

The NCCN

Palliative Care

Clinical Practice Guidelines in Oncology™

Michael H. Levy, MD, PhD; Anthony Back, MD; Costantino Benedetti, MD; J. Andrew Billings, MD; Susan Block, MD; Barry Boston, MD; Eduardo Bruera, MD; Sydney Dy, MD; Catherine Eberle, MD; Kathleen M. Foley, MD; Sloan Beth Karver, MD; Sara J. Knight, PhD; Sumathi Misra, MD; Christine S. Ritchie, MD, MSPH; David Spiegel, MD; Linda Sutton, MD; Susan Urba, MD; Jamie H. Von Roenn, MD; and Sharon M. Weinstein, MD

Overview

Palliative care is both a philosophy of care and an organized, highly structured system for delivering care

to persons with life-threatening or debilitating illness. Palliative care is patient- and family-centered 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 goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of disease stage or the need for other therapies. Palliative care can be delivered concurrently with life-prolonging care or as the main focus of care.

The standards of palliative care are as follows:

- Institutions should develop a process ensuring that all patients have access to palliative care services from the initial visit.
- All cancer patients should be screened for pallia-

Palliative Care Clinical Practice Guidelines in Oncology

Key Words

NCCN Clinical Practice Guidelines, palliative care, end-of-life issues, death and dying, hospice care, supportive care, advance directives, terminal care (*JNCCN* 2009;7:436–473)

NCCN Categories of Evidence and Consensus

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

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

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

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

All recommendations are category 2A unless otherwise noted.

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

Please Note

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

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Disclosures for the NCCN Palliative Care Guidelines Panel

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

Individual disclosures for the NCCN Palliative Care Guidelines Panel members can be found on page 473. (To view the most recent version of these guidelines and accompanying disclosures, visit the NCCN Web site at www.nccn.org.)

These guidelines are also available on the Internet. For the latest update, please visit www.nccn.org.

tive care needs at their initial visit, at appropriate intervals, and as clinically indicated.

- Patients and families should be informed that palliative care is an integral part of their comprehensive cancer care.
- Palliative care should be delivered based on clinical practice guidelines.
- 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 should be readily available to provide consultative or direct care to patients/families who request or require their expertise.

- Medical care contracts should include appropriate reimbursement for palliative care.
- Clinical health outcomes measurement should include palliative care domains.
- Quality of palliative care should be monitored by institutional quality improvement programs.

The goal of these guidelines is to help assure that each cancer patient experiences the best quality of life possible throughout the illness trajectory. The NCCN Palliative Care Panel is an interdisciplinary panel of representatives from NCCN member institutions, comprised of medical oncologists, neurologists and neurooncologists, anesthesiologists, psychiatrists, internists, palliative care and pain management specialists, and geriatric medicine specialists. These guidelines were developed from the

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NCCN Palliative Care Panel Members

*Michael H. Levy, MD, PhD/Chair†£
Fox Chase Cancer Center

Anthony Back, MD†£
Fred Hutchinson Cancer Research Center/
Seattle Cancer Care Alliance

Costantino Benedetti, MD£φ
Arthur G. James Cancer Hospital & Richard J. Solove
Research Institute at The Ohio State University

J. Andrew Billings, MD‡£
Massachusetts General Hospital Cancer Center

Susan Block, MD£θ
Dana-Farber/Brigham and Women's Cancer Center

Barry Boston, MD†£
St. Jude Children's Research Hospital/
University of Tennessee Cancer Institute

Eduardo Bruera, MD†£
The University of Texas M. D. Anderson Cancer Center

Sydney Dy, MD£
The Sidney Kimmel Comprehensive Cancer Center at
Johns Hopkins

Catherine Eberle, MD£▯
UNMC Eppley Cancer Center at
The Nebraska Medical Center

Kathleen M. Foley, MD‡
Memorial Sloan-Kettering Cancer Center

Sloan Beth Karver, MD£
H. Lee Moffitt Cancer Center & Research Institute

Sara J. Knight, PhDθ
UCSF Helen Diller Family Comprehensive Cancer Center

Sumathi Misra, MD‡£
Vanderbilt-Ingram Cancer Center

Christine S. Ritchie, MD, MSPH▯£
University of Alabama at Birmingham
Comprehensive Cancer Center

David Spiegel, MDθ
Stanford Comprehensive Cancer Center

Linda Sutton, MD†£
Duke Comprehensive Cancer Center

Susan Urba, MD†£
University of Michigan Comprehensive Cancer Center

Jamie H. Von Roenn, MD†£
Robert H. Lurie Comprehensive Cancer Center of
Northwestern University

Sharon M. Weinstein, MD£‡
Huntsman Cancer Institute at the University of Utah

KEY:

*Writing Committee Member

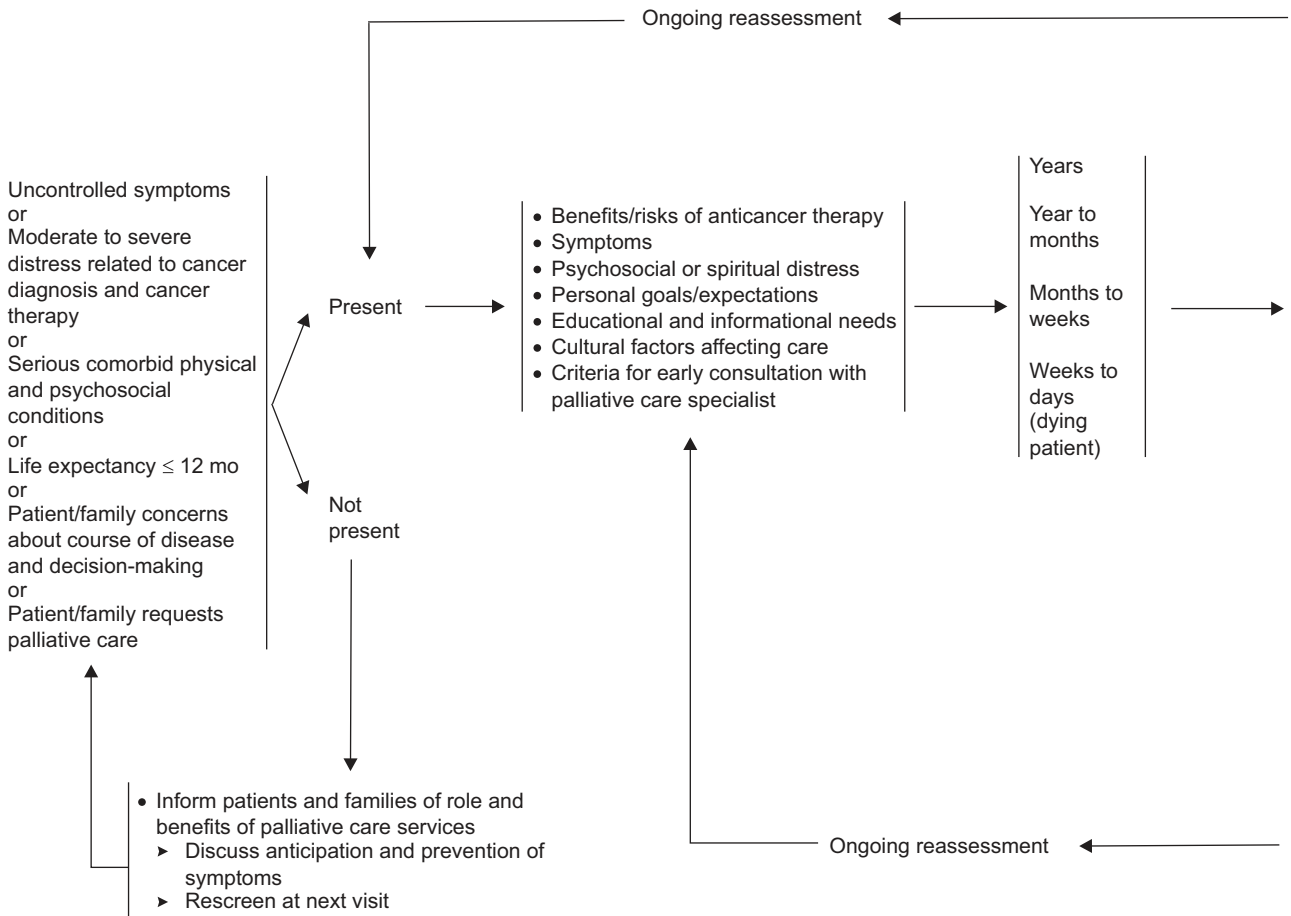
Specialties: †Medical Oncology; £Supportive Care Including Palliative and Pain Management; φAnesthesiology; ▯Internal Medicine; θPsychiatry, Psychology, Including Health Behavior; ▯Geriatric Medicine; ‡Neurology/Neuro-Oncology

