

NCCN

Palliative Care

Clinical Practice Guidelines in Oncology

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Abstract

These guidelines were developed and updated by an interdisciplinary group of experts based on clinical experience and available scientific evidence. The goal of these guidelines is to help patients with cancer experience the best quality of life possible throughout the illness trajectory by providing guidance for the primary oncology team for symptom screening, assessment, palliative care interventions, reassessment, and afterdeath care. Palliative care should be initiated by the primary oncology team and augmented by collaboration with an interdisciplinary team of palliative care experts. (*JNCCN* 2012;10:1284–1309)

NCCN Categories of Evidence and Consensus

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

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

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

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

All recommendations are category 2A unless otherwise noted.

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

Overview

The goal of these guidelines is to help assure that each patient with cancer experiences the best quality of life possible throughout the illness trajectory by providing guidance for the primary oncology team. The Palliative Care Panel is an interdisciplinary group of representatives from NCCN Member Institutions, comprising medical oncologists, neurologists and neuro-oncologists, anesthesiologists, psychiatrists and psychologists, internists, palliative care and pain management specialists, and geriatric medicine specialists. These guidelines were developed and updated from the collaborative efforts of these experts based on their clinical experience and available scientific evidence.

Please Note

The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) are a statement of consensus of the authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult the NCCN Guidelines® is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network® (NCCN®) makes no representation or warranties of any kind regarding their content, use, or application and disclaims any responsibility for their applications or use in any way. **The full NCCN Guidelines for Palliative Care are not printed in this issue of JNCCN but can be accessed online at NCCN.org.**

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Disclosures for the NCCN Palliative Care Panel

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

Individual disclosures for the NCCN Palliative Care Panel members can be found on page 1309. (The most recent version of these guidelines and accompanying disclosures are available on the NCCN Web site at NCCN.org.)

These guidelines are also available on the Internet. For the latest update, visit NCCN.org.

Palliative Oncology

More than 1.6 million people will be diagnosed with cancer in the United States in 2012, and more than 0.5 million people will die of the disease.¹ Global cancer rates are increasing, as is the number of cancer survivors living with symptoms and disabilities as a result of their disease and/or its treatment.² A great need exists for comprehensive care for patients with cancer and their families. Approximately 16% of patients with cancer being discharged from a single hospital in Germany were assessed as having palliative care needs, with the greatest need in patients with head and neck cancer, melanoma, and brain tumors.³ More than one-third of patients with cancer in a large observational cohort study reported moderate to severe symptoms in most categories (pain, nausea,

anxiety, depression, shortness of breath, drowsiness, well-being, loss of appetite, and tiredness) in the last weeks of life.⁴

During the past 20 years, increasing attention has been given to quality-of-life issues in oncology.^{2,5-9} As the hospice movement has grown in this country, palliative care has developed into an integral part of comprehensive cancer care.^{2,10-14} However, most patients who receive hospice care in this country are referred too late for comprehensive palliative care to exert its full benefit, and many patients are never referred at all.^{15,16} Furthermore, administration of chemotherapy late in the course of cancer care, including in the last days of life, is growing more common,^{17,18} and oncologists have reported that they have found hospice regulations too restrictive.¹⁹

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SCREENING^{a,b}

ASSESSMENT^{a,b}

ESTIMATED LIFE EXPECTANCY

Uncontrolled symptoms
or
Moderate-to-severe distress
related to cancer diagnosis
and cancer therapy
or
Serious comorbid
physical and psychosocial
conditions
or
Life expectancy ≤ 12 mo
or
Patient/family concerns
about course of disease and
decision-making
or
Patient/family requests
for palliative care

Present
Not present

- Benefits/risks of anticancer therapy
- Symptoms
- Psychosocial or spiritual distress
- Personal goals/expectations
- Educational and informational needs
- Cultural factors affecting care
- Criteria for consultation with palliative care specialist

Years
Years to months
Months to weeks
Weeks to days (dying patient)

- Inform patients and families of role and benefits of palliative care services
 - Discuss anticipation and prevention of symptoms and advance care planning
 - Rescreen at next visit

Ongoing reassessment ←

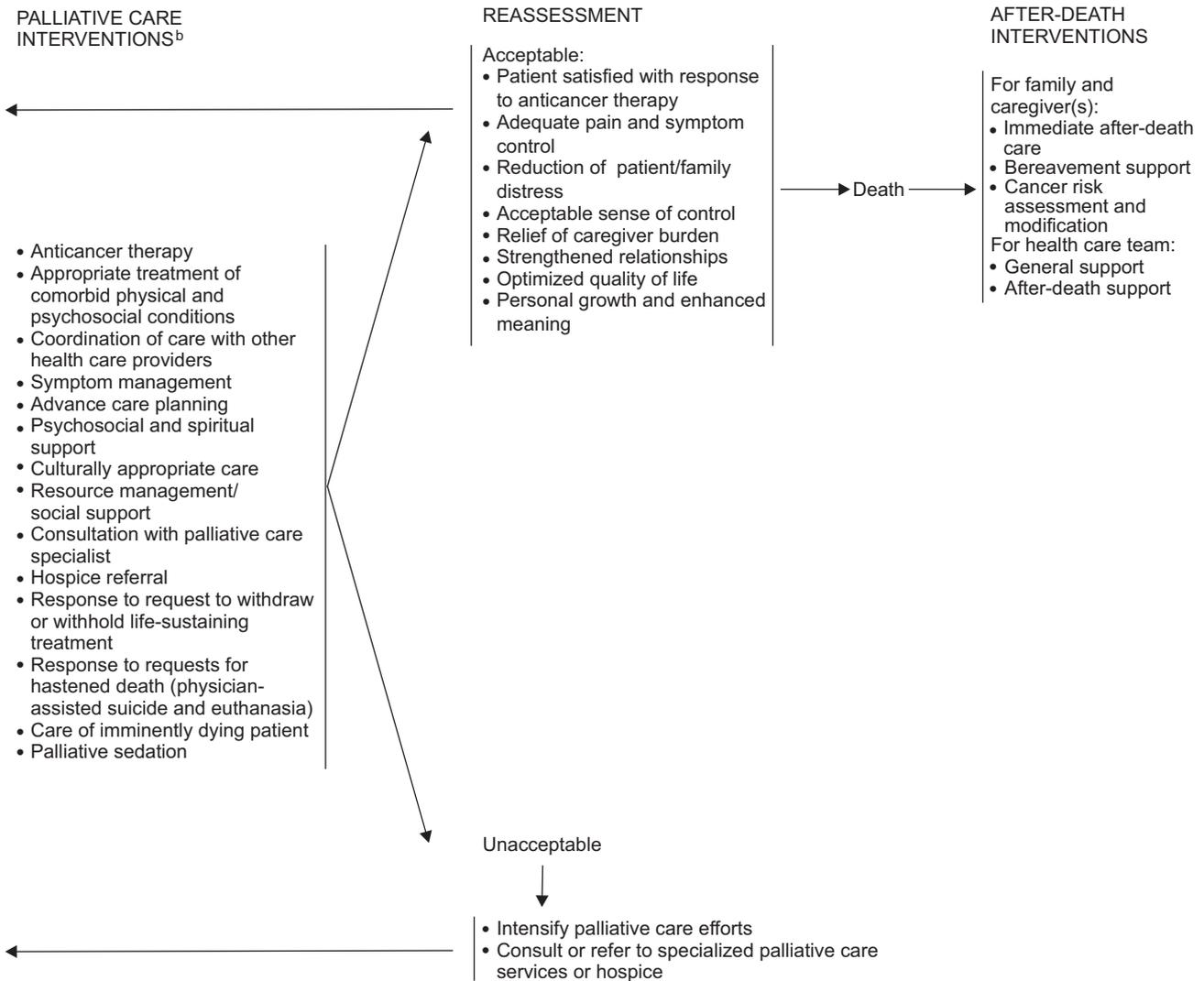
Ongoing reassessment ←

^aManagement of any patient with positive screening requires a care plan developed by an interdisciplinary team of physicians, nurses, social workers and other mental health professionals, chaplains, nurse practitioners, physician assistants, and dietitians.

