Disorders

Anxiety is the most common symptom of distress occurring near the end of life. It often stems from fears related to shortness of breath, pain, unremitting physical symptoms, and uncertainty about the future. Reactive anxiety symptoms alone, or mixed with depressive symptoms, constitute the mildest DSM-IV psychiatric disorder, Adjustment Disorder With Anxiety (American Psychiatric Association, 2000*b*). The patient requires careful evaluation for



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

EVALUATION/TREATMENT/FOLLOW-UP

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

No suicidal risk →

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

→

- Antidepressant (category 1) ± anxiolytic + psychotherapy
- Psychiatric follow-up for hospitalized patients and outpatients
- Consider referral to social work services or pastoral counseling See Social work services (DIS-22) or Pastoral services (DIS-23)

No/partial response → See Mood Disorder (DIS-13)

Response → Follow-up

Suicidal risk → Assure patient safety
Consider hospitalization → Psychiatric treatment and follow-up for hospitalized and outpatients

Return to Psychological/Psychiatric Guidelines (DIS-8)

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Note: All recommendations are category 2A unless otherwise indicated.
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DIS-12

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

EVALUATION/TREATMENT/FOLLOW-UP

No or partial response to treatment for signs and symptoms of mood disorder in cancer → Reevaluate diagnosis and response/adjust medications as indicated ± psychotherapy

No/partial response →
- Consider augmenting or changing medications
- Consider electroconvulsive therapy
- Consider consult/second opinion

→ Follow-up

Response → Follow-up

Return to Psychological/Psychiatric Guidelines (DIS-8)

Return to Distress Management Table of Contents

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DIS-13

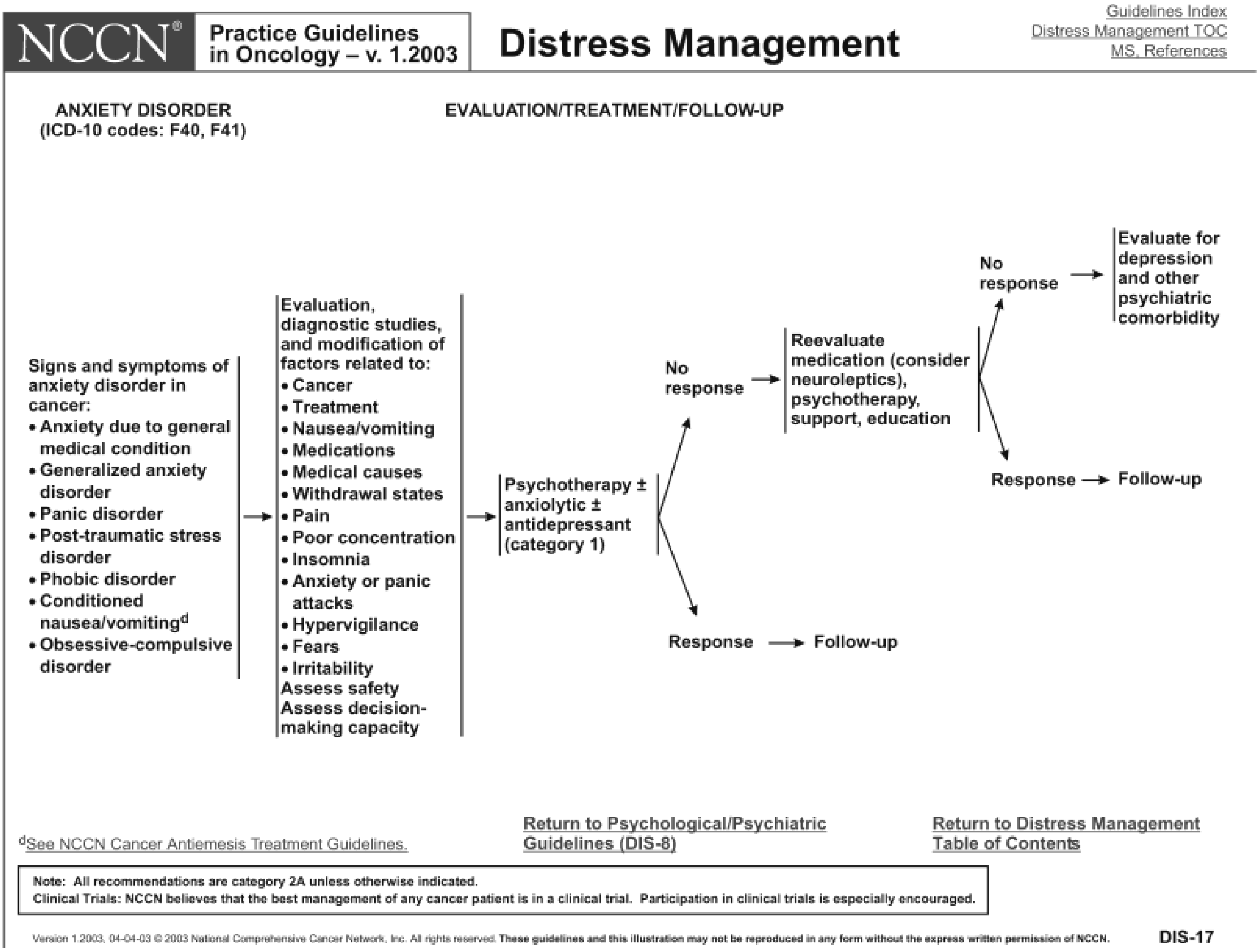
Fig. 5. Mood disorder—evaluation/treatment/follow-up. (Reproduced with permission of NCCN.)