PALLIATIVE CARE OVERVIEW

SCREENING^{a,b}

ASSESSMENT

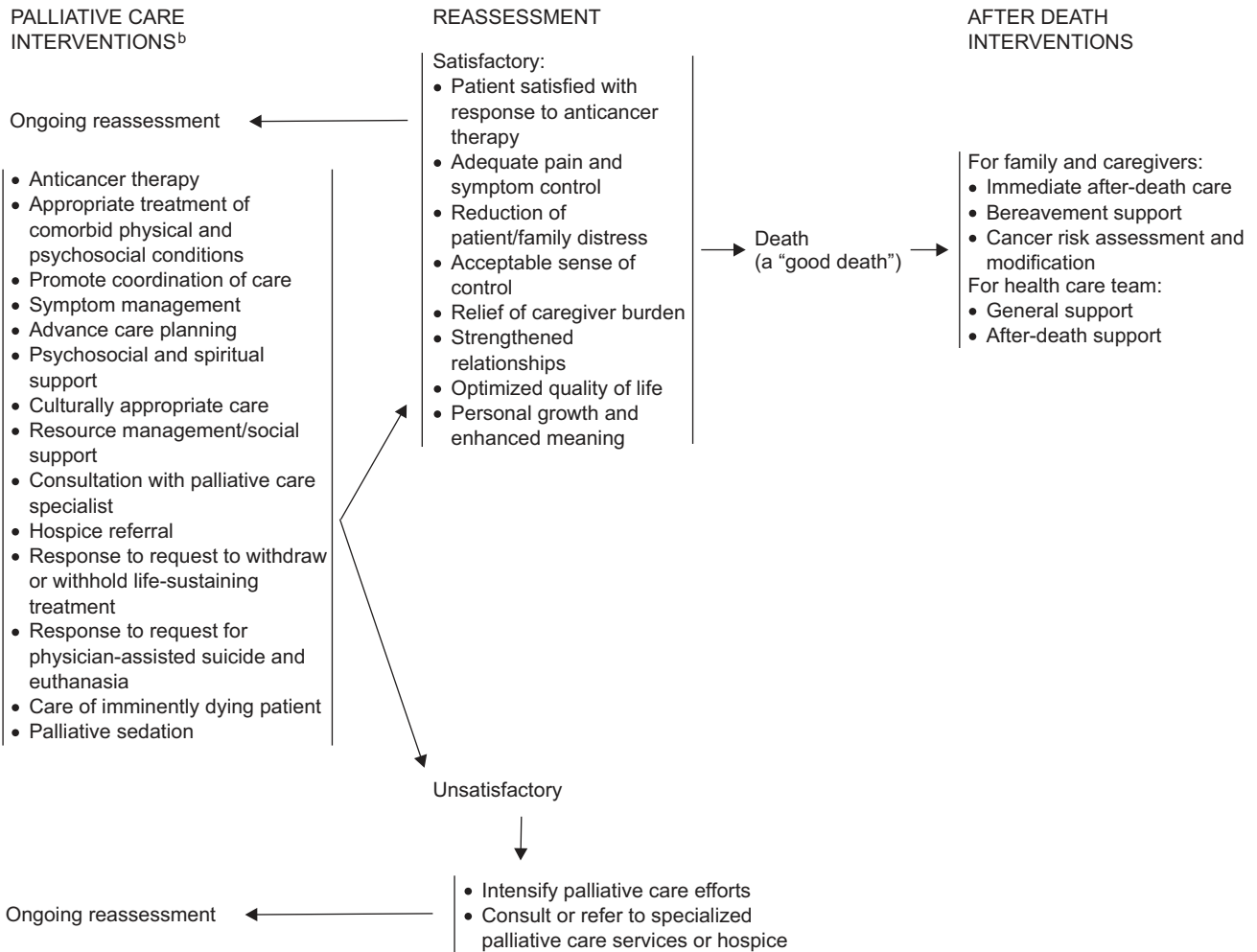
ESTIMATED LIFE EXPECTANCY



^a Management of any patient with positive screening requires a care plan developed by an interdisciplinary team of physicians, nurses, mental health professionals, and chaplains.

^b Oncologists should integrate palliative care into general oncology care for patients who meet screening criteria. Consultation/collaboration with a palliative care specialist/hospice team is recommended for patients with more complex issues.

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^bOncologists should integrate palliative care into general oncology care for patients who meet screening criteria. Consultation/collaboration with a palliative care specialist/hospice team is recommended for patients with more complex issues.

SCREENING^{a,b}

- Uncontrolled symptoms
or
- Moderate to severe distress related to cancer diagnosis and/or cancer therapy
or
- Serious comorbid physical and psychosocial conditions
or
- Life expectancy \leq 12 mo
 - ▶ Potential indicators include:
 - ◊ Poor performance status:
ECOG \geq 3 or KPS \leq 50
 - ◊ Hypercalcemia
 - ◊ Brain or cerebrospinal fluid metastasis
 - ◊ Delirium
 - ◊ Superior vena cava syndrome
 - ◊ Spinal cord compression
 - ◊ Cachexia
 - ◊ Malignant effusions
 - ◊ Bilirubin \geq 2.5
 - ◊ Creatinine \geq 3
- or
- Patient/family concerns about course of disease and decision-making
or
- Patient/family requests palliative care

Present

Not present

Rescreen at next visit

ASSESSMENT

- Benefits/risks of anticancer therapy
- Symptoms
- Psychosocial distress

- Personal goals/expectations
- Educational and informational needs
- Cultural factors affecting care

Criteria for early consultation with palliative care specialist

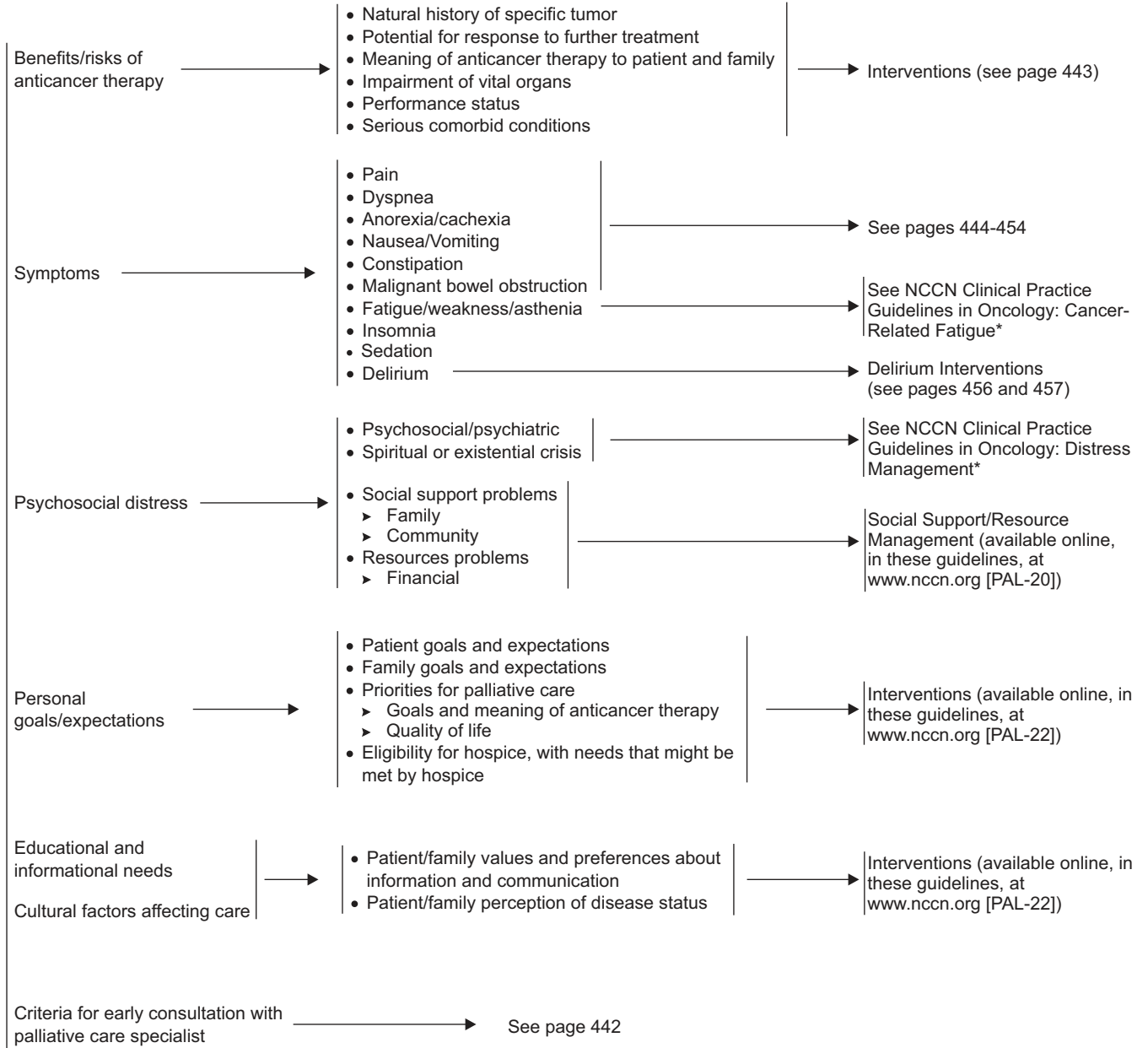
See page 442

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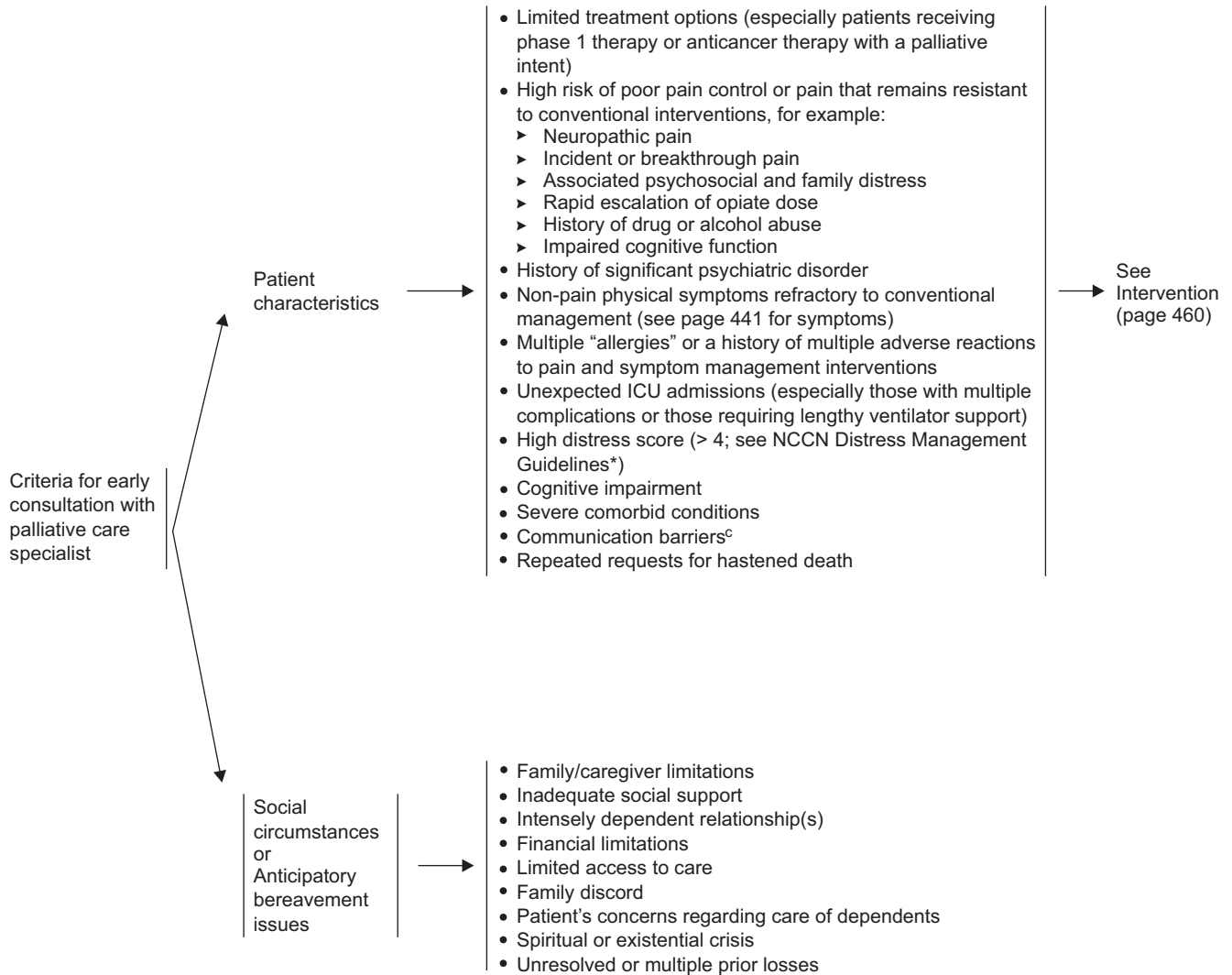
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PALLIATIVE CARE ASSESSMENT



*For the most recent version of these guidelines, visit the NCCN Web site at www.nccn.org.