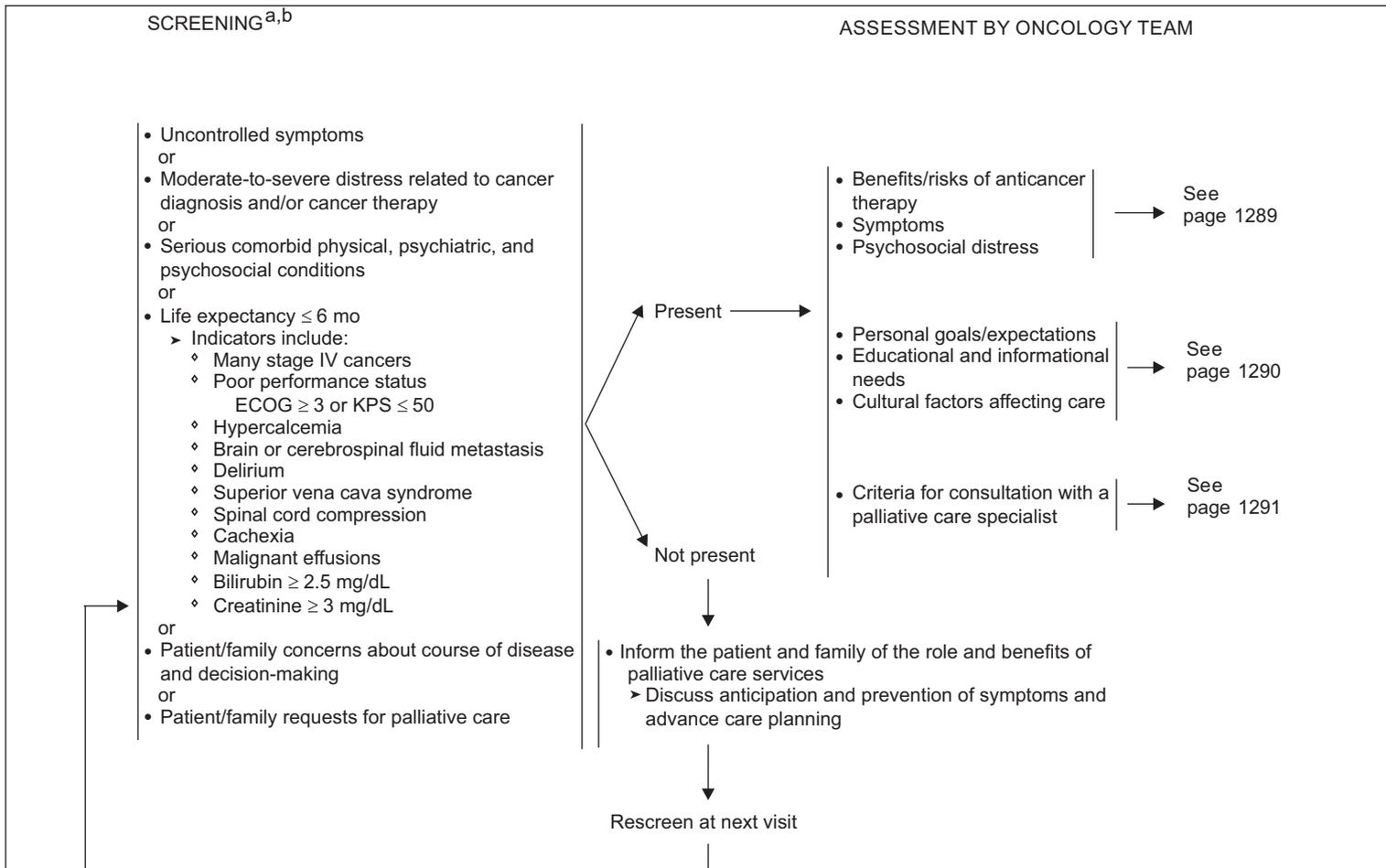
^bOncologists should integrate palliative care into general oncology care. Early consultation/collaboration with a palliative care specialist/hospice team should be considered to improve quality of life and survival.

PAL-2 (1 of 2)

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^bOncologists should integrate palliative care into general oncology care. Early consultation/collaboration with a palliative care specialist/hospice team should be considered to improve quality of life and survival.

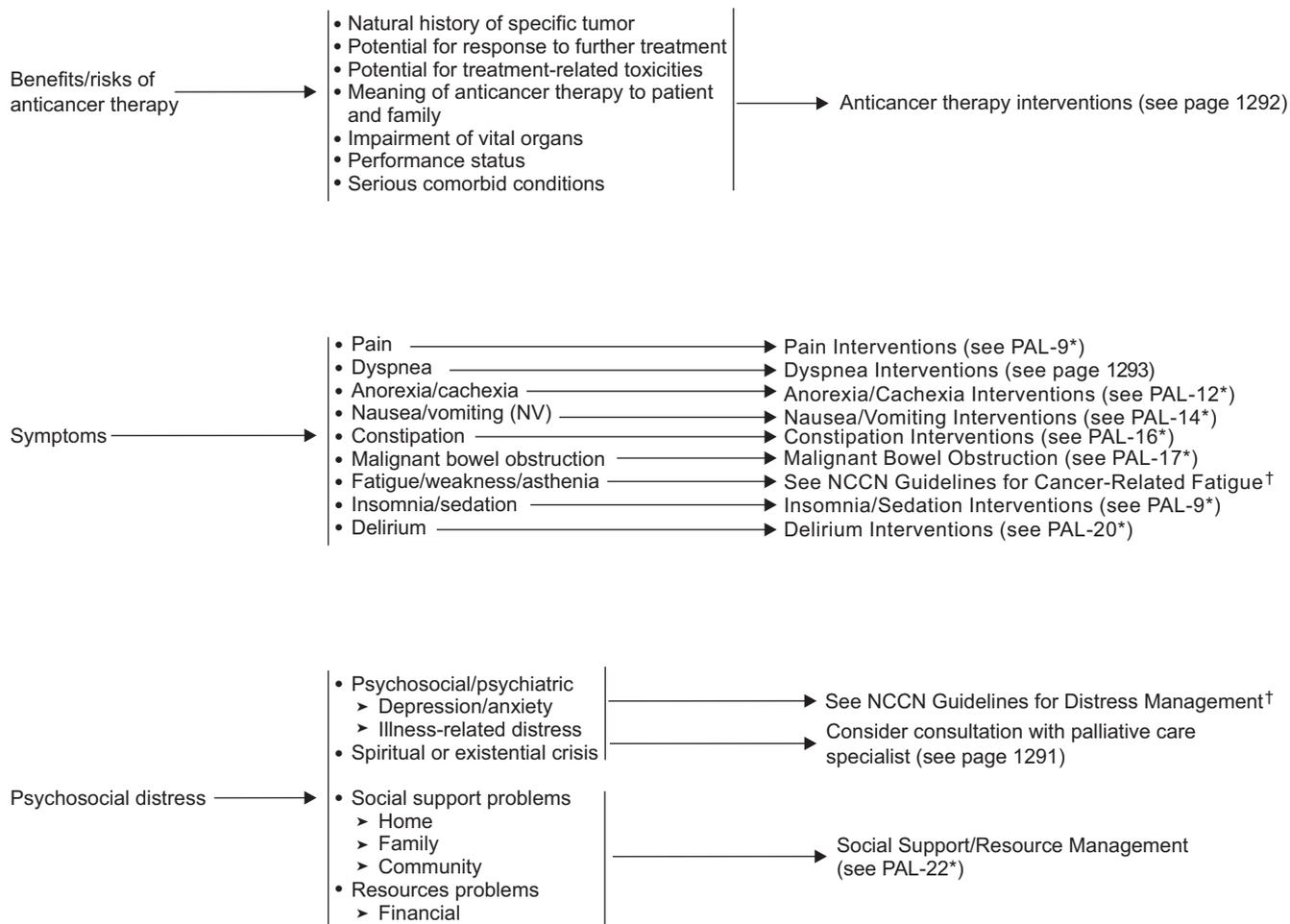


^aManagement of any patient with positive screening requires a care plan developed by an interdisciplinary team of physicians, nurses, social workers and other mental health professionals, chaplains, nurse practitioners, physician assistants, and dietitians.
^bOncologists should integrate palliative care into general oncology care. Early consultation/collaboration with a palliative care specialist/hospice team should be considered to improve quality of life and survival.

PAL-3

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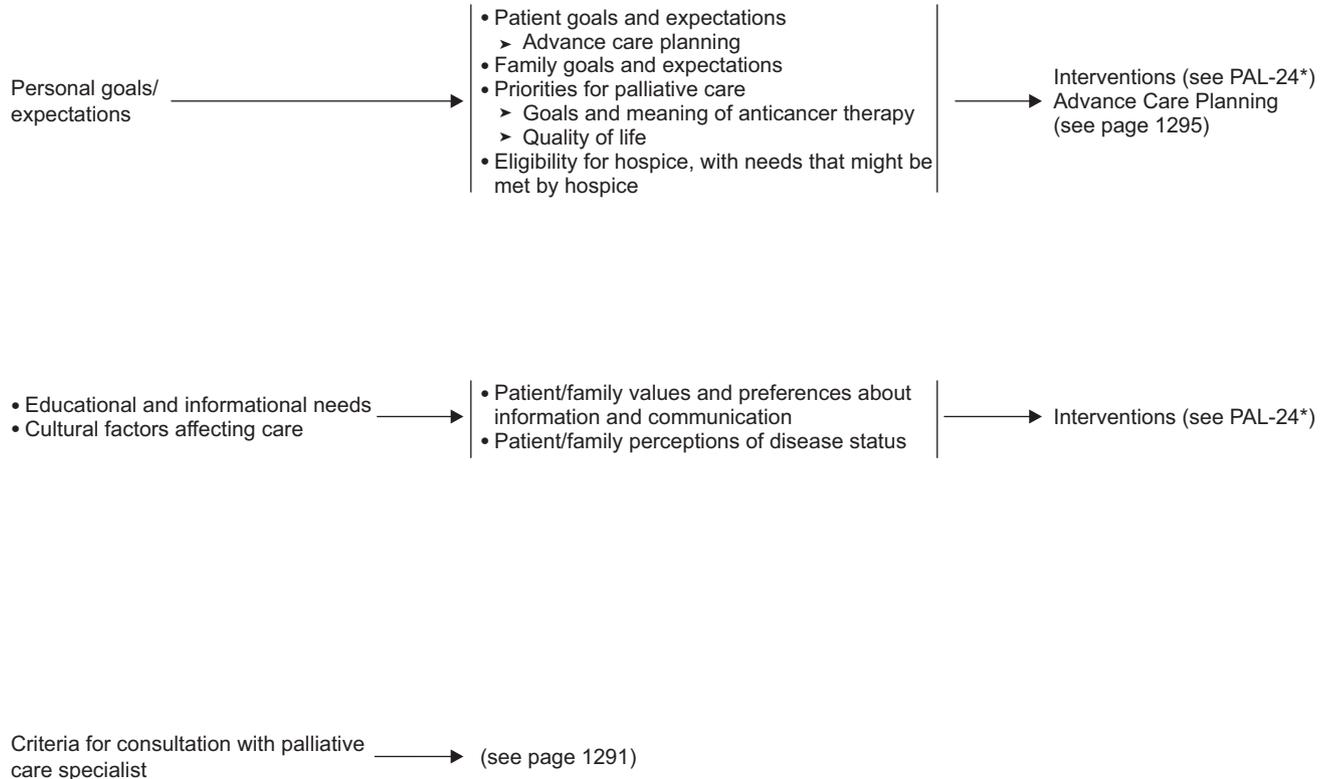
ASSESSMENT BY ONCOLOGY TEAM



*Available online, in these guidelines, at NCCN.org.