illness or medication-related causes: neuroleptic-induced akathisia, corticosteroids, hypoxia or hypercarbia, glucose imbalance, bronchodilators, drug intoxication or withdrawal, and metabolic changes. All must be considered when failure of vital organs is occurring. Diagnosis of generalized anxiety disorder, panic, or obsessive-compulsive, occurs in this context as exacerbation of prior problems. Explanation of symptoms and preparation of the patient and family for approaching death are imperatives. Communication about fears plays an essential role in modulating patient and family anxiety and distress. Assessment of patients' safety and supportive psychotherapy, with or without an anxiolytic or antidepressant medication, is indicated. Medications to control anxiety symptoms are highly efficacious, particularly when psychotherapy is not realistic because of the level of illness. Figure 6 shows the NCCN guideline for the management of anxiety.

Practice Guidelines for Supportive Services

Social Work Services Guidelines

The guidelines developed by the interdisciplinary panel of the NCCN constitute the first algorithm-based treatment guidelines for delivery of social work services in cancer (Fig. 7). Services given by social workers fall into two domains: psychosocial and concrete services (e.g., transportation). The role of social workers varies enormously across institutions. In some, they provide all psychosocial services as they address the range of psychosocial needs of both patients and families during palliative treatment. In other settings, they are a member of a larger psychosocial team that ideally includes mental health and pastoral counselors. (See Table 1 for guidelines status.)



[d] See NCCN Cancer Antiemesis Treatment Guidelines.