ASSESSMENT

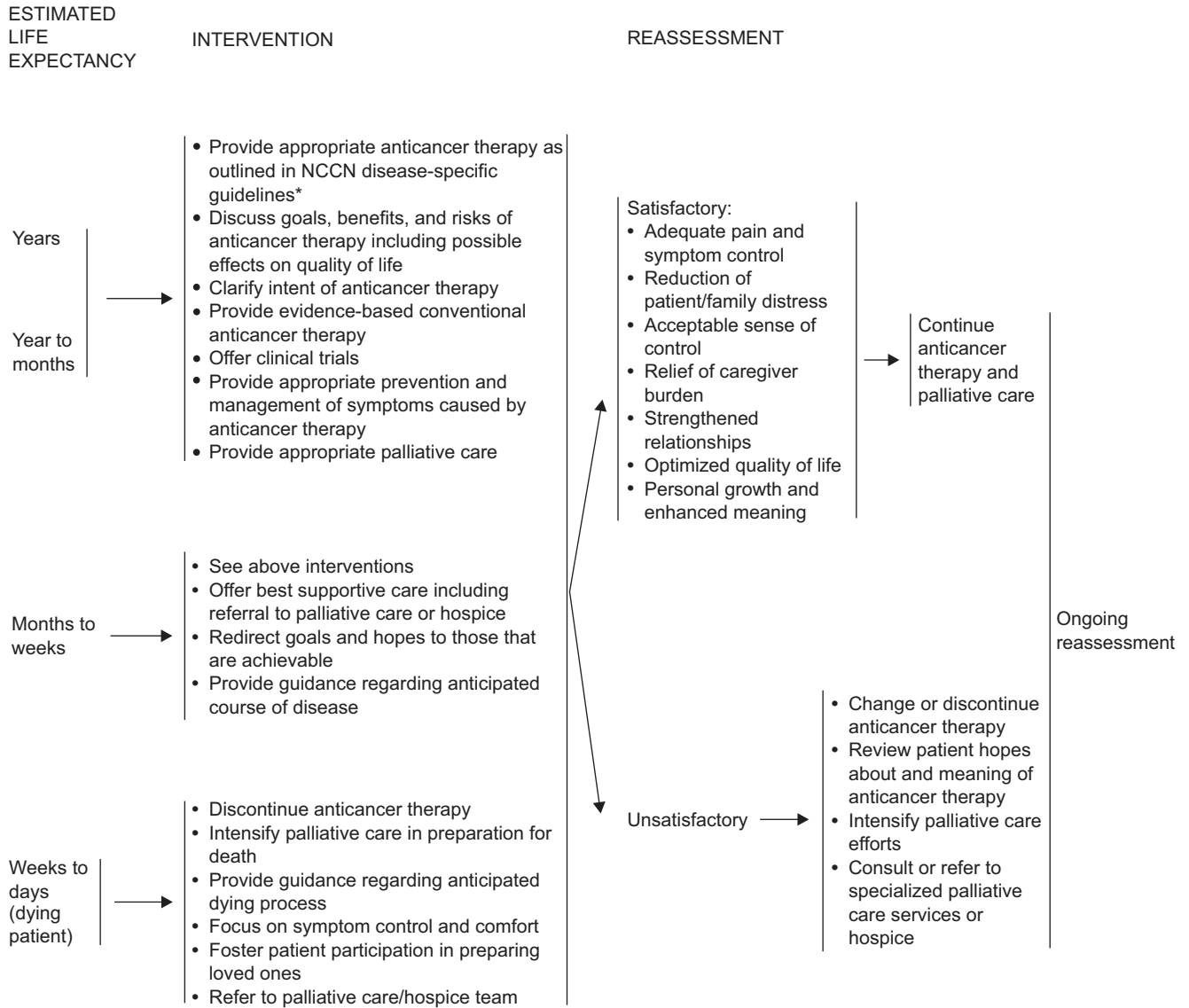


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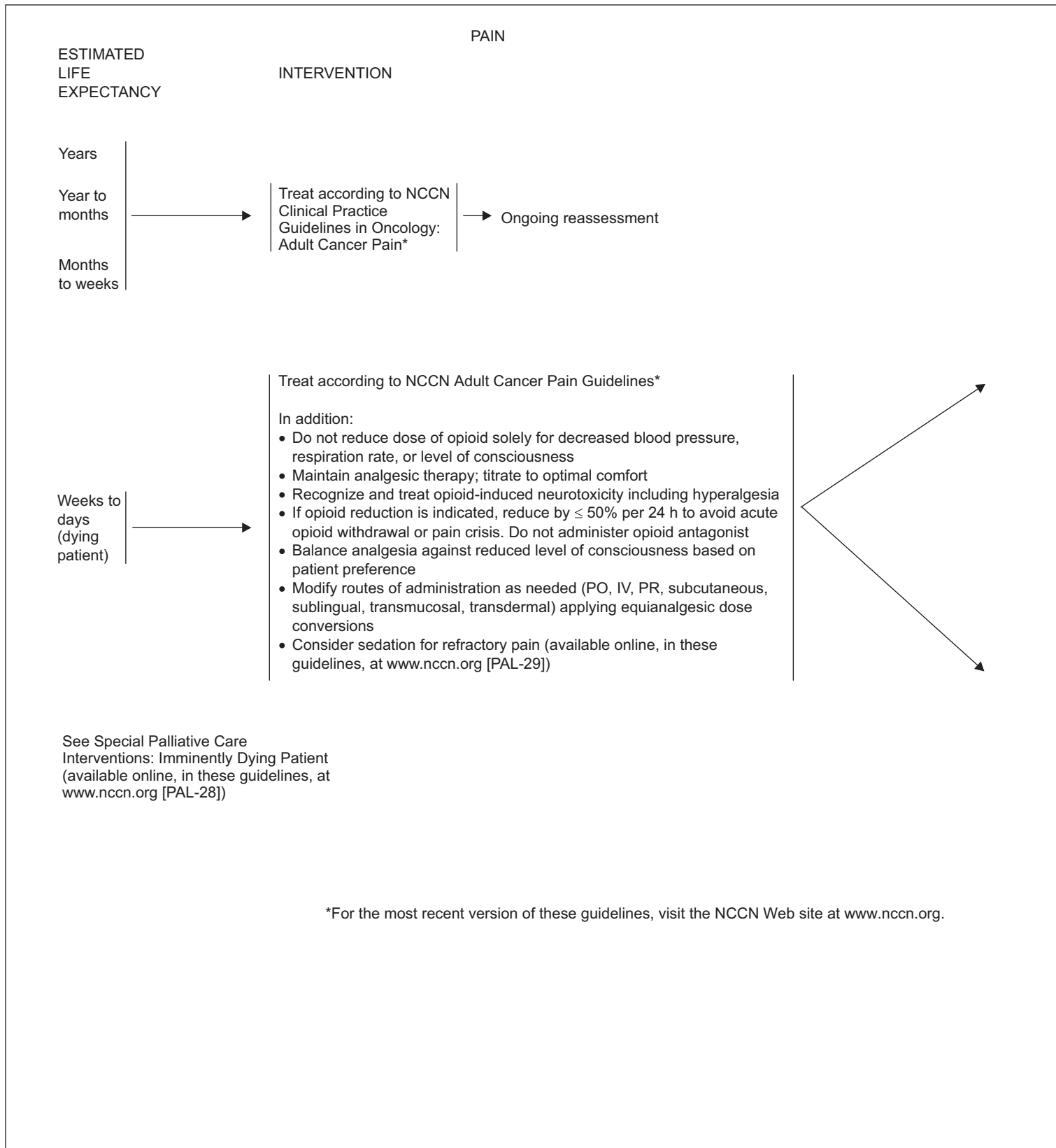
^cCommunication barriers include language, literacy, and physical barriers.

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BENEFIT/RISK OF ANTICANCER THERAPY



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PAIN

REASSESSMENT

Satisfactory:

- Adequate pain 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



- Continue to treat according to NCCN Adult Cancer Pain Guidelines*
- Monitor symptoms and quality of life to determine whether additional end of life measures are required

→ Ongoing reassessment

Unsatisfactory



- Continue to treat according to NCCN Adult Cancer Pain Guidelines*
- Consider consultation with pain management/palliative care specialist

*For the most recent version of these guidelines, visit the NCCN Web site at www.nccn.org.