†To view the most recent version of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines), visit NCCN.org.

PALLIATIVE CARE ASSESSMENT



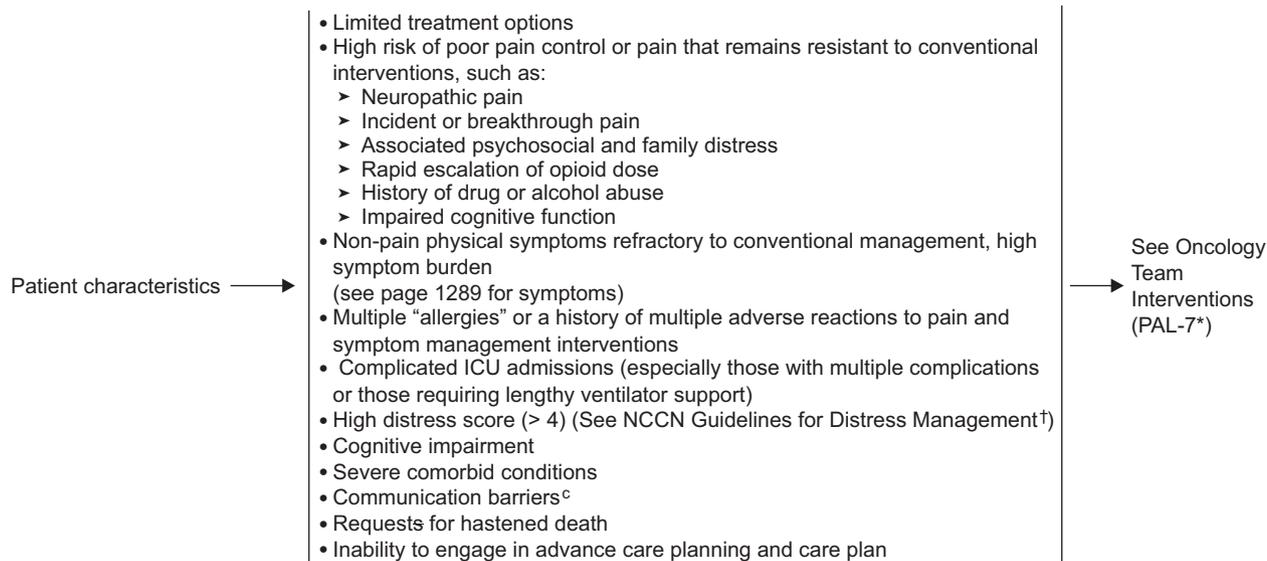
*Available online, in these guidelines, at NCCN.org.

PAL-5

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CRITERIA FOR CONSULTATION WITH PALLIATIVE CARE SPECIALIST

ASSESSMENT



Social circumstances
or
Anticipatory
bereavement issues

-
- Family/caregiver limitations
 - Inadequate social support
 - Intensely dependent relationship(s)
 - Financial limitations
 - Limited access to care
 - Family discord
 - Patient’s concerns regarding care of dependents
 - Spiritual or existential crisis
 - Unresolved or multiple prior losses

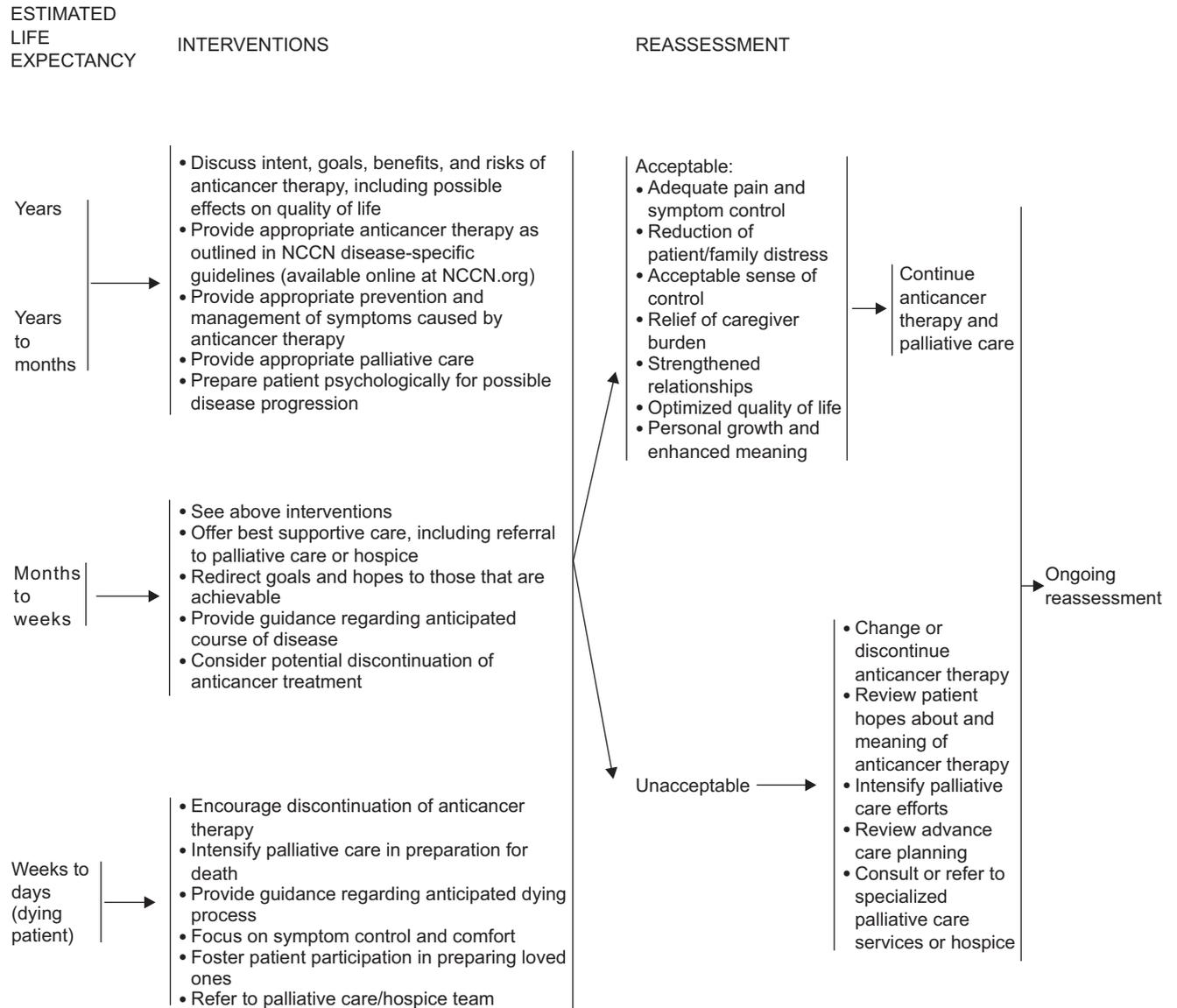
*Available online, in these guidelines, at NCCN.org

[†]To view the most recent version of these guidelines, visit NCCN.org.