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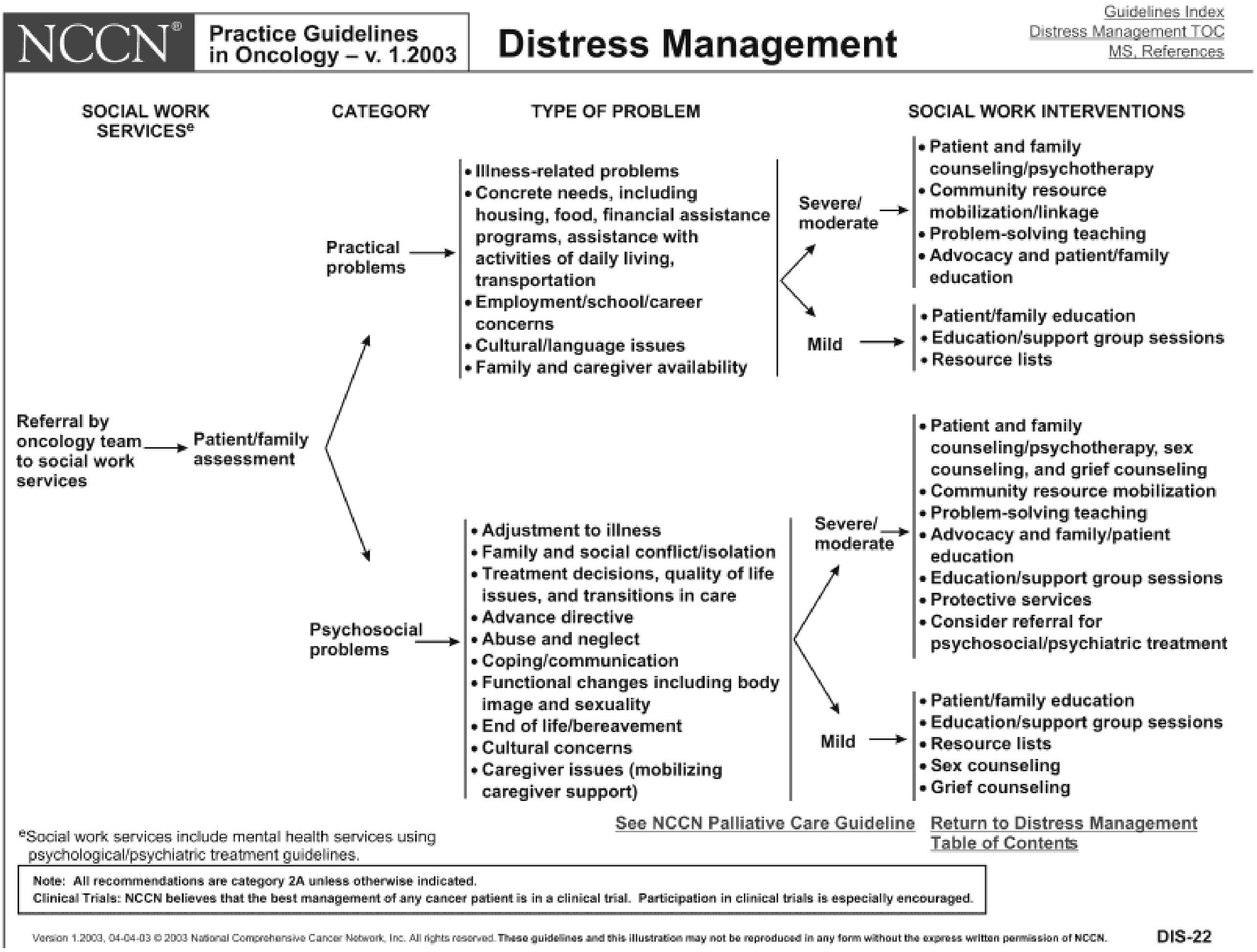
Fig. 6. Anxiety disorder—evaluation/treatment/follow-up. (Reproduced with permission of NCCN.)



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SOCIAL WORK SERVICES[e] | CATEGORY | TYPE OF PROBLEM | SOCIAL WORK INTERVENTIONS

Referral by oncology team to social work services → Patient/family assessment

Practical problems →
- Illness-related problems
- Concrete needs, including housing, food, financial assistance programs, assistance with activities of daily living, transportation
- Employment/school/career concerns
- Cultural/language issues
- Family and caregiver availability

Severe/moderate →
- Patient and family counseling/psychotherapy
- Community resource mobilization/linkage
- Problem-solving teaching
- Advocacy and patient/family education

Mild →
- Patient/family education
- Education/support group sessions
- Resource lists

Psychosocial problems →
- Adjustment to illness
- Family and social conflict/isolation
- Treatment decisions, quality of life issues, and transitions in care
- Advance directive
- Abuse and neglect
- Coping/communication
- Functional changes including body image and sexuality
- End of life/bereavement
- Cultural concerns
- Caregiver issues (mobilizing caregiver support)

Severe/moderate →
- Patient and family counseling/psychotherapy, sex counseling, and grief counseling
- Community resource mobilization
- Problem-solving teaching
- Advocacy and family/patient education
- Education/support group sessions
- Protective services
- Consider referral for psychosocial/psychiatric treatment

Mild →
- Patient/family education
- Education/support group sessions
- Resource lists
- Sex counseling
- Grief counseling

See NCCN Palliative Care Guideline

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[e] Social work services include mental health services using psychological/psychiatric treatment guidelines.

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DIS-22

Fig. 7. Algorithm-based treatment guidelines for delivery of social work services in cancer. (Reproduced with permission of NCCN.)