ESTIMATED LIFE EXPECTANCY		DYSYPNEA	INTERVENTION
Years	→		<ul style="list-style-type: none"> • Assess symptom intensity • Treat underlying causes/comorbid conditions: <ul style="list-style-type: none"> ▶ Radiation/chemotherapy ▶ Thoracentesis/pleurodesis/pleural drainage catheter ▶ Bronchoscopic therapy ▶ Bronchodilators, diuretics, steroids, antibiotics, transfusions • Relieve symptoms <ul style="list-style-type: none"> ▶ Temporary ventilatory (CPAP, BiPAP) support if clinically indicated for severe reversible condition ▶ O₂ therapy for hypoxia ▶ Benzodiazepines for anxiety (if benzodiazepine-naïve, starting dose lorazepam, 0.5-1 mg PO every 4 h prn) ▶ Opioids for cough or dyspnea (if opioid-naïve, morphine, 2.5-10 mg PO every 4 h prn) ▶ Nonpharmacologic therapies including fan, cooler temperatures, stress management, relaxation therapy, and physical comfort measures ▶ Educational, psychosocial, and emotional support
Year to months			
Months to weeks			

Weeks to days (dying patient)	→		<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"> ▶ Opioids for cough/dyspnea/air hunger (if opioid-naïve, morphine, 2.5-10 mg PO every 4 h prn; 1-4 mg IV every 4 h prn) ▶ Benzodiazepines for anxiety/agitation/air hunger (if benzodiazepine-naïve, starting dose lorazepam, 0.5-1 mg PO or IV every 4 h prn) ▶ Nonpharmacologic therapies; educational, psychosocial, and emotional support (see above) ▶ Reduce excessive secretions (scopolamine, hyoscyamine, atropine, glycopyrrolate) ▶ O₂ if subjective report of relief • Withhold/withdraw/time-limited trial of mechanical ventilation as indicated <ul style="list-style-type: none"> ▶ Address patient and family preferences, prognosis, reversibility ▶ Sedation as needed • Discontinue fluid support/consider low-dose diuretics if fluid overload may be contributing factor • Anticipatory guidance for patient/family regarding dying of respiratory failure • Provide emotional support
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DYSPNEA

REASSESSMENT

Satisfactory:

- 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



Continue to treat and monitor symptoms and quality of life to determine whether status warrants change in strategies

Unsatisfactory



- Intensify palliative care efforts
- Consult or refer to specialized palliative care services or hospice

Satisfactory

- 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



Continue to treat and monitor symptoms and quality of life to determine whether status warrants change in strategies

Unsatisfactory



- Intensify palliative care interventions and consider consultation with palliative care specialist
- Consider sedation for intractable symptoms (available online, in these guidelines, at www.nccn.org [PAL-29])

→ Ongoing reassessment

ANOREXIA/CACHEXIA

ESTIMATED
LIFE EXPECTANCY

INTERVENTION

Years

Year to
months

- Evaluate rate/severity of weight loss
- Treat readily reversible cause of anorexia:
 - ▶ Early satiety
 - ◊ Metoclopramide
 - ▶ Symptoms that interfere with intake
 - ◊ Depression
 - ◊ Eating disorders/body image
 - ◊ Constipation
 - ◊ Pain
 - ◊ Xerostomia
 - ◊ Mucositis
 - ◊ Nausea/vomiting
 - ◊ Fatigue
- Review/modify medications that interfere with intake
- Evaluate for endocrine abnormalities:
 - ▶ Hypogonadism
 - ▶ Thyroid dysfunction
 - ▶ Metabolic abnormalities (e.g., increased calcium)
- Consider appetite stimulant (e.g., megestrol acetate)
- Exercise program
- Assess economic factors
- Consider nutrition consult
- Consider nutrition support clinical trials

Months to
weeksWeeks to days
(dying patient)

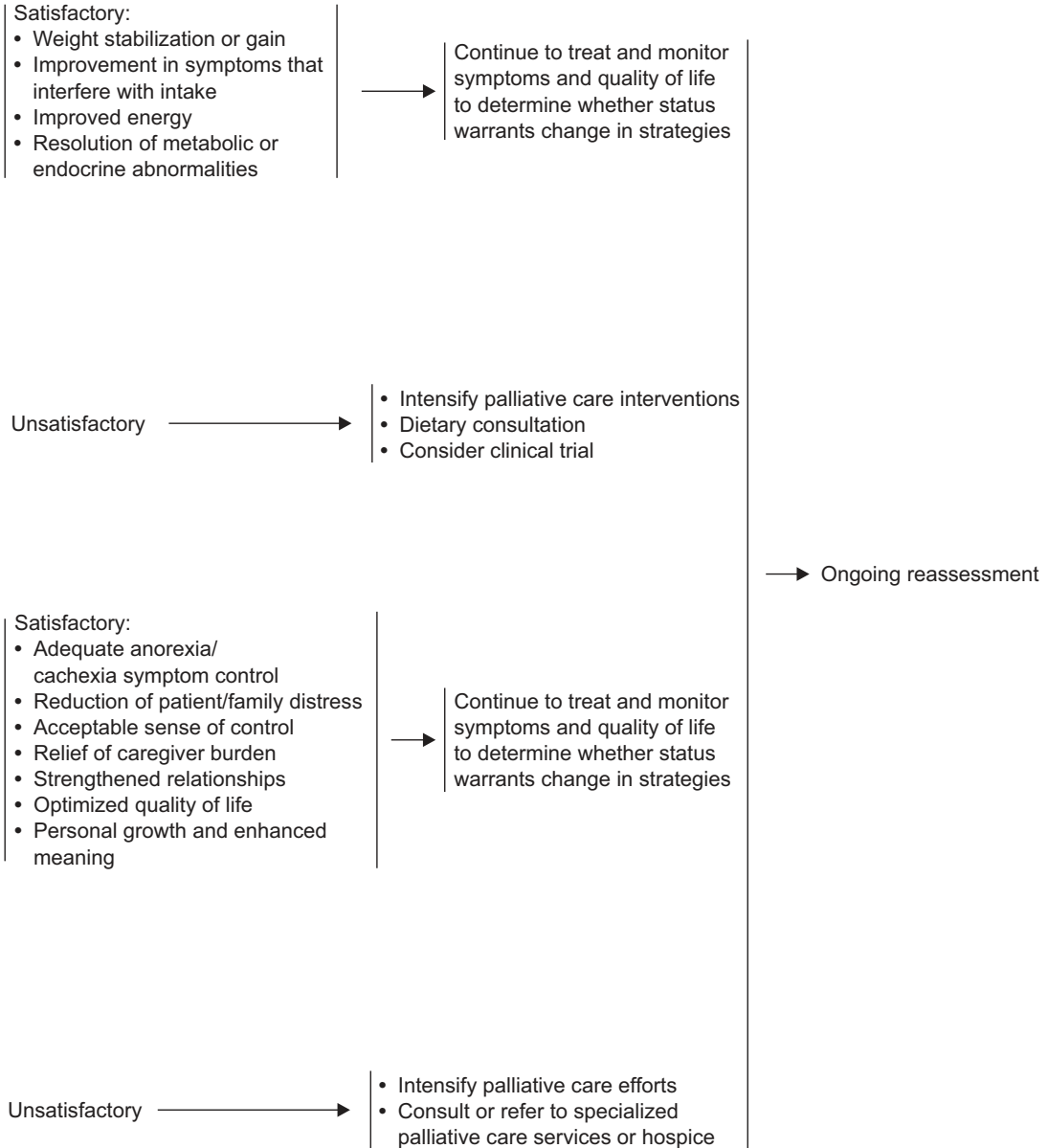
- Assess importance of symptoms of anorexia and cachexia to patient and family
 - ▶ If important, consider short course of corticosteroids
- Treat for depression
- Recognize that discontinuation of nutrition is a value-laden issue. Consider consultation with bioethicist or spiritual counselor
- Inform patient and family of natural history of disease, including the following points:
 - ▶ Absence of hunger and thirst is normal in the dying patient
 - ▶ Nutritional support may not be metabolized in patients with advanced cancer
 - ▶ There are risks associated with artificial nutrition and hydration, including fluid overload, infection, and hastened death
 - ▶ IV hydration may increase excretion of drug metabolites providing benefit to the patient
 - ▶ Symptoms like dry mouth can be treated with local measures (e.g., mouthcare, small amounts of liquids)
 - ▶ Withdrawal of IV or nasogastric (NG) tube feeding is ethically permissible in this setting. It will not cause exacerbation of symptoms and may improve some symptoms
- Focus on patient goals and preferences
- Provide family with alternate ways of caring for the patient
- Provide emotional support

See Special Palliative Care

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ANOREXIA/CACHEXIA

REASSESSMENT



NAUSEA AND VOMITING

ESTIMATED
LIFE
EXPECTANCYINTERVENTION^{e,f}

Years

Year to
monthsMonths to
weeks^dWeeks to
days
(dying
patient)^d

- Chemotherapy/radiation therapy-induced
 - ▶ See NCCN Clinical Practice Guidelines in Oncology: Antiemesis*
- Severe constipation/fecal impaction (see pages 452 and 453)
- Gastroparesis (metoclopramide, 10-20 mg every 6 h)
- Bowel obstruction (see page 454)
- CNS involvement (brain, meninges)
 - ▶ Corticosteroids (dexamethasone, 4-8 mg tid-qid)
 - ▶ Palliative radiation therapy
- Gastric outlet obstruction (squashed stomach syndrome) from intra-abdominal tumor and liver metastasis
 - ▶ If not contraindicated by comorbid conditions, treat with corticosteroids, proton pump inhibitor, metoclopramide, and consider stenting
- Metabolic abnormalities
 - ▶ Correct hypercalcemia
 - ▶ Treat dehydration
- Medication-induced
 - ▶ Discontinue any unnecessary medications
 - ▶ Check available blood levels of necessary medications (digoxin, phenytoin, carbamazepam, tricyclic antidepressants)
 - ▶ Treat medication-induced gastropathy (proton pump inhibitor, metoclopramide)
 - ▶ If due to opioids, initiate opioid rotation and/or consider reducing opioid requirement with non-nauseating coanalgesics or anesthesiologic/neurosurgical procedures
- Psychogenic
 - ▶ Consider psychiatric consultation if patient has eating disorder, somatization, phobia, or panic disorder causing nausea and vomiting
- Non-specific nausea and vomiting (NV)
 - ▶ Initiate pharmacologic management with dopamine receptor antagonists (e.g., haloperidol, metoclopramide, prochlorperazine)
 - ▶ If anxiety contributes to NV, consider adding a benzodiazepine
 - ▶ If oral route not feasible, consider rectal, subcutaneous, or intravenous administration of anti-nauseant therapy

If NV stops,
see
Reassessment
(facing page)If NV persists,
see
Interventions
(facing page)*For the most recent version of these guidelines, visit the NCCN Web site at www.nccn.org.^dIn patients with advanced cancer, nausea and vomiting (NV) may be secondary to the cachexia syndrome (chronic nausea, anorexia, asthenia, changing body image, and autonomic failure).^eAround-the-clock dosing schedule would likely provide the greatest benefit to the patient.^fContinuous intravenous or subcutaneous infusions of different antiemetics may be necessary for the management of intractable NV.