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

PAL-6

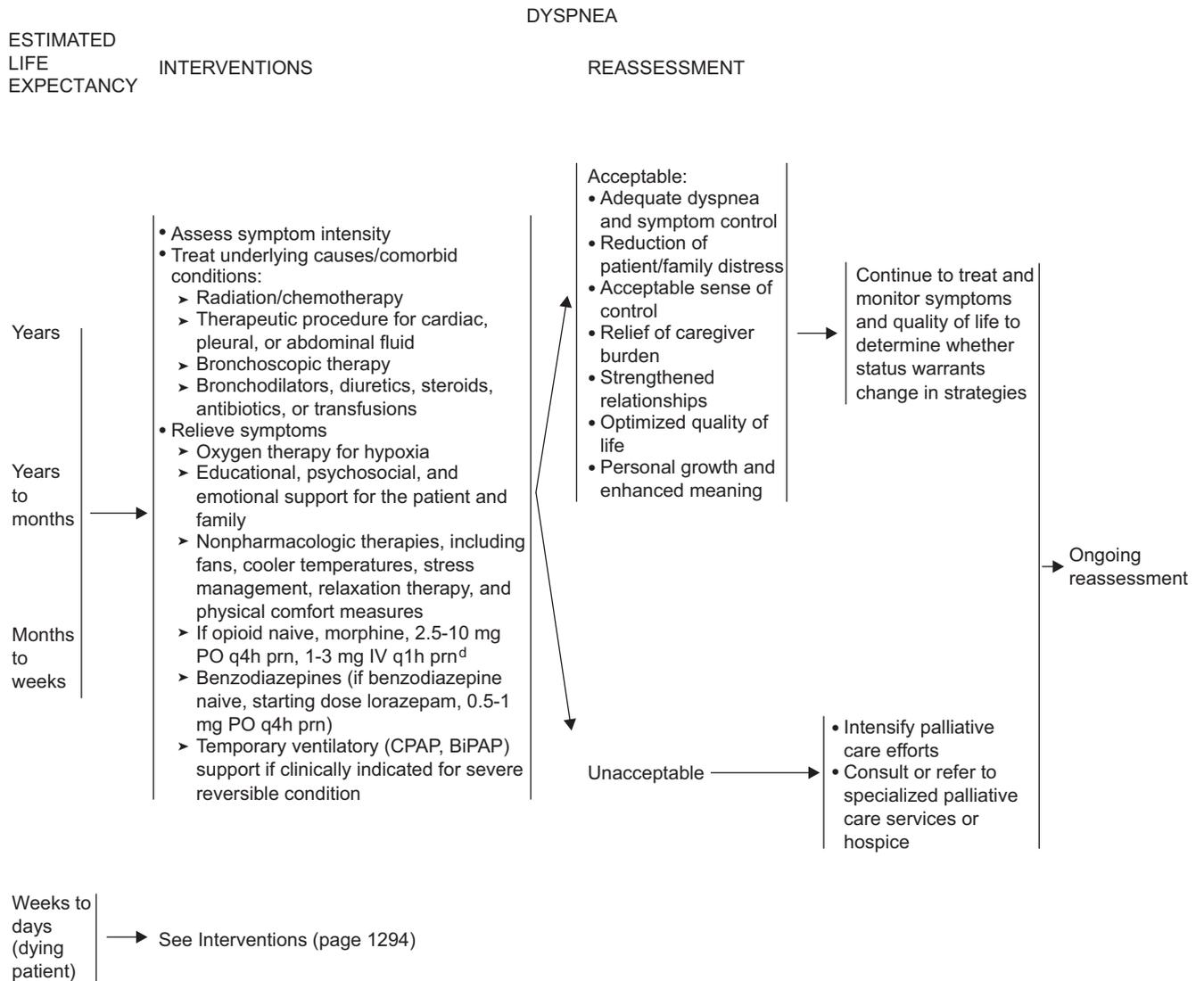
BENEFITS/RISKS OF ANTICANCER THERAPY



PAL-8

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

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^dFor acute progressive dyspnea, more aggressive titration may be required.

DYSPNEA		
ESTIMATED LIFE EXPECTANCY	INTERVENTIONS	REASSESSMENT
<p>Years</p> <p>Years to months</p> <p>Months to weeks</p> <p>Weeks to days (dying patient)</p>	<p>See Interventions (page 1293)</p> <ul style="list-style-type: none"> • Assess symptom intensity <ul style="list-style-type: none"> ➢ Use physical signs of distress as potential dyspnea in noncommunicative patients • Focus on comfort <ul style="list-style-type: none"> ➢ Continue to treat underlying condition as appropriate • Relieve symptoms <ul style="list-style-type: none"> ➢ Fans ➢ Oxygen if hypoxic and/or subjective relief is reported ➢ Nonpharmacologic therapies; educational, psychosocial, and emotional support (see page 1293) ➢ If opioid naive, morphine, 2.5-10 mg PO q4h prn, 1-3 mg IV q1h prn^d ➢ Benzodiazepines (if benzodiazepine naive, starting dose lorazepam, 0.5-1 mg PO q1h prn) ➢ Reduce excessive secretions^e with scopolamine, 0.4 mg SC q4h prn; 1.5 mg patches, 1-6 patches q3d; atropine 1% ophthalmic solution 1-2 drops SL q4h prn; or glycopyrrolate 0.2-0.4 mg IV or SQ q4h prn • Withhold/withdraw/initiate time-limited trial of mechanical ventilation as indicated <ul style="list-style-type: none"> ➢ Address patient and family preferences, prognosis, and reversibility ➢ Provide sedation as needed • Discontinue fluid support/consider low-dose diuretics if fluid overload may be a contributing factor • Provide anticipatory guidance for patient/family regarding dying of respiratory failure • Provide emotional and spiritual support 	<p>Acceptable:</p> <ul style="list-style-type: none"> • Adequate dyspnea and symptom control • Reduction of patient/family distress • Acceptable sense of control • Relief of caregiver burden • Strengthened relationships • Optimized quality of life • Personal growth and enhanced meaning <p>Unacceptable →</p> <ul style="list-style-type: none"> • Intensify palliative care interventions and consider a consultation with a palliative care specialist • Consider sedation for intractable symptoms (see PAL-30*) <p>Continue to treat and monitor symptoms and quality of life to determine whether status warrants change in strategies</p> <p>Ongoing reassessment</p>

*Available online, in these guidelines, at NCCN.org

^dFor acute progressive dyspnea, more aggressive titration may be required.

^eHughes A, Wilcock A, Corcoran R, et al. Audit of three antimuscarinic drugs for managing retained secretions. *Palliat Med* 2000;14:221-222.

PAL-11

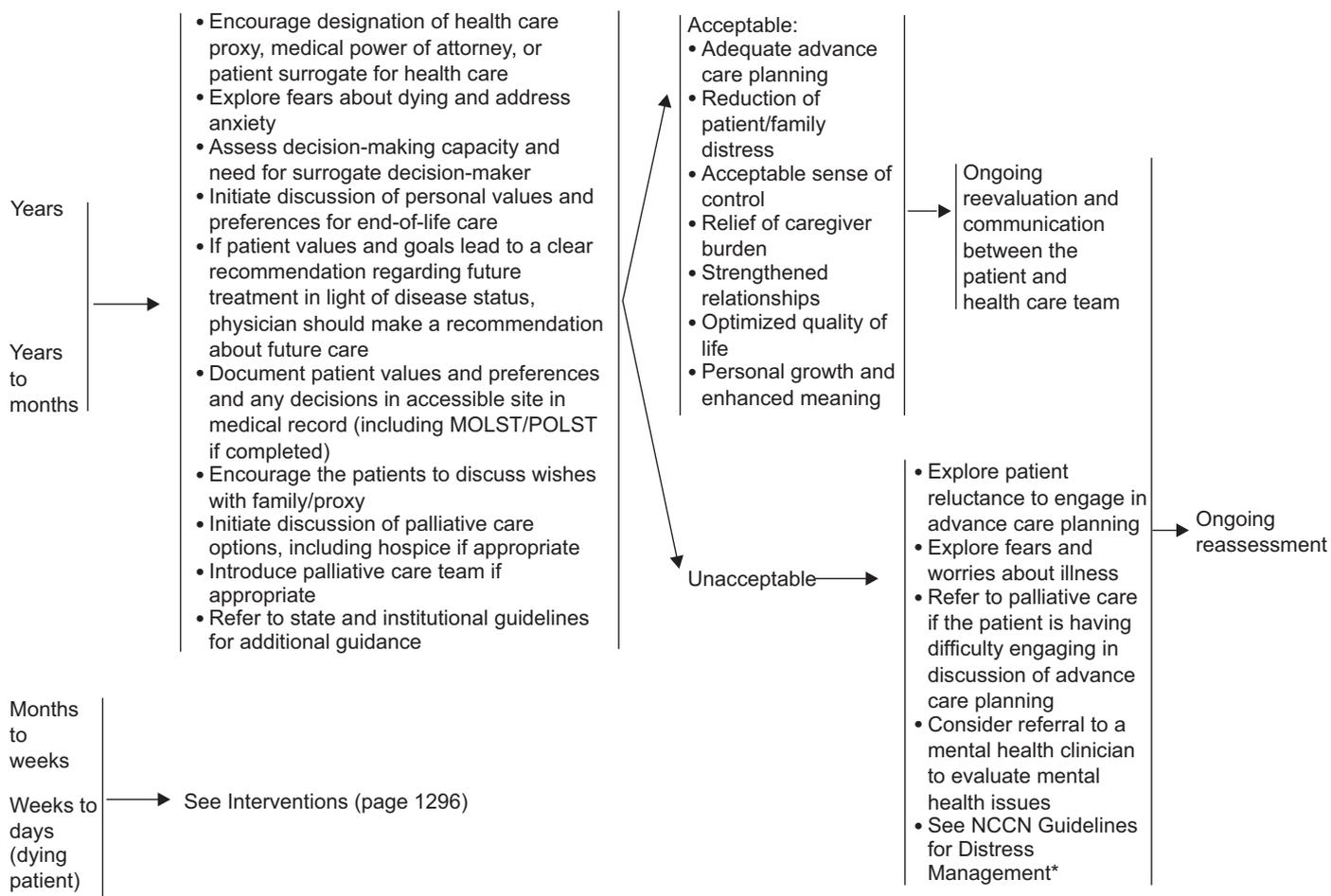
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ADVANCE CARE PLANNING