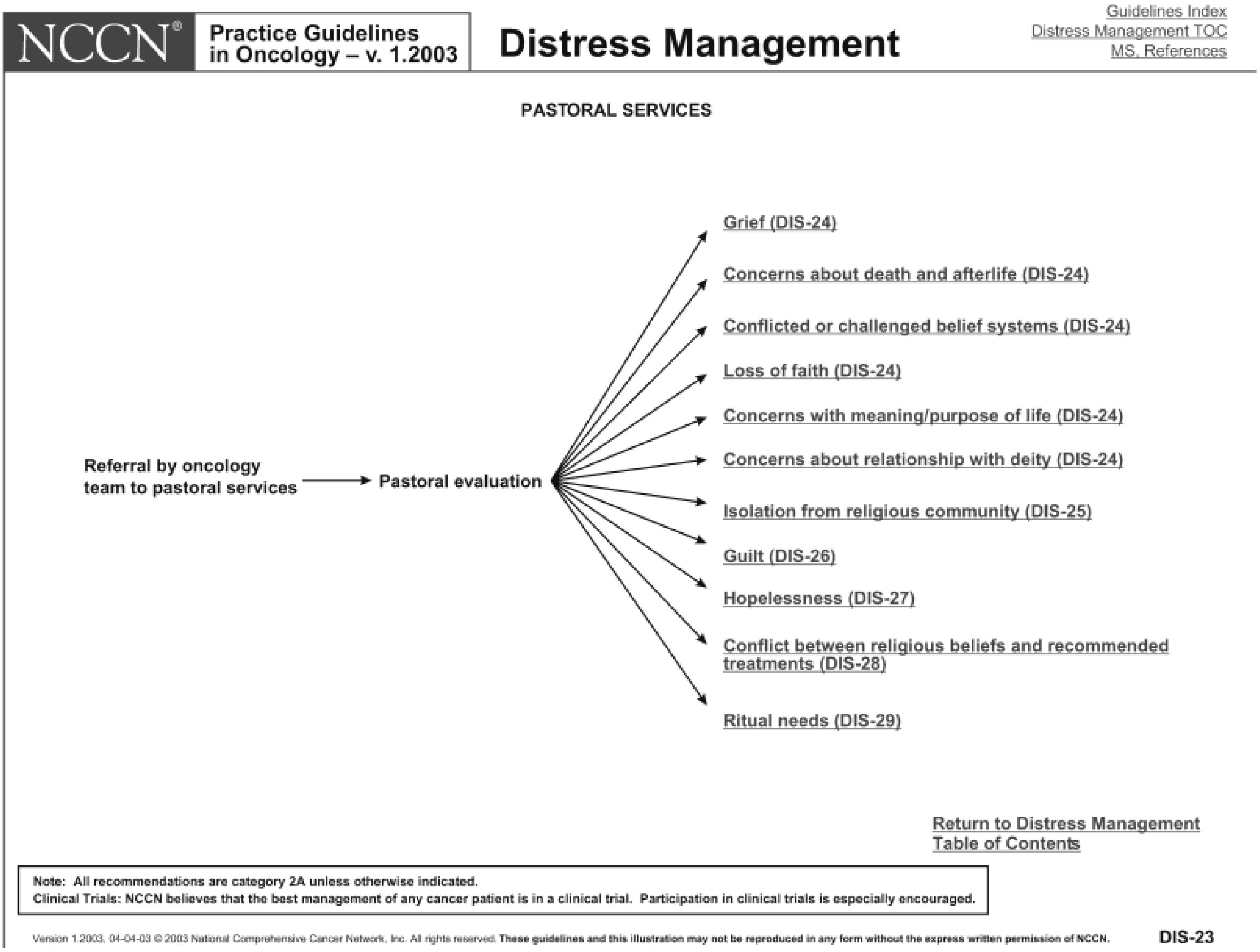
Pastoral Counseling Guidelines

Long an integral part of hospice care, interest is growing in how to better incorporate the spiritual and religious domains in mainstream palliative care, in addition to hospice settings (Post et al., 2000). The development of pastoral counseling guidelines by the NCCN (Fig. 8) underscores the need to include them in supportive, psychosocial services (Holland, 1999). When life ebbs, beliefs and philosophy take on new meaning so that the clinician should be sensitive to these areas, and refer the patient to a pastoral counselor when concerns are expressed about spiritual or religious matters (Puchalski & Romer, 2000). The common problems referred to pastoral counselors are grief, concerns about death/afterlife, conflicted belief systems, loss of faith, concerns about the meaning/purpose of life, relationship to God, isolation from religious community, guilt, hopelessness, conflicts between religious beliefs and recommended treatment, and ritual needs (Speck, 1998). Clergy who have been trained in pastoral counseling should be available to assist in end-of-life care. Problems such as guilt, hopelessness, and grief may require mental health or social work evaluation, prompting the need for close collaboration among all staff taking care of patients in a palliative setting. (See Table 1 for guidelines status.)

POLICY RECOMMENDATIONS

Doctor–Patient Communication

1. Training of doctors in communication is critical to ensure quality end-of-life care by developing simple protocol/practice guidelines and standards (see Table 1). The best teaching model is one that uses faculty from the physician's own discipline (e.g., oncologists) as well as a physician or mental health clinician skilled in teaching communication. Because such workshops have a low priority for voluntary attendance, mandating participation via



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MS, References

PASTORAL SERVICES

Referral by oncology team to pastoral services → Pastoral evaluation →

- Grief (DIS-24)
- Concerns about death and afterlife (DIS-24)
- Conflicted or challenged belief systems (DIS-24)
- Loss of faith (DIS-24)
- Concerns with meaning/purpose of life (DIS-24)
- Concerns about relationship with deity (DIS-24)
- Isolation from religious community (DIS-25)
- Guilt (DIS-26)
- Hopelessness (DIS-27)
- Conflict between religious beliefs and recommended treatments (DIS-28)
- Ritual needs (DIS-29)

Return to Distress Management Table of Contents

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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DIS-23

Fig. 8. Pastoral counseling guidelines. (Reproduced with permission of NCCN.)

required risk-management lectures is useful. The content of the skills teaching sessions is best acquired when the groups are small in number, when they use video tapes of model patterns of communication, and when they include role play that enhances awareness of/sensitivity to patients' emotional responses, and also the doctor's own responses.