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PERSISTENT NAUSEA AND VOMITING

INTERVENTION

REASSESSMENT

Titrate dopamine receptor antagonist (e.g., prochlorperazine, haloperidol, metoclopramide) to maximum benefit and tolerance

Add a 5-HT₃ antagonist (e.g., ondansetron) ± an anticholinergic agent (e.g., scopolamine) ± antihistamine (e.g., meclizine) ± cannabinoid
If NV persists:

Add corticosteroid (e.g., dexamethasone)
If NV persists:

Consider using a continuous IV/SC infusion of antiemetics; consider an opioid rotation if patient on opioids
If NV persists:

Consider adding alternative therapies (e.g., acupuncture), or palliative sedation (available online, in these guidelines, at www.nccn.org [PAL-29])

- Satisfactory:
- Adequate nausea/vomiting 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

Continue to treat and monitor symptoms and quality of life to determine whether status warrants change in strategies

Unsatisfactory

- Intensify palliative care efforts
- Consult or refer to specialized palliative care services or hospice

Ongoing Reassessment (see opposite page)

ESTIMATED LIFE EXPECTANCY		CONSTIPATION	
		INTERVENTION	
Years			
Year to months			
Months to weeks	<ul style="list-style-type: none"> • Preventive measures <ul style="list-style-type: none"> ▶ Prophylactic medications <ul style="list-style-type: none"> ▶ Stimulant laxative + stool softener (senna + docusate, 2 tablets every night) ▶ Increase dose of laxative and stool softener (senna + docusate, 2-3 tablets bid-tid) with goal of 1 non-forced bowel movement every 1-2 d • Increase fluids • Increase dietary fiber if patient has adequate fluid intake and physical activity • Exercise, if appropriate 	<ul style="list-style-type: none"> • If constipation present: <ul style="list-style-type: none"> • Assess for cause and severity of constipation • Rule out impaction, especially if diarrhea accompanies constipation (overflow around impaction) • Rule out obstruction (physical exam, abdominal radiograph) • Treat other causes (hypercalcemia, hypokalemia, hypothyroidism, diabetes mellitus, medications) • Add and titrate bisacodyl 10-15 mg daily tid with goal of 1 non-forced bowel movement every 1-2 d • If impacted: <ul style="list-style-type: none"> ▶ Administer glycerine suppository ± mineral oil retention enema ▶ Perform manual disimpaction following premedication with analgesic ± anxiolytic • If constipation persists: <ul style="list-style-type: none"> • Reassess for cause and severity of constipation • Recheck for impaction or obstruction • Consider adding other laxatives, such as bisacodyl (1 suppository rectally daily bid); polyethelene glycol (1 capful/8 oz water bid); lactulose (30-60 mL bid-qid); sorbitol (30 mL every 2 h x 3, then prn); magnesium hydroxide (30-50 mL daily bid); or magnesium citrate (8 oz daily) • Consider methylnaltrexone, 0.15 mg/kg subcutaneous, every other day, no more than 1 per day • Phosphasoda or tap water enema until clear • Consider use of a prokinetic agent (e.g., metoclopramide, 10-20 mg PO qid) 	
Weeks to days (dying patient)			

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CONSTIPATION

REASSESSMENT

Satisfactory:

- Adequate constipation 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



Continue to treat and monitor symptoms and quality of life to determine whether status warrants change in strategies



Ongoing reassessment

Unsatisfactory



- Intensify palliative care efforts
- Consult or refer to specialized palliative care services or

MALIGNANT BOWEL OBSTRUCTION^gESTIMATED
LIFE
EXPECTANCY

ASSESSMENT

Years

Year to
monthsMonths to
weeks

- Screen for and treat underlying benign reversible causes
 - ▶ Adhesions
 - ▶ Radiation-induced strictures
 - ▶ Internal hernias
- Assess for malignant causes
 - ▶ Tumor mass
 - ▶ Carcinomatosis
- Assessment of the goals of treatment for the patient can help guide the intervention^h (e.g., decrease NV, allow patient to eat, decrease pain, allow patient to go home/hospice)

Weeks to
days
(dying
patient)^h

- Consider medical management rather than surgical management
- Assessment of goals of treatment for the patient can help guide the intervention^h (e.g., decrease NV, allow patient to eat, decrease pain, allow patient to go home/hospice)

- Pharmacologic management
- Intravenous or subcutaneous fluids
- Endoscopic management
- Nasogastric (NG) tube drainage
 - ▶ Consider only if other measures fail to reduce vomiting

See Reassessment
(facing page)

^gPlain film radiography evaluation is usually enough to establish the diagnosis of bowel obstruction. Consider CT scan if surgical intervention is contemplated as it is more sensitive and helps identify the cause of obstruction.

^hMost malignant bowel obstructions are partial, allowing time to discuss with patient and family appropriate interventions.

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MALIGNANT BOWEL OBSTRUCTION

INTERVENTION

- Operative managementⁱ
 - ▶ Risks must be discussed with patient/family (mortality, morbidity, reobstruction)
 - ▶ Improved quality of life should be the primary goal of surgical treatment
- Endoscopic management
 - ▶ Percutaneous endoscopic gastrostomy tube for drainage
 - ▶ Endoscopic stent placement
- Pharmacologic management
 - ▶ Use rectal, transdermal, subcutaneous, or intravenous routes of administration
 - ▶ Consider as an adjunct to invasive procedure when invasive procedures not an option
 - ▶ Opioids
 - ▶ Antiemetics: do not use antiemetics that increase gastrointestinal mobility, such as metoclopramide, but these may be beneficial in incomplete bowel obstruction
 - ▶ Octreotide: consider early in the diagnosis due to high efficacy and tolerability (start 150 mcg SC bid up to 300 bid or via continuous subcutaneous infusion)
 - ▶ Anticholinergics (scopolamine, hyoscyamine, glycopyrrolate)
 - ▶ Corticosteroids (discontinue if no improvement noted in 3-5 d; up to 60 mg/d of dexamethasone)
- Intravenous or subcutaneous fluids
 - ▶ Consider if evidence of dehydration
- NG tube drainage
 - ▶ Usually uncomfortable
 - ▶ Increased risk of aspiration
 - ▶ Consider on a limited trial basis only if other measures fail to reduce vomiting
- Total parenteral nutrition (TPN)
 - ▶ Consider only if expected improvement of quality of life with life expectancy of many months to years

REASSESSMENT

- Satisfactory:
- Adequate control of malignant bowel obstruction symptoms
 - Reduction of patient/family distress
 - Acceptable sense of control
 - Relief of caregiver burden
 - Strengthened relationships
 - Optimized quality of life
 - Personal growth and enhanced meaning

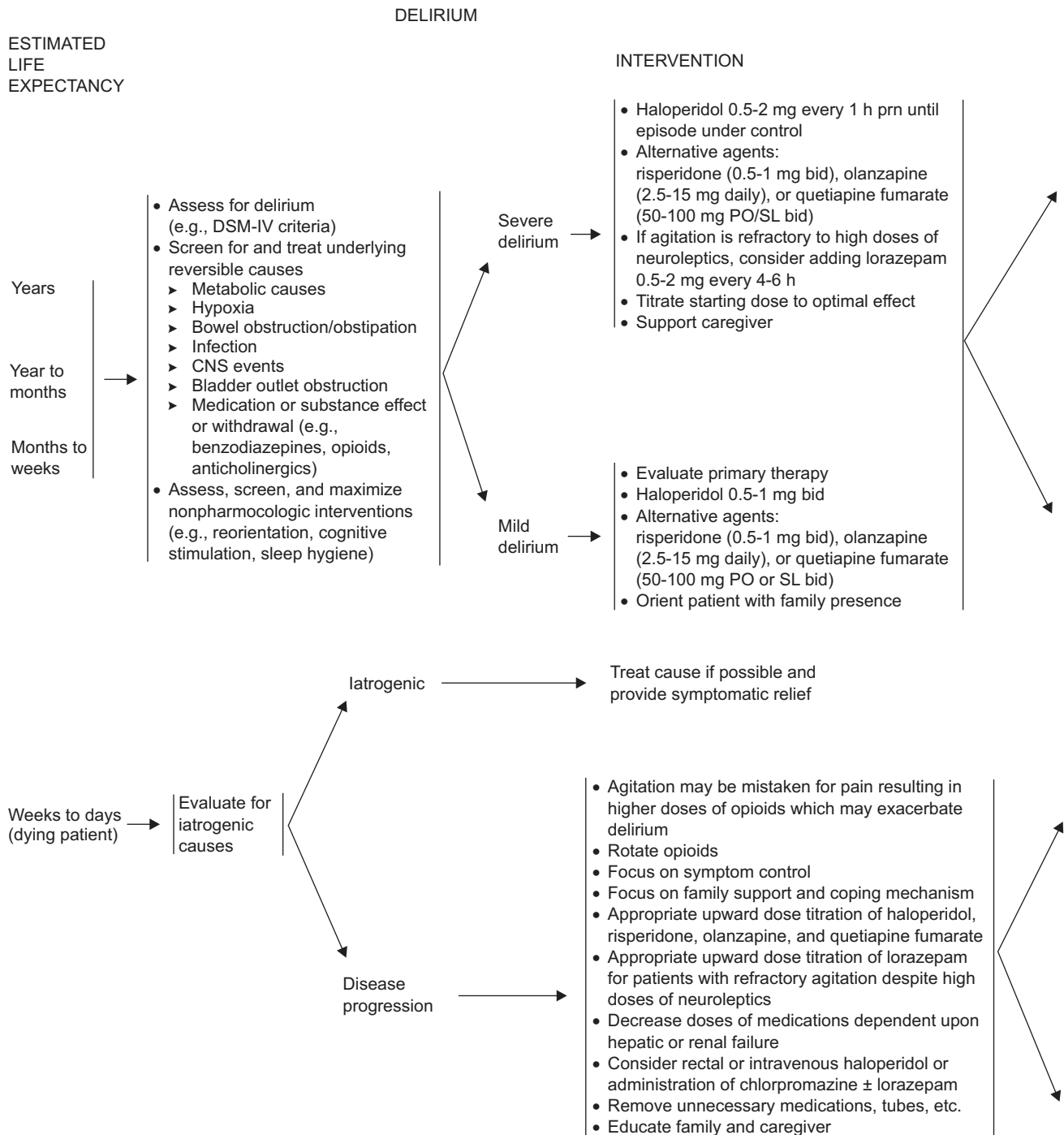
Continue to treat and monitor symptoms and quality of life to determine whether status warrants change in strategies

Unsatisfactory

- Intensify palliative care efforts
- Consult or refer to specialized palliative care services or hospice

Ongoing Reassessment (see previous page)

ⁱPoor prognosis criteria for surgery include: ascites, carcinomatosis, palpable intraabdominal masses, multiple bowel obstructions, previous abdominal radiation, very advanced disease, and poor overall clinical status.