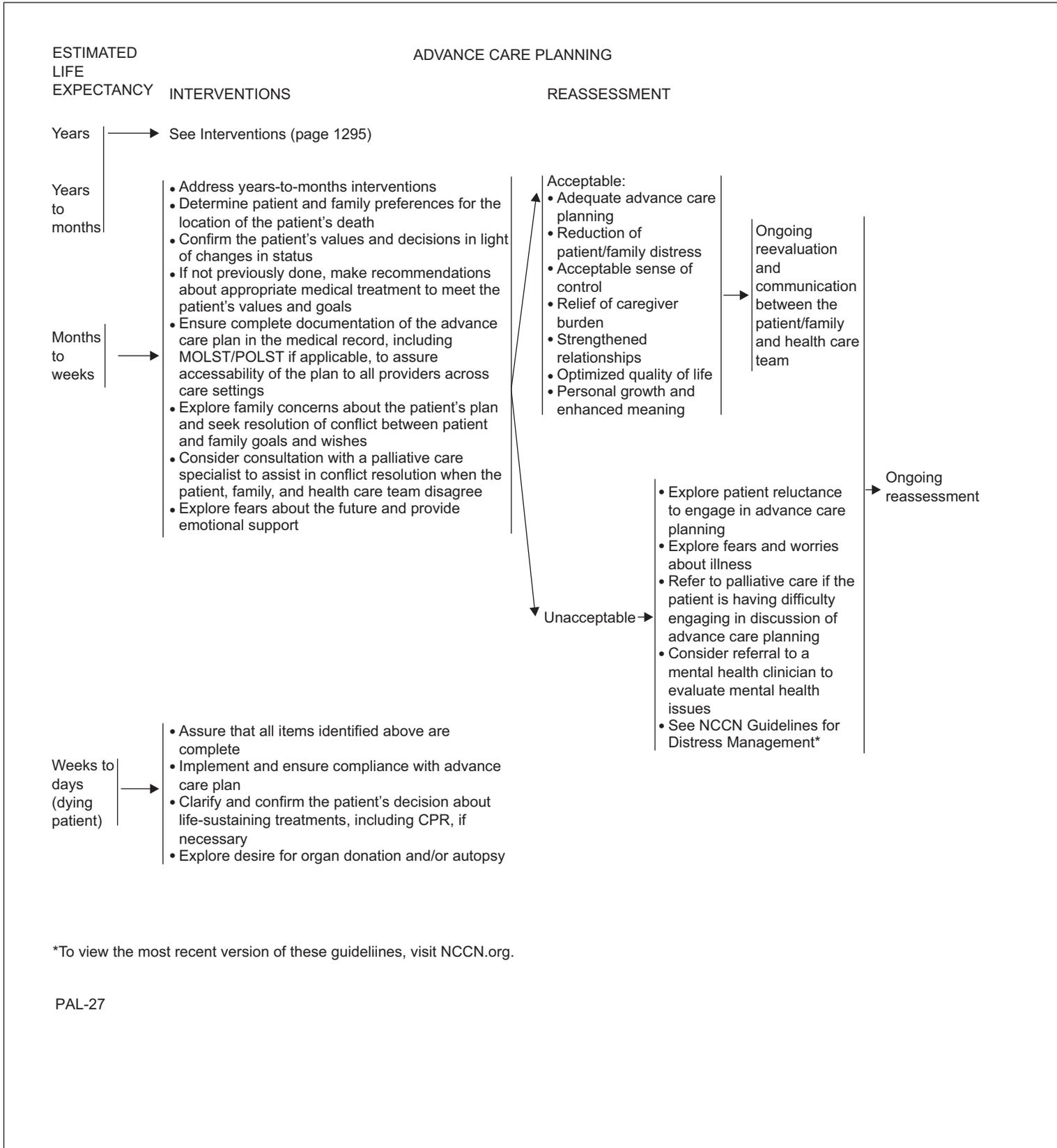
ESTIMATED
LIFE
EXPECTANCY

INTERVENTIONS

REASSESSMENT



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



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

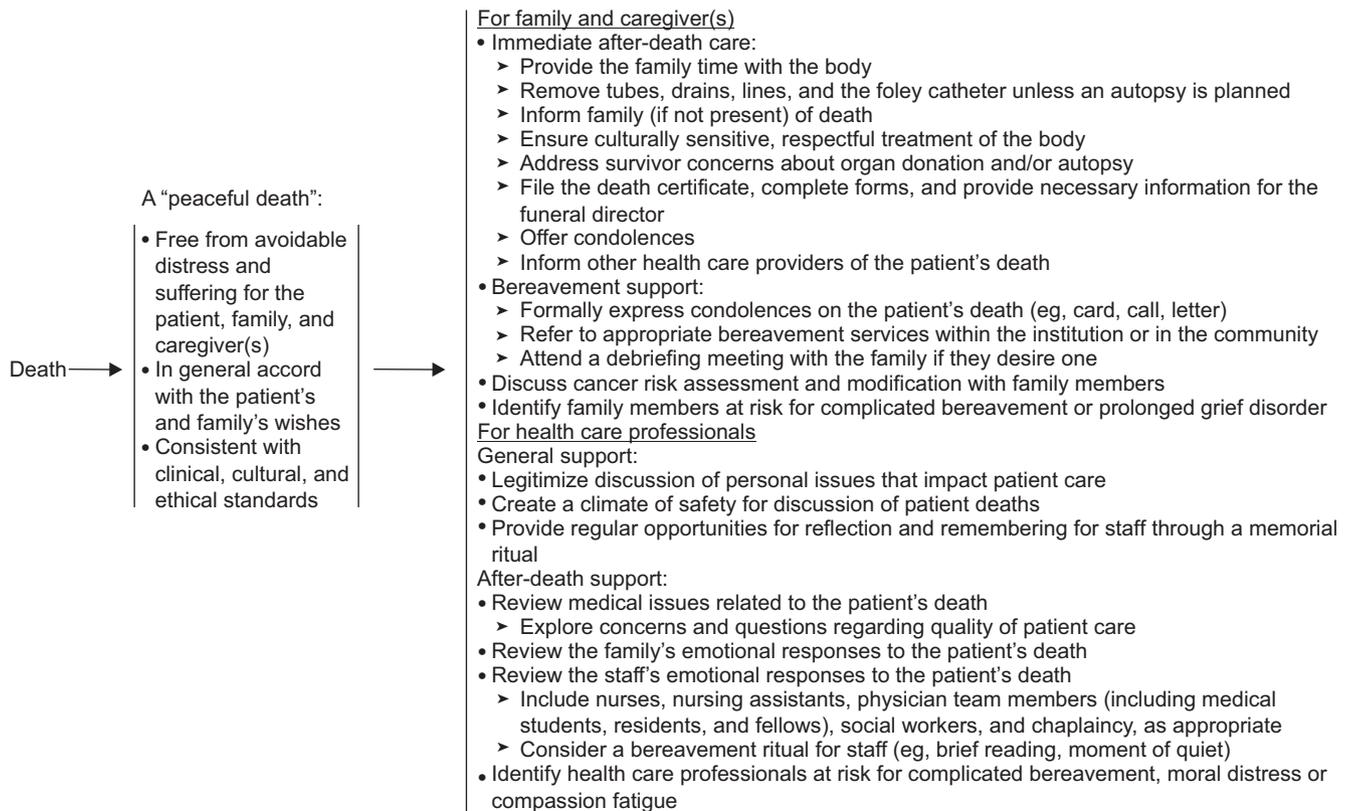
PAL-27

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DEATH

ASSESSMENT

AFTER-DEATH INTERVENTIONS



PAL-31

Palliative Care

Text continued from p. 1285

Although palliative care previously focused on end-of-life care, there is increasing understanding that palliative care must be integrated earlier into the continuum of cancer care^{20–24}; it needs to exist from the time of diagnosis through survivorship and/or end-of-life care. Palliative care should begin with the presentation of symptoms, even before the source of those symptoms has been fully determined. Building on the WHO's recommended model of resource allocation in cancer care,¹⁰ an NCCN task force recommended that palliative symptom-modifying therapy should be provided simultaneously with disease-modifying therapy from diagnosis.²⁵ As the cancer progresses and anticancer therapy becomes less effective, appropriate and desired palliative care becomes the major focus of the continuing care for the patient and family.²⁶ Patients with increased risk for cancer should also be provided with supportive care, along with risk-reduction therapies. Palliative care should continue even after the patient's death in the form of bereavement support for the survivors.

Patients and families should be informed that palliative care is an integral part of their comprehensive cancer care.^{27,28} Initially, the primary oncology team (interdisciplinary team of physicians, nurses, social workers, other mental health professionals, chaplains, physician assistants, and dietitians) can provide most of the palliative care needed by the patient. Intractable symptoms or complex psychosocial problems can benefit from the inclusion of palliative care experts. As the disease progresses and the prognosis becomes a matter of months, collaboration with palliative/hospice teams is usually advised to best meet the many needs of the patient and family. Skilled palliative care specialists and interdisciplinary palliative care teams should be readily available to provide consultative or direct care to patients/families that request or require their expertise. Clear, consistent, and empathetic communication with patient and family about the natural history of the cancer and its prognosis is at the core of effective palliative care.^{29,30} The Center to Advance Palliative Care (www.capc.org) was established to increase the availability of quality palliative care services in hospitals and other health care settings for people with advanced illness.