2. Research is needed to determine the best teaching methods. Approaches based on a theoretical model of stress are effective, such as the Transpersonal Model of Stress, which examines the physicians' and patients' responses at each phase of the discussion (Ptacek & Eberhardt, 1996).

3. Improving communication with family is recommended, especially in view of the role families now play in physical care at the end of life, and because of the intense psychological impact of this time in their lives and for years to come. We have to explore ways to educate the family in how to manage pain, distress, and other symptoms in the patient, and how to communicate with the doctor about their concerns.

Standards for Psychosocial Care

1. Standards for psychosocial care and clinical practice guidelines for supportive services should be endorsed by major organizations involved in end-of-life care. They should be promulgated in a manner similar to that used with pain management.

2. Educational standards for end-of-life care must include training in the recognition of distress and its management by the primary care team. Such standards should also be included in the curricula of both mental health professionals (psychologists, psychiatrists, psychiatric social workers, and nurses) and the clergy qualifying as pastoral counselors.

3. Pastoral counseling should be included in psychosocial services, because they should not be fragmented and distanced from other aspects of care during end of life.

4. Patients and families must be educated to understand that the psychosocial/spiritual domains are an integral part of their end-of-life care and should not be viewed as disconnected and unrelated.

5. Governmental/managed care organizations must be made aware of the inequity in reimbursement for the nonphysical aspects of end-of-life care, which impacts negatively on ensuring quality of care to reduce suffering and distress.

SUMMARY

Algorithm-based clinical practice guidelines relating to psychiatric, psychosocial, and spiritual domains can effect a major improvement in end-of-life care by defining a gold standard for clinicians in an area not previously subjected to such a level of scrutiny. This article outlines the status of these guidelines and offers recommendations for policy development relative to doctor–patient communication and management of distress (psychological, social, existential, spiritual) and psychiatric disorders. The arching principle of these standards and guidelines is the recognition that the physical and the psychosocial are interrelated and overlapping in end-of-life care, and that patients should receive their total care as a seamless integration of physical and supportive services.

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