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DELIRIUM

REASSESSMENT

Satisfactory:

- Adequate delirium 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



Continue to treat and monitor symptoms and quality of life to determine whether status warrants change in strategies

Unsatisfactory



Intensify palliative care interventions and consider consultation with palliative care specialist or psychiatrist

→ Ongoing reassessment

Satisfactory:

- Adequate delirium 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



Continue to treat and monitor symptoms and quality of life to determine whether status warrants change in strategies

Unsatisfactory



- Intensify palliative care interventions
- Consult with a palliative care specialist or psychiatrist

ADVANCE CARE PLANNING

ESTIMATED
LIFE EXPECTANCY

INTERVENTION

Years

Year to
months

- Discuss palliative care options, including hospice
- Consider introducing palliative care team
- Assess for decision-making capacity and need for surrogate decision maker
- Elicit personal values and preferences for end of life care and congruence with values and preferences of family and health care team
- Provide information about advance directive and encourage exploration of DNR option
- Encourage the patient to discuss wishes with family
- Encourage designation of health care proxy, medical power of attorney, durable power of attorney, or patient surrogate for health care
- Inquire about desire for organ donation and/or autopsy
- Explore fears about dying and address anxiety

Months to
weeks

- Determine patient and family preferences for the location of patient's death
- Confirm and ensure complete documentation of advance care directives including cardiopulmonary resuscitation (CPR), mechanical ventilation, artificial nutrition/hydration, blood products, antibiotics, dialysis
- Ensure advance care directives are available to all caregivers regardless of treatment setting
- Seek resolution of conflict between patient and family goals and wishes
- Explore fears about dying and provide emotional support
- Discuss desire for organ donation and/or autopsy

Weeks to
days (dying
patient)

- Ensure advance care directives are available to all caregivers regardless of treatment setting
- Implement and ensure compliance with advance care directive
- Clarify patient's decision regarding CPR
- Consider ethics, social work, or chaplaincy consultation to assist in conflict resolution when patient, family, and/or professional team do not agree on benefit/utility of interventions
- Confirm desire for organ donation and/or autopsy

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

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ADVANCE CARE PLANNING

REASSESSMENT

Satisfactory:

- Adequate advance care planning
- Reduction of patient/family distress
- Acceptable sense of control
- Relief of caregiver burden
- Strengthened relationships
- Optimized quality of life
- Personal growth and enhanced meaning



Ongoing reevaluation and communication between the patient and health care team

Unsatisfactory



- Intensify efforts to communicate palliative care options
- Consider referral to psychiatrist to evaluate and treat psychiatric disorders
- See NCCN Distress Management Guidelines*

Satisfactory:

- Adequate advance care planning
- Reduction of patient/family distress
- Acceptable sense of control
- Relief of caregiver burden
- Strengthened relationships
- Optimized quality of life
- Personal growth and enhanced meaning



Ongoing reevaluation and communication between the patient/family and health care team

Unsatisfactory



- Intensify efforts to communicate palliative care options
- Consult with a psychiatrist to evaluate and treat psychiatric disorders
- See NCCN Distress Management Guidelines*



Ongoing reassessment

*For the most recent version of these guidelines, visit the NCCN Web site at www.nccn.org.

CRITERIA FOR EARLY CONSULTATION WITH PALLIATIVE CARE SPECIALIST

INTERVENTION

- ▶ Early consultation with palliative care specialist/team
- ▶ Collaborate with other physicians treating the patient
- ▶ Refer to appropriate health care professionals
 - ▶ Mental health and social services
 - ▶ Health care interpreters
 - ▶ Others
- ▶ Mobilize community support
 - ▶ Religious
 - ▶ School
 - ▶ Community agencies
- ▶ Expedite referral to hospice team when appropriate

REASSESSMENT

- Satisfactory:
- ▶ Patient satisfied with response to anticancer therapy
 - ▶ Adequate pain 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

Ongoing reevaluation and communication between the patient and health care team

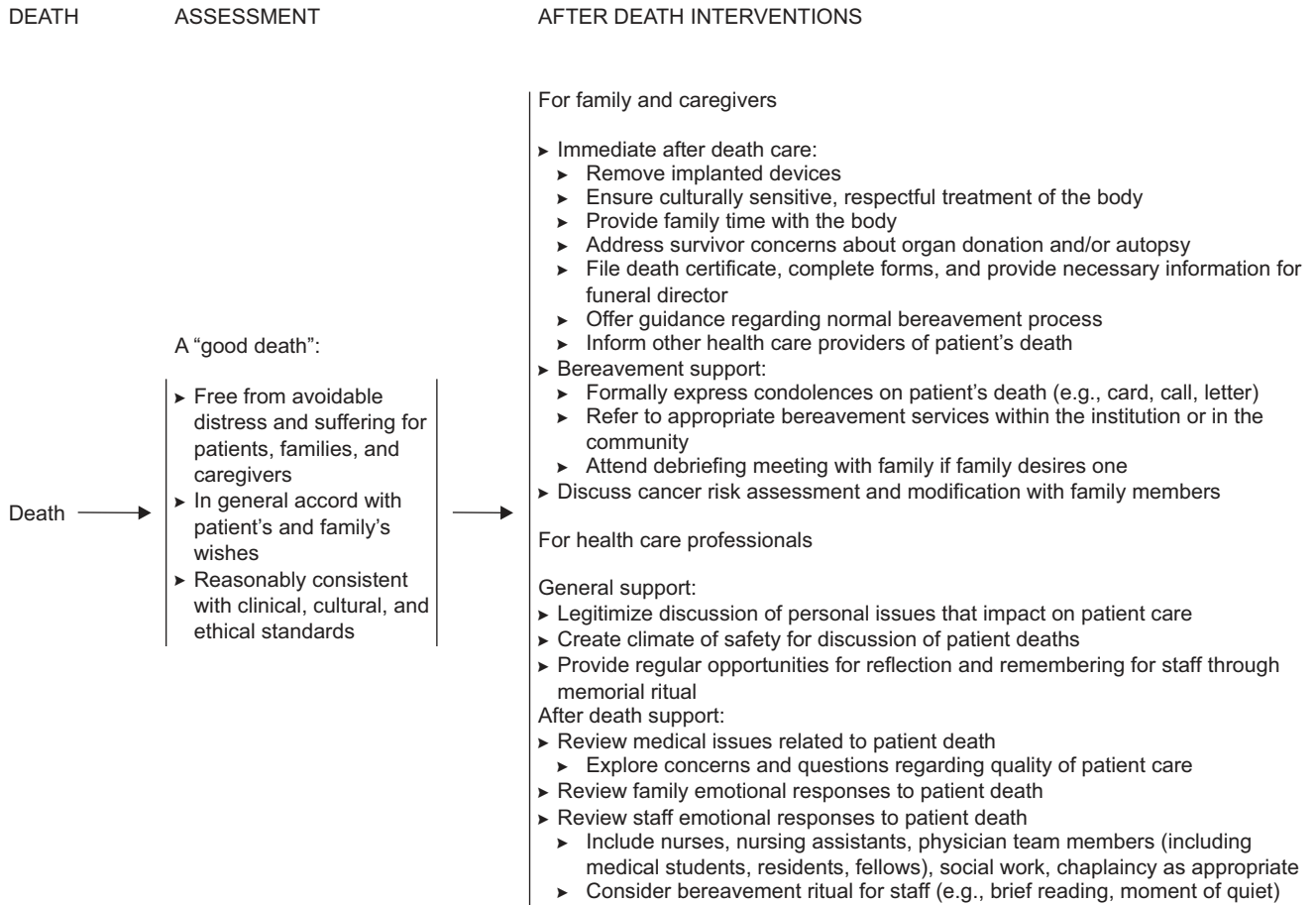
Unsatisfactory

- ▶ Intensify efforts to communicate palliative care options
- ▶ Consult with a psychiatrist to evaluate and treat preexisting psychiatric disorders, substance abuse, and dysfunctional adjustment reactions
- ▶ See NCCN Distress Management Guidelines*

Ongoing reassessment

*For the most recent version of these guidelines, visit the NCCN Web site at www.nccn.org

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collaborative efforts of these experts based on their clinical experience and available scientific evidence.

Palliative Oncology

During the past 20 years, increasing attention has been paid to quality-of-life issues in oncology.¹⁻⁴ Statistics show that an estimated 39.3% of patients diagnosed with cancer will die of their disease.⁵ As the hospice movement has grown in this country, palliative care has developed into an integral part (rather than the antithesis) of comprehensive cancer care.⁶⁻¹⁰ Although 39.3% of the cancer patients who die each year in this country receive hospice care, most patients are referred too late for comprehensive palliative care to exert its full benefit, and many are never referred at all. Administration of chemotherapy late in the course of cancer care, including in the last days of life, is becoming more common.¹¹ In addition, oncologists have reported that they have difficulty obtaining the services they need for their dying patients.¹²

Palliative care must be integrated earlier into the continuum of cancer care.¹³⁻¹⁷ Palliative care needs exist right from the time of diagnosis through survivorship and end-of-life care. Building on the WHO's recommended model of resource allocation in cancer care,⁹ palliative, symptom-modifying therapy should be provided simultaneously with disease-modifying therapy from diagnosis.¹⁸ As the cancer progresses and anticancer therapy becomes less effective, appropriate, or desired, palliative care becomes the major focus of the continuing care for the patient and family.¹⁹ Palliative care should begin with the presentation of symptoms, even before the source of those symptoms has been fully determined. 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 patient's survivors.

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 is receiving an unprecedented level of support from at least 7 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. 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. Support for expanding 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 areas such as pain, psychosocial care, personal awareness, and hospice care.

Palliative care should be delivered based on clinical practice guidelines. Patients and families should be informed that palliative care is an integral part of their comprehensive cancer care.^{20,21} Initially, the primary oncology team (interdisciplinary team of physicians, nurses, mental health professionals, and chaplains) 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. Effective palliative care also requires an interdisciplinary team approach. 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 the patient and family about the natural history of the cancer and its prognosis is at the core of effective palliative care.^{22,23}

In December 2004, the National Institutes of Health (NIH) held a state-of-the-science conference on improving end-of-life care, indicating that palliative medicine is a recognized research area. The final statement from this NIH conference is a useful resource for understanding the complex issues surrounding end-of-life care. Some conclusions include:

1. "End-of-life care is often fragmented among providers and provider settings, leading to a lack of

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continuity of care and impeding the ability to provide high-quality, interdisciplinary care.