In February 2012, ASCO published a provisional clinical opinion based on 7 randomized controlled trials and expert consensus.³¹ The ASCO panel

stated that there is substantial evidence to show that “palliative care – when combined with standard cancer care or as the main focus of care – leads to better patient and caregiver outcomes.” The ASCO panel concluded that strong consideration should be given to the integration of palliative care with standard oncology care early in the course of illness for patients with metastatic cancer and/or high symptom burden.

A remarkable recent study showed that early introduction of palliative care can not only improve quality of life for patients with advanced cancer but also improve survival.³² A secondary analysis of this study further showed that patients receiving early palliative care were less likely to receive chemotherapy in the last 60 days of life (odds ratio, 0.47; 95% CI, 0.23–0.99; $P = .05$),³³ probably because they had a more accurate understanding of their prognosis, which impacted decisions about their care.³⁴ In addition, a recent analysis of the SEER database revealed that men with advanced prostate cancer who were enrolled in hospice were less likely to receive high-intensity care, including intensive care unit (ICU) admission and inpatient stays, at the end of life.¹⁵

Educational programs should be provided to all health care professionals and trainees so that they can develop effective palliative care knowledge, skills, and attitudes. The number of palliative care programs in the United States is rapidly increasing. The establishment of palliative medicine as a medical subspecialty received an unprecedented level of support from at least 10 cosponsoring American Board of Medical Specialties (ABMS; www.abms.org) boards, including Anesthesiology, Family Medicine, Internal Medicine, Physical Medicine and Rehabilitation, Psychiatry and Neurology, Surgery, and Pediatrics. Support for expansion of palliative medicine education has been offered by the Liaison Committee on Medical Education (LCME; www.lcme.org), which has mandated palliative medicine education for medical schools. In addition, the Accreditation Council for Graduate Medical Education (ACGME; www.acgme.org) now requires training in palliative medicine for oncology fellows, including training in pain, psychosocial care, personal awareness, and hospice care. A recent randomized controlled trial showed that specific training programs for oncologists can be effective.³⁵ Unfortunately, however, a recent survey of 254 hematology/oncology fellows

found that palliative care education is still lacking, with only 32% of respondents reporting formal training in managing end-of-life depression and only 33% reporting explicit training in opioid rotation.³⁶

Assessing outcomes and evaluating palliative cancer care are essential to ensure high-quality, evidence-based care. Lorenz et al³⁷ performed a systematic review of end-of-life care and outcomes and found that many aspects of palliative care lack high-quality evidence. The second edition of the Clinical Practice Guidelines for Quality Palliative Care by the National Consensus Project was published in 2009,³⁸ and the National Quality Forum has developed a national quality framework for evaluating palliative care programs, extending beyond terminally ill patients with cancer to include a broad spectrum of patients with multiple illnesses.³⁹ These guidelines provide an in-depth assessment of many issues surrounding palliative care (eg, cultural, ethical, legal, physical, psychological, social, spiritual, and existential aspects of care). In addition, the American College of Physicians developed evidence-based guidelines to improve palliative care of pain, dyspnea, and depression experienced at the end of life.⁴⁰

In the United Kingdom in 2004, the National Consensus Project and the National Institute for Health and Clinical Excellence (NICE) issued guidance on how supportive and palliative care services should be provided for adults with cancer.⁴¹ Some of the key recommendations are listed below:

- Patients and their caregivers should have access to a range of specialist services that help them cope with cancer and its treatment.
- Whenever possible, significant information should be given to patients by a senior health professional who has received advanced level training and is assessed as being an effective communicator.
- Good-quality information should be available free of charge to help people affected by cancer make decisions about their care.

ASCO recently published a statement on individualized care for patients with advanced cancer.⁸ Although significant improvements over the past decade were noted (eg, improvements in palliative care education and training for oncologists, and an increase in hospital-based palliative care programs and community-based hospice organizations), the statement points out that conversations with patients about their palliative needs are still happening

too late in the progression of their disease. Some of the key elements of individualized care listed in the report state that patients should be given

- enough information to enable them to make informed choices regarding their treatment,
- encouragement to focus on symptom-directed palliative care when disease-directed therapies fail,
- the opportunity to participate in clinical trials that may improve their outcome or that of future patients, and
- the opportunity to die with dignity and peace of mind.

Other resources that may be useful for patients, their caregivers, and/or clinicians are listed in Table 1 available online, in these guidelines, at NCCN.org (MS-19).

Palliative Care Standards

In August 2011, the Commission on Cancer (CoC) of the American College of Surgeons (ACS) released new accreditation standards for hospital cancer programs (<http://www.facs.org/news/2011/coc-standards0811.html>).⁴² Their patient-centered focus requires that patients have access to palliative and hospice care, psychosocial support, and pain management, either on-site or by referral. The standards also state that palliative care should be provided by an interdisciplinary team of medical and mental health professionals, social workers, and spiritual counselors, and should be available beginning at the time of diagnosis and continuously throughout treatment, surveillance, and bereavement.

Palliative Care Guidelines

These NCCN Guidelines were developed to facilitate the appropriate integration of palliative care into oncology practice. The guidelines outline procedures for screening, assessment, palliative care interventions, reassessment, and after-death care. The panel chose to focus on the needs of patients in their last 12 months of life. The panel chose this period to distill the content of textbooks and curricula into guidelines that could facilitate clinical decision-making in the same way that NCCN disease- and symptom-oriented guidelines have, although patients and families can certainly benefit from palliative care integrated throughout the illness trajectory.

Palliative Care

The guidelines define palliative care as a special kind of patient- and family-centered health care that focuses on effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient/family needs, values, beliefs, and cultures. The goals of palliative care are to anticipate, prevent, and reduce suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care begins at diagnosis and should be delivered concurrently with disease-directed, life-prolonging therapies and should facilitate patient autonomy, access to information, and choice. Palliative care becomes the main focus of care when disease-directed, life-prolonging therapies are no longer effective, appropriate, or desired. Palliative care should be initiated by the primary oncology team and then augmented by collaboration with an interdisciplinary team of palliative care experts.

Palliative Care Screening

The primary oncology team should screen all patients at every visit for 1) uncontrolled symptoms; 2) moderate to severe distress related to cancer diagnosis and therapy; 3) serious comorbid physical, psychiatric, and psychosocial conditions; 4) life expectancy of 6 months or less; 5) patient or family concerns about the disease course and decision-making; and/or 6) a specific request for palliative care by the patient or family. Patients who meet these screening criteria should undergo a full palliative care assessment.

Patients who do not meet these screening criteria should be rescreened at the next visit. In addition, the oncology team should inform patients and their family members about the role and benefits of palliative care services. Anticipation of palliative care needs and prevention of symptoms should also be discussed, and conversations regarding advance care planning should be initiated.

Palliative Care Assessment

Patients who meet screening criteria should undergo a comprehensive palliative care assessment by their primary oncology team to evaluate the benefits and risks of anticancer therapy; physical symptoms; psychosocial or spiritual distress; personal goals and expectations; educational and informational needs; and cultural factors affecting care.⁵⁻⁷

Benefits and Risks of Anticancer Therapy: Assessment of the benefits and risks of anticancer therapy is based on the existing NCCN disease-specific guidelines (available online at NCCN.org). Special attention should be given to the natural history of the specific tumor; the potential for response to further treatment; the meaning of anticancer therapy to patient and family; the potential for treatment-related toxicities, including impairment of vital organs and performance status; and serious comorbid conditions. Specific recommendations regarding anticancer therapy for patients with various life expectancies are discussed in “Palliative Care Interventions,” page 1301.

Physical Symptoms: The most common symptoms that must be assessed are pain, dyspnea, anorexia, cachexia, nausea, vomiting, constipation, malignant bowel obstruction, fatigue, weakness, asthenia, insomnia, daytime sedation, and delirium.

Psychosocial Distress: Assessment of psychosocial distress should focus on illness-related distress and psychosocial, spiritual, or existential issues according to the NCCN Guidelines for Distress Management (to view the most recent version of these guidelines, visit NCCN.org). Special problems with social support and resources (ie, home, family, community, or financial issues) must also be assessed. Recommendations for the management of psychosocial distress can be found in the NCCN Guidelines for Distress Management and in these guidelines, available online, at NCCN.org.

Personal Goals and Expectations: Patients and their families should also be asked about their personal goals and expectations. Their priorities for palliative care, including their goals and perceived meaning of anticancer therapy and the importance they place on quality of life, should be assessed. Goals and expectations that might be better met by the hospice model of palliative care should be identified.

Educational and Information Needs and Cultural Factors Affecting Care: The values and preferences of patients and families about information and communication should also be assessed. The oncology team should inquire about cultural factors affecting care and the patient/family’s perceptions of the patient’s disease status.

Consultation With Palliative Care: Criteria for consultation with a palliative care specialist are based on patient characteristics, social circumstances, and

Palliative Care

anticipatory bereavement issues. The oncology team should consider consultation in the case of patients with limited treatment options; refractory nonpain symptoms or a high symptom burden; history of allergies or adverse effects to multiple palliative interventions; complicated ICU admissions; a high distress score (≥ 4 ; see the NCCN Guidelines for Distress Management, available online at NCCN.org); cognitive impairment; severe comorbid conditions; or communication barriers. In addition, consultation with palliative care specialists should be considered for those at high risk for poor pain control; those who make requests for hastened death; and/or those who are unable to engage in advance care planning. Social circumstances or anticipatory bereavement issues that indicate a need for referral for consultation with a palliative care specialist include family/caregiver limitations, inadequate social support, financial limitations, limited access to care, family discord, intensely dependent relationships, financial limitations, limited access to care, patient concern regarding care of dependents, spiritual or existential distress, and/or unresolved or multiple prior losses.