2. Enhanced communication among patients, families, and providers is crucial to high-quality end-of-life care.

3. The design of the current Medicare hospice benefit limits the availability of the full range of interventions needed by many persons at the end of life²⁴ (e.g., radiation therapy for symptom management).

Lorenz et al.²⁵ performed a systematic review of end-of-life care and outcomes as the background for NIH State-of-the-Science Conference on End-of-Life Care. Clinical practice guidelines for quality palliative care by the National Consensus Project were published in 2004 and the National Quality Forum has developed a national quality framework for evaluating palliative care programs, extending beyond terminally ill cancer patients to include a broad spectrum of patients with multiple illnesses.²⁶ These guidelines provide an indepth assessment of many issues surrounding palliative care (e.g., cultural, ethical, legal, physical, psychological, social, spiritual, and existential aspects of care). National Consensus Project and National Institute for Clinical Excellence (NICE) issued guidance in 2004 on how supportive and palliative care services should be provided for adults with cancer. Some key recommendations include:

1. Patients and their caregivers should have access to a range of specialist services that help them cope with cancer and its treatment.

2. Whenever possible, patients should receive significant information from a senior health professional who has received advanced level training and is assessed as an effective communicator.

3. Good quality information should be available for free to help people affected by cancer make decisions about their care.²⁷

Other resources that may be useful for patients, their caregivers, and/or clinicians are listed in Table 1 (available online, in these guidelines, at www.nccn.org [MS-12]).

Palliative Care Guidelines

These guidelines were developed to facilitate the appropriate integration of palliative care into oncology practice. The guidelines outline procedures for screening, assessment, palliative care interven-

tions, 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.

The guidelines define palliative care as both a philosophy of care and an organized, highly structured system for delivering care to persons with life-threatening or debilitating illness. Palliative care is patient- and family-centered care that focuses on effective management of pain and other distressing symptoms while incorporating psychosocial, spiritual, and existential support according to patient/family needs, values, beliefs, and cultures. The goal of palliative care is to prevent and relieve 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 can be delivered concurrently with life-prolonging care (integrated model) or as the main focus of care.

Palliative Care Screening

All cancer patients should be screened for palliative care needs at their initial visit, at appropriate intervals, and as clinically indicated. Use of these guidelines should be considered in the following clinical situations: 1) uncontrolled symptoms, 2) moderate to severe distress related to cancer diagnosis and therapy, 3) serious comorbid physical and psychosocial conditions, 4) advanced or progressive disease for which no effective curative therapy is available and/or life expectancy is 1 year or less, 5) when the patient or family has concerns about disease course and decision-making, and/or 6) the patient or family specifically requests palliative care. An estimate of life expectancy in terms of a year to months, months to weeks, or weeks to days should be made to guide the use of specific palliative care interventions. Potential indicators that patients are in their last year of life include decreased performance status (ECOG score ≥ 3 ; Karnofsky performance score [KPS] ≤ 50), hypercalcemia, central nervous system metastases, delirium, superior vena cava syndrome, spinal cord compression, cachexia, malignant effusions, liver

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failure, kidney failure, or other serious comorbid conditions. Some patients, such as those with stage IV lung cancer, pancreatic cancer, and glioblastoma multiforme, would benefit from palliative care beginning at diagnosis, because expected survival is usually less than a year. Clinicians should integrate palliative care into general oncology care for patients who meet these screening criteria. These patients should undergo a comprehensive palliative care assessment by their primary oncology team. Comorbid physical and psychosocial conditions should be treated by appropriate clinicians. Consultation or collaboration with palliative care specialists is recommended for patients with more complex problems.

Patients who do not meet these screening criteria should be rescreened at regular intervals. In addition, patients and family members should be informed about the role and benefits of palliative care services. Anticipation of palliative care needs and prevention of symptoms should also be discussed. Reassessment should be ongoing, with continuation or modification of life-expectancy-guided palliative care until the patient's death.

Palliative Care Assessment

A comprehensive palliative care assessment evaluates the benefits and risks of anticancer therapy, physical symptoms, psychosocial or spiritual distress, personal goals and expectations, educational and informational needs, cultural factors affecting care, and criteria for early consultation with a palliative care specialist.²⁻⁴ Assessment of the benefits and risks of anticancer therapy is based on the existing NCCN disease-specific guidelines for that patient's cancer (the most recent version of all guidelines can be found on the NCCN Web site at www.nccn.org). Special attention should be given to the natural history of specific tumors, potential for response to further treatment, meaning of anticancer therapy to patient and family, impairment of vital organs, performance status, and serious comorbid conditions. Symptom assessment should look for common symptoms, such as pain, dyspnea, anorexia, cachexia, nausea, vomiting, constipation, malignant bowel obstruction, fatigue, weakness, asthenia, sleep disturbance, sedation, and delirium. Assessment of psychosocial distress should focus on psychosocial, spiritual, or existential issues according to the

NCCN Clinical Practice Guidelines in Oncology: Distress Management (for the most recent version of these guidelines, visit the NCCN Web site at www.nccn.org). Special problems with social support and resources must be addressed and managed. Patients and their families should be asked about their personal goals and expectations; priorities for palliative care; goals and meaning of anticancer therapy and quality of life; and the patient's eligibility for hospice based on needs that might be met by the hospice model of palliative care. Patients and families should also be assessed for their educational and informational needs and cultural factors affecting their care, including values and preferences about information and communication and perception of the patient's disease status.

Criteria for early consultation with a palliative care specialist are based on patient characteristics, social circumstances, and anticipatory bereavement issues. Patient-based criteria include patients with limited treatment options, high risk for poor pain control, history of significant psychiatric disorder, refractory nonpain symptoms, history of allergies or adverse effects to multiple palliative interventions, unexpected ICU admissions, high distress score (> 4; see the NCCN Distress Management Guidelines [available at www.nccn.org]), cognitive impairment, severe comorbid conditions, communication barriers, and/or repeated requests for hastened death.

Social circumstances or anticipatory bereavement issues that indicate a need for early referral for early consultation with a palliative care specialist include family/caregiver limitations, inadequate social support, financial limitations, limited access to care, family discord, intensely dependent relationships, patient's concern regarding care of dependents, spiritual or existential distress, and unresolved or multiple recent losses.

Palliative Care Interventions

The panel divided patients into 3 groups to address the effect of life expectancy on the delivery of palliative care interventions: 1) patients with years to months to live, 2) patients 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 es-

timating life expectancy but believes this delineation will be useful for the delivery of appropriate palliative care interventions. Optimal provision of palliative care requires ongoing reassessment and modification of strategies. Criteria include adequate pain and symptom control, reduction of patient/family distress, acceptable sense of control, relief of caregiver burden, strengthened relationships, optimized quality of life, and personal growth and enhanced meaning.²⁸⁻³¹ The patient and family's personal, spiritual and existential, cultural, and religious goals and expectations may change throughout these 3 timeframes. Anticipation of patient and family needs is important.

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 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 as well. In addition, it is necessary to determine the decision-making styles of patients and their families. This will help facilitate congruence of a patient's goals and expectations with those of the family. Clinicians must also determine patients' assessments of 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 to 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 are 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. Information 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 ac-

curate about their prognosis than their physicians, which can affect their preferences for cardiopulmonary resuscitation and for life-extending measures.³²

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 managed carefully.³³ Finally, social 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 as outlined in the algorithms. More palliative care interventions for other symptoms will be developed as deemed necessary.

Benefits and Risks of Anticancer Therapy

Patients who have years to months to live and a good performance status may be interested in continuing anticancer therapy to prolong survival and reduce cancer-related symptoms.³⁴⁻³⁷ Anticancer therapy may be conventional evidence-based treatment as outlined in the NCCN disease-specific guidelines (available on the NCCN Web site at www.nccn.org) or treatment in the context of a clinical trial. In some of the advanced-stage cancers, chemotherapy may be superior to best supportive care and may prolong survival.^{38,39} For example, 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 therapies.⁴⁰ Physicians, patients, and their families should discuss goals, range of choices, benefits and risks of anticancer therapy, and possible effects on quality of life. Patients with months to weeks to live should be provided with guidance regarding the anticipated disease course. These patients are typically tired of therapy, homebound, and more concerned about the side effects of

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more treatment. The focus of treatment for these patients shifts from prolonging life towards maintaining quality of life. These patients should be offered best supportive care, including referral to palliative care or hospice.^{41,42} 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 (i.e., dying patients) should not be given anticancer therapy, but should be given intensive palliative care focusing on symptom control and preparation for the anticipated dying process.

Pain

See the NCCN Clinical Practice Guidelines in Oncology: Adult Cancer Pain and Pediatric Cancer Pain (for the most recent versions of these guidelines, visit the NCCN Web site at www.nccn.org).

Dyspnea

Dyspnea is one of the most common symptoms in patients with advanced lung cancer.⁴³ In patients with years to months to live experiencing dyspnea, symptom intensity must be assessed, followed by treatment of underlying causes or comorbid conditions using chemotherapy or radiation therapy, thoracentesis, pleurodesis or pleural drainage catheters, bronchoscopic therapy or bronchodilators diuretics, antibiotics, or transfusions. Symptom intensity in noncommunicative patients with weeks to days to live should be assessed using other distress markers of dyspnea. As life expectancy decreases, the role of mechanical ventilation and oxygen diminishes and the role of opioids, benzodiazepines, glycopyrrolate, and scopolamine increases.⁴⁴⁻⁴⁶

Anorexia/Cachexia

Anorexia/cachexia syndrome is prevalent in most patients with advanced cancer.⁴⁷ Anorexia is defined as loss of desire to eat, whereas cachexia results from loss of skeletal muscle mass, leading to asthenia, changing body image, and autonomic failure. In patients with a life expectancy of years to months, interventions for anorexia or cachexia include treatment of early satiety, treatment of symptoms that interfere with intake or use of appetite stimulants (e.g., megestrol acetate, medroprogesterone acetate, steroids),⁴⁸ and/or evaluation of endocrine abnormalities. Nutrition support consultation^{49,50} or participation in nutrition support clinical trials can be considered when the disease or treatment affects the ability to eat. The goals and intensity of nutritional

support change as life expectancy is reduced to weeks to days. Family members should be informed of alternate ways to care for dying patients. Overly aggressive enteral or parenteral nutrition therapies can actually increase the suffering of dying patients. In terms of hydration and nutrition, palliative care in the final weeks of life typically includes treating dry mouth and thirst, and providing family education and support for handling the psychosocial aspects of discontinuing feeding.

Nausea and Vomiting

Chemotherapy-induced nausea and vomiting (CINV) has a major impact on a patient's quality of life.⁵¹ Nausea and vomiting induced by chemotherapy or radiation therapy should be managed as outlined in the NCCN Clinical Practice Guidelines in Oncology: Antiemesis (for the most recent version of these guidelines, visit the NCCN Web site at www.nccn.org). Continuous intravenous or subcutaneous infusions of different antiemetics may be necessary for managing intractable nausea and vomiting. Nonspecific nausea and vomiting can be managed with dopamine receptor antagonists or benzodiazepines (anxiety-related nausea). Persistent nausea and vomiting can be treated by titrating dopamine receptor antagonists (e.g., prochlorperazine, haloperidol, metoclopramide) to maximum benefit and tolerance. For persistent nausea, adding 5HT₃ (5hydroxytryptamine₃) receptor antagonists, and/or anticholinergic agents, and/or antihistamines, corticosteroids, continuous infusion of antiemetics, antipsychotics (e.g., olanzapine, haloperidol), or cannabinoids can be considered. Alternative therapies (e.g., acupuncture) or palliative sedation can also be considered.

Constipation

Constipation occurs in approximately 50% of patients with advanced cancer and most patients treated with opioids.⁵² Although several drugs are known to cause constipation,⁵³ including antacids, anticholinergic drugs (e.g., antidepressants, antispasmodics, phenothiazines, haloperidol), and antiemetics, opioid analgesics are most commonly associated with constipation. Opioid-induced constipation should be anticipated and treated prophylactically with a stimulating laxative to increase bowel motility, with stool softeners as indicated.⁵⁴ Increasing fluid intake, dietary fiber, and physical activity must also be en-

couraged, when appropriate. If constipation is present, the cause and severity must be assessed. Impaction, obstruction, and other treatable causes, such as hypercalcemia, hypokalemia, hypothyroidism, and diabetes mellitus, must be ruled out.

Persistent constipation may be treated by adding bisacodyl 10 to 15 mg, 2 to 3 times daily, with a goal of one nonforced bowel movement every 1 to 2 days. If impaction is observed, glycerine suppositories may be administered or manual disimpaction performed. If constipation persists, adding other laxatives may be considered, such as rectal bisacodyl 2 times daily or oral polyethylene glycol, lactulose, magnesium hydroxide, or magnesium citrate. If gastroparesis is suspected, the addition of a prokinetic agent, such as metoclopramide, may be considered. Recent studies have shown that methylnaltrexone, a peripherally acting antagonist of opioid receptors, helps relieve opioid-induced constipation while maintaining pain control.^{55,56} Based on these observations, the NCCN Palliative Care Panel recommends considering 0.15 mg per kilogram of body weight of methylnaltrexone every other day (no more than 1 per day) for patients experiencing constipation that has not responded to standard laxative therapy.

Malignant Bowel Obstruction

Malignant bowel obstructions are usually diagnosed clinically and confirmed with radiography. Patients with years to months to live should be screened for malignant bowel obstructions and reversible causes treated appropriately. Although surgery is the primary treatment for malignant obstruction, some patients with advanced disease or patients in generally poor condition are unfit for surgery and require alternative management to relieve distressing symptoms. In imminently dying patients with weeks to days to live, medical management is preferable to surgical management. Several treatment options are now available for patients with advanced and terminal cancer who develop symptomatic intestinal obstruction. Medical measures such as opioid analgesics, anticholinergic drugs, corticosteroids, and antiemetics may be used alone or in combination to relieve symptoms. Use of octreotide is highly recommended early in the diagnosis because of its high efficacy and tolerability.⁵⁷ CT scan is used to identify the cause of obstruction if surgical intervention is contemplated for improvement of quality of life. Surgical risks should be discussed with patients and families. Total parenteral nutrition

(TPN) can be considered to improve quality of life in patients with a life expectancy of months to years.

Delirium

Delirium should be assessed using the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSMIV) criteria.⁵⁸ Reversible causes should be identified and treated appropriately. The symptoms of delirium should be controlled with antipsychotic, neuroleptic drugs such as haloperidol, risperidone, olanzapine, or quetiapine fumarate.⁵⁹ A benzodiazepine, such as lorazepam, should be added for agitation that is refractory to high doses of neuroleptics. The dosages of these symptom-control medications should be titrated to optimal relief. In addition, the use of nonpharmacologic interventions, such as re-orientation, cognitive stimulation, and sleep hygiene, should be maximized. Caregivers should be supported in caring for their loved one and coping with this distressing condition.

In patients with a life expectancy limited to weeks or days, iatrogenic causes should be eliminated whenever possible. Persistent delirium may shorten prognosis.⁶⁰ If delirium is a result of disease progression, palliative care must be focused on symptom control and family support. Neuroleptic and benzodiazepine medications should have their dose increased and/or their route of administration changed to ensure adequate delirium symptom control.⁶¹ Opioid rotation can be considered (see NCCN Adult Cancer Pain Guidelines; for the most recent version of these guidelines, visit the NCCN Web site at www.nccn.org) if the delirium is believed to be caused by neurotoxicity of the current opioid. Unnecessary medications and tubes should be removed. Family and caregivers must be supported and educated about the anticipated course of disease progression and the dying process.

Fatigue/Weakness/Asthenia

See NCCN Clinical Practice Guidelines in Oncology: Cancer-Related Fatigue (for the most recent version of these guidelines, visit the NCCN Web site at www.nccn.org).

Psychosocial Distress

Palliative care of physical symptoms should follow the NCCN Adult Cancer Pain and Cancer-Related Fatigue Guidelines (for the most recent version of these guidelines, visit the NCCN Web site at www.nccn.org).^{62,63} The algorithms delineate spe-

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cial considerations in implementing these guidelines based on life expectancy. 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; acceptance of loss of function for the sake of symptom relief; and treatment of unique symptoms in their final hours of life. Nutrition support consult may also be considered.

Patients experiencing psychosocial distress should be assured that they will be cared for in a safe environment. They should be provided with emotional support to address any intra-family conflict regarding palliative care interventions. Patients and family members benefit from ongoing discussion about the natural history of the disease and prognosis in clear, consistent language. Support and education should be provided to caregivers and family members. Patients should be reassessed regularly. If psychosocial distress persists, palliative care options should be intensified and the patients should be managed according to the NCCN Distress Management Guidelines (available at www.nccn.org).⁶⁴

Advance Care Planning

Advance care planning in patients with a year to months to live should include an open discussion about palliative care options, such as hospice; elicitation of personal values and preferences for end-of-life care; exploration for congruence between the patient's wishes/expectations and those of the family/health care team; and provision of information about advance directives. Patients should be asked if they have completed any advance care planning, such as a living will, power of attorney, or delineation of specific limitations regarding lifesustaining treatments, including cardiopulmonary resuscitation, mechanical ventilation, and artificial nutrition/hydration.

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. Where the patient wants to die should also be determined and the desire for organ donation and/or autopsy discussed. Dying in a hospital can be traumatic for patients and their families, although some patients request to remain in a facility for terminal care. Providing palliative care services has been

shown to decrease deaths in intensive care units;⁶⁵ most cancer patients wish to die at home. According to the National Home and Hospice Care Survey, the number of adult cancer patients using hospice care doubled during 1991/1992 through 1999/2000.⁶⁶

As the patient's life expectancy decreases to months to weeks, compliance with advance directives should be ensured regardless of treatment setting. In patients with a life expectancy of weeks to days, the patient's decision regarding cardiopulmonary resuscitation must be clarified. Ethics, social work, or other consultation, such as chaplains, must be considered to assist in conflict resolution when the patient, family, and/or medical professional team do not agree on benefit/efficacy of interventions. The desire for organ donation and/or autopsy must also be confirmed with the patient.

Special Palliative Care Interventions

Special palliative care interventions include responses to requests for hastened death (physician-assisted suicide, active euthanasia). The most appropriate response to a request for assisted suicide is to intensify palliative care. Open exploration of the patient's request for aid in dying can often identify unmet needs and new palliative care interventions that may be helpful. Alternatives to physician-assisted suicide, such as treatment withdrawal, voluntary cessation of eating and drinking, and/or sedation, should be considered and discussed with patients and families. Psychiatric consultation to diagnose and treat reversible causes of psychological suffering should be requested. Patients should be assured that their health care team is committed to providing continuing care. Although physician-assisted suicide, under specified conditions, is legal in the state of Oregon and will soon be in Washington, euthanasia is not legal in the rest of the United States.

Palliative Sedation

Palliative sedation can be an effective symptom control treatment for imminently dying patients or those with refractory symptoms and a life expectancy of hours to days. Typical sedatives used for palliative sedation through parenteral infusions include pentobarbital, thiopental, and midazolam. Palliative sedation is best performed by palliative care experts and

has its ethical justification in the Doctrine of Double Effect.⁶⁷⁻⁷¹ Clinicians may find that applying usual benefit/risk analysis to this type of intervention will suffice in medical decision-making. Patients who are actively dying and in their final hours of life should be allowed to spend uninterrupted time with family. Diagnostic tests should be discontinued, the family should be prepared and supported, and advance directives should be honored. Secretions should be minimized and delirium controlled with regular administration of appropriate medications through a feasible route of administration. Patients should be repositioned regularly for comfort, and monitored for urinary retention and fecal impaction. Privacy and respectful space for the family should be provided to facilitate closure. Most protocols for sedation to provide comfort at end-of-life include planned periods of medication withdrawal that allow reevaluation with direct assessment of the patient.

Palliative Care Reassessment of Outcomes

The outcome measures for these guidelines are much more difficult to define than those for NCCN disease-specific guidelines. The panel adapted a list of end-of-life outcomes from several surveys of North American citizens.²⁶ For the purpose of these guidelines, and until more precise outcome measures are available, the panel chose Singer's outcomes. Satisfactory palliative care should provide the following: adequate pain and symptom management, reduction of patient and family distress, acceptable sense of control, relief of caregiver burden, optimized quality of life, personal growth, and enhanced meaning, insofar as this is desired. Research is ongoing regarding better ways to measure "dying well."⁷² For now, patients should be reassessed regularly for these 5 outcomes, and palliative care efforts should be intensified