Palliative Care Interventions

The oncology team should initiate palliative treatments following the specific recommendations described in these guidelines for common symptoms. Comorbid physical and psychosocial conditions should be treated by appropriate clinicians. Consultation or collaboration with palliative care specialists or teams is recommended for patients with more complex problems to improve their quality of life and survival.^{31,32} Referrals should be made as needed to mental health and social services, health care interpreters, hospice services, or other specialists. Finally, the oncology team can be helpful in mobilizing community support through religious organizations, schools, or community agencies.

The panel divided patients into 3 groups to address the effect of life expectancy on the delivery of palliative care interventions: 1) those with years to months to live, 2) those with months to weeks to live, and 3) dying patients in their final weeks to days. Patients in their final hours of life are referred to as *imminently dying* and may require special interventions. The panel recognizes the lack of precision in estimating life expectancy but believes that this delineation will be useful for the delivery of appropriate palliative care interventions. The patient and

family's personal, spiritual and existential, cultural, and religious goals and expectations may change throughout these time frames. Optimal provision of palliative care requires ongoing reassessment and modification of strategies, and ongoing communication among the patient, family, and health care team.

Indicators that patients are in their last 6 months of life include decreased performance status (ECOG score ≥ 3 ; Karnofsky performance score ≤ 50), hypercalcemia, central nervous system metastases, delirium, superior vena cava syndrome, spinal cord compression, cachexia, malignant effusions, liver failure, kidney failure, and other serious comorbid conditions. Many patients with stage IV cancers, especially those with stage IV lung cancer, pancreatic cancer, and glioblastoma multiforme, would benefit from palliative care beginning at diagnosis, because expected survival is limited.

For patients whose life expectancy is “years to months” or “months to weeks,” it is important to determine how much information a patient wishes to know and how much of that information should be shared with the patient's family. Patients will also require answers to any questions about what to expect in the next few months, and anticipatory guidance on the dying process. In addition, determining the decision-making styles of patients and their families helps facilitate congruence of a patient's goals and expectations with those of the family. Clinicians should also determine the patient's assessment of the relative importance of quality of life compared with length of life. Patients should be assisted in reviewing and revising their life priorities, resolving their unfinished business, and putting their financial and personal affairs in order.

Dying patients may wish to prepare for death and help prepare family members to go on without them. Both patients and families benefit from education on the dying process. Families should be guided through their anticipatory grief, and arrangements should be made to ensure that the patient's and family's needs and goals regarding the dying process are respected. Planning to ensure continuing care and referrals to appropriate care is important. Arrangements should be available to ensure that the patient does not die alone unless that is the patient's preference.

Clinicians should discuss the prognosis with patients and their families clearly and consistently to help them develop realistic expectations. Informa-

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tion about the natural history of the specific tumor and the realistic outcomes of anticancer therapy should be included in the discussion. Many investigators have shown that seriously ill middle-aged and older patients tend to be more optimistic and less accurate about their prognosis than their physicians; such misunderstanding of the situation can affect patients' preferences for cardiopulmonary resuscitation and life-extending measures.⁴³

Spiritual, existential, and cultural issues are often best addressed through collaboration with pastoral care counselors, professional translators, the patient's personal clergy, and representatives from the patient's cultural community. Religious and cultural issues surrounding the beliefs and practices near the time of death must be anticipated and carefully managed.⁴⁴ Finally, social and spiritual support and resource management interventions should be provided to ensure a safe end-of-life care environment, a competent primary caregiver, and access to necessary medications and treatments. Providers must be sensitive to cultural values that may influence the best way for this information to be presented and discussed.

Palliative care interventions for managing specific symptoms and the benefits and risks of anticancer therapy are discussed in the following sections as outlined in the algorithms (for a more detailed discussion of symptom management, see the full version of these guidelines, available online, at NCCN.org). Additional palliative care interventions for other symptoms will be developed as deemed necessary.

Anticancer Therapy: Patients who have years to months to live and a good performance status are likely to be interested in continuing anticancer therapy to prolong survival and reduce cancer-related symptoms.⁴⁵⁻⁴⁸ Anticancer therapy may be conventional evidence-based treatment as outlined in the NCCN disease-specific guidelines (available online at NCCN.org), or treatment in the context of a clinical trial. For some of the advanced-stage cancers, chemotherapy may be superior to best supportive care and may prolong survival.^{49,50} Furthermore, patients with advanced non-small cell lung cancer who are not eligible for systemic chemotherapy may benefit from targeted therapies that are effective for relieving symptoms, maintaining stable disease, and improving quality of life without the adverse events that may be associated with cytotoxic cancer thera-

pies.⁵¹ Physicians, patients, and their families should discuss intent, goals, range of choices, and benefits and risks of anticancer therapy, and possible effects on quality of life. In addition, the oncology team should prepare the patient psychologically for possible disease progression.

Patients with months to weeks to live should be provided with guidance regarding the anticipated course of the disease. These patients are typically tired of therapy, homebound, and more concerned about the side effects of more treatment. The focus of treatment for these patients shifts from prolonging life toward maintaining quality of life. These patients should consider potential discontinuation of anticancer treatment and be offered best supportive care, including referral to palliative care or hospice.^{52,53} To avoid demeaning the value of end-of-life care, palliative care should not be described as "just hospice."

In general, patients with weeks to days to live (ie, dying patients) should not be given anticancer therapy, but should be given intensive palliative care focusing on symptom control and preparation for the dying process.

Symptoms: Special considerations in the implementation of these guidelines based on life expectancy are delineated in the algorithms. The major focus of these special considerations is the withholding and withdrawal of aggressive interventions, prevention and elimination of side effects associated with pharmacologic pain management, the acceptance of loss of function for the sake of symptom relief, and the treatment of unique symptoms in the final hours of life. With regard to symptoms, the control of pain, dyspnea, anorexia/cachexia, nausea and vomiting, constipation, malignant bowel obstruction, fatigue, delirium, and psychological distress is fundamental and discussed in detail in the full version of these guidelines, available online at NCCN.org. Dyspnea in particular is discussed here.

Dyspnea: Dyspnea is one of the most common symptoms in patients with advanced lung cancer.⁵⁴ The American Thoracic Society consensus statement defines dyspnea as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity."⁵⁵

Symptom intensity should first be assessed in all patients. Symptom intensity in noncommunicative patients with weeks to days to live should be assessed using other distress markers of dyspnea. Next, under-

lying causes or comorbid conditions should be treated using chemotherapy or radiation therapy; therapeutic procedures for cardiac, pleural, or abdominal fluid⁵⁶⁻⁵⁸; bronchoscopic therapy; or bronchodilators, diuretics, steroids, antibiotics, or transfusions.

Both pharmacologic and nonpharmacologic interventions have been assessed for management of dyspnea. A recent review concluded that few definitive data are available evaluating the effectiveness of dyspnea interventions, and that randomized controlled trials are needed.⁵⁹ Other reviews have determined that data are sufficient to make treatment recommendations.^{57,60} Pharmacologic interventions include opioids or benzodiazepines.^{57,61-64} Scopolamine, atropine, hyoscyamine, and glycopyrrolate are options to reduce excessive secretions associated with dyspnea.⁶⁵⁻⁶⁹ Glycopyrrolate does not effectively cross the blood-brain barrier⁷⁰ and thus is less likely than the other drug options to cause delirium.^{71,72} Scopolamine can be administered subcutaneously or transdermally; however, physicians should be aware that the onset of benefit with transdermal scopolamine patches is approximately 12 hours,⁷³ and they are therefore not an appropriate choice for imminently dying patients. A subcutaneous injection of scopolamine can be administered when the patch is applied or if control of secretions is inadequate. Benzodiazepines can be tried for treatment of dyspnea when other options have failed, but their beneficial effect on breathing in patients with advanced cancer is small.⁶⁴

A recent study revealed that nebulized fentanyl reduces the intensity and unpleasantness of dyspnea in patients with chronic obstructive pulmonary disease.⁷⁴ Nebulized fentanyl has not yet been studied in patients with cancer, but can be considered in patients who do not respond well to the other interventions in these guidelines.

Nonpharmacologic interventions include the use of handheld fans directed at the face. A randomized, controlled, crossover trial showed that breathlessness was reduced in patients when they directed a handheld fan toward their faces.⁷⁵ A time-limited trial of mechanical ventilation, as clinically indicated, and/or oxygen therapy for hypoxia may also be beneficial.

As life expectancy decreases, the role of mechanical ventilation and oxygen diminishes and the role of opioids, benzodiazepines, glycopyrrolate, and scopolamine increases.

Advance Care Planning: The oncology team should initiate discussions of personal values and preferences for end-of-life care while patients have a life expectancy of years to months. Recent studies have shown that these discussions occur too late in the disease trajectory, often during acute hospital care and often with health professionals other than the primary oncologist.⁷⁶

Advance care planning should include an open discussion about palliative care options, such as hospice; personal values and preferences for end-of-life care; the congruence between the patient's wishes/expectations and those of the family/health care team; and information about advance directives. Patients should be asked if they have completed any advance care planning, such as living wills, powers of attorney, or delineation of specific limitations regarding life-sustaining treatments, including cardiopulmonary resuscitation, mechanical ventilation, and artificial nutrition/hydration. The patient's values and preferences and any decisions should be documented in the medical record, including MOLST or POLST (Medical Orders for Life-Sustaining Treatment or Physician Orders for Life-Sustaining Treatment), if completed.

When the patient's life expectancy is reduced to months to weeks, the oncology team should actively facilitate completion of appropriate advance directives and ensure their availability in all care settings. MOLST/POLST should be documented and accessible to all providers across care settings. The team should also confirm the patient's values and decisions in light of changes in status. Palliative care consultation can be considered to assist in conflict resolution when the patient, family, and/or medical professional team do not agree on the benefit/efficacy of interventions.

Where the patient wants to die should be determined. Dying in a hospital can be traumatic for patients and their families. A recent prospective study showed that patients dying in an intensive care unit had higher levels of physical and emotional distress than those dying at home or in hospice, and that caregivers of these patients had greater incidence of prolonged grief disorder.⁷⁷ In fact, most patients with cancer wish to die at home. According to the National Home and Hospice Care Survey, the number of adult patients with cancer using hospice care tripled during 1991-1992 through 1999-2000.⁷⁸ Still,

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some patients request to remain in a facility for end-of-life care, and providing palliative care services has been shown to decrease deaths in ICUs.⁷⁹

If advance care plans have not been completed, the oncology team should explore the patient's reluctance to engage in this planning, and refer to palliative care if needed.

In patients with a life expectancy of only weeks to days, their decision regarding cardiopulmonary resuscitation and other life-sustaining treatments must be clarified and confirmed. The desire for organ donation and/or autopsy must also be explored. Overall, the oncology team must implement and ensure compliance with the advance care plan.

Palliative Care Reassessment

The outcome measures for these guidelines are much more difficult to define than those for NCCN disease-specific guidelines. The panel reviewed end-of-life care outcomes from several surveys of North American citizens.⁸⁰⁻⁸³ The panel chose a modified version of Singer's outcomes until more precise outcome measures are available. Acceptable palliative care should provide the following: 1) adequate pain and symptom management, 2) reduction of patient and family distress, 3) acceptable sense of control, 4) relief of caregiver burden, 5) strengthened relationships, and 6) optimized quality of life, personal growth, and enhanced meaning. The panel added "having an advance care plan in progress" as part of the criteria for acceptable outcome. Research is ongoing regarding better ways to measure "dying well."⁸⁴

All patients should be reassessed regularly, and effective communication and information sharing must exist among the patient, caregivers, and health care providers. Patients and family members benefit most from ongoing discussions about the natural history of the disease and the prognosis in clear, consistent language. If the interventions are unacceptable on reassessment, the oncology or palliative care team should intensify palliative care efforts and reassess the patient and family situation. The oncology team should also consult specialized palliative care services, hospice, or an ethics committee. Referral to a psychiatrist or psychologist to evaluate and treat undiagnosed psychiatric disorders, substance abuse, and inadequate coping mechanisms should be considered. If psychosocial distress persists, palliative care options should be intensified and patients should be managed according to the NCCN Guidelines for Distress Management (available at NCCN.org).

Reassessment should be ongoing, with continuation or modification of life expectancy-guided palliative care until the patient's death or survivorship.

Special Palliative Care Interventions

A Peaceful Death: These NCCN Guidelines are the first to include death as an expected outcome, and after-death care for the family as an essential part of the continuum of cancer care. Many studies have attempted to define a "good death" or a "peaceful death" from the perspective of clinicians, patients, and families.⁸⁵⁻⁸⁸ Interestingly, one study found that patients, families, and physicians had very similar ideas of what constitutes a peaceful death, with freedom from pain, being at spiritual peace, and being with family ranked among the top 3 considerations by all 3 groups.⁸⁸ End-of-life care should be flexible enough to ensure that the death is viewed as a peaceful death by those involved.⁸⁸ The definition of "peaceful" used by the NCCN Palliative Care Panel is "one that is free from avoidable distress and suffering for patients, families and caregivers; in general accord with patient's and family's wishes; and consistent with clinical, cultural, and ethical standards."²²

After-Death Care Interventions: Comprehensive palliative care for the patient's family and caregivers continues after the patient's death. Immediate issues include ensuring culturally sensitive and respectful treatment of the body, including removal of tubes, drains, lines, and the Foley catheter (unless an autopsy is planned); providing family time with the body; addressing survivor concerns about organ donation or autopsy; facilitating funeral arrangements through completion of necessary paperwork; and informing insurance companies and other health care providers of the patient's death. Bereavement support should be offered, beginning with a personal visit or telephone call from the patient's primary oncology team, followed by a condolence letter. Family members at risk for complicated bereavement or prolonged grief disorder should be identified, and complicated grief should be treated.⁸⁹⁻⁹¹ Bereavement care is often best provided by an experienced hospice team or a skilled mental health care professional. The family may request a debriefing meeting from the medical team and may require assistance in identifying community bereavement resources. A well-supported end-of-life care experience will facilitate the family's acceptance of appropriate referrals for cancer risk assessment and risk modification.

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Psychosocial support should also be provided for the staff. A bereavement or memorial ritual for medical staff (eg, brief reading, moment of quiet) can be considered. Funeral attendance by health care professionals can be considered for individual patients. Health care professionals should also review medical issues related to patient death, explore concerns and questions about quality of patient care, and review emotional responses of family and staff to the patient's death. Emerging literature shows that health care professionals can be at risk for complicated bereavement, moral distress, or compassion fatigue⁹²⁻⁹⁵; these staff should be identified and assisted.

Putting Palliative Care Guidelines Into Practice

These guidelines have the goal of providing the best quality of life possible for each patient, and were developed to accompany the appropriate cancer treatment guidelines. Institutions should develop processes for integrating palliative care into cancer care, both as part of usual oncology care and for patients with specialty palliative care needs. Patients and families should be informed that palliative care is an integral part of their comprehensive cancer care. Educational programs should be provided to all health care professionals and trainees so that they can develop effective palliative care knowledge, skills, and attitudes. Skilled palliative care specialists and interdisciplinary palliative care teams, including board certified palliative care physicians, advanced practice nurses, and physician assistants, should be readily available to provide consultative or direct care to patients and families who request or require the expertise. Finally, the quality of palliative care should be monitored by institutional quality improvement programs.

Patients' experiences with cancer throughout the disease course begin with the diagnosis. Patient conditions usually move from ambulatory to sedentary as the disease advances and performance status worsens. When life expectancy is a matter of days or hours, patients may become unable to communicate. These patients may be at home, living with a family member, or in a health care facility. Through understanding the patient's status relative to the natural disease trajectory and by using these guidelines, the oncology team can provide the most

appropriate treatment for each patient. Oncologists and patients should discuss at the outset whether the treatment will be curative or palliative. Many palliative care questions must be considered early in each patient's comprehensive cancer care. The primary oncology team is responsible for working with patients to raise and answer these questions. Oncologists must identify patients' goals for the remainder of life to get a better sense of whether they understood and accepted the diagnosis and prognosis. Additionally, oncologists must explain the types of therapies that are available and how these therapies can affect the patient's daily life. As the cancer progresses and the value of further anticancer therapy diminishes, palliative therapy should be intensified. The issue of whether patients want more anticancer therapy must be openly addressed. The delivery of clear and consistent prognostic information can help patients make the most appropriate decisions.

Patients should be made aware that undergoing anticancer therapy does not have to sidetrack them from addressing end-of-life issues. Collaborating with palliative care experts extends oncologists' therapeutic repertoire and diminishes the stress of caring for patients who have incurable disease. Increasing emphasis on palliative care in oncology should improve patient outcomes and provide new avenues for clinical research and professional satisfaction. Timely introduction of members of the institutional or community palliative care team allows patients to meet the individuals who will help them and their families through their experience. Because the diagnosis of cancer and impending death is such a frightening experience, oncologists must try to alleviate those fears by assuring patients that the members of a team will work with them and their families to make things less burdensome. Additionally, oncologists must discuss the natural history of the patient's disease and prognosis with the family and palliative care team to anticipate and manage symptoms and problems commonly associated with the diagnosis and treatment of cancer.

Palliative care is intensified late in the course of disease to help patients and families understand the disease and begin to make end-of-life plans. Sometimes patients and families do not accept the prognosis or do not begin to make preparations.^{96,97} These things may be a sign that patients do not fully

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understand the disease, and may lead to the desire of patients and families to pursue aggressive treatments that may be both futile and toxic.⁹⁷ Palliative care supports education so that patients can better understand the disease.

Oncologists must ensure that advance care plans are in place as early as possible in the disease trajectory. This focus on the patients' wishes assures patients that they will be provided with no more and no less aggressive care than they desire, and also relieves them of concerns about burdening family members with difficult end-of-life decisions. The combined efforts of the oncology team and the hospice/palliative care team can improve the overall outcome for patients and their families.

Hope

These guidelines are intended to help oncology teams provide the best care possible for patients with incurable cancer. The care outlined in these guidelines provides a different kind of hope than that for cure of the disease itself. Palliative care provides hope for dignity, comfort, and closure, and for growth at the end of life.

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Palliative Care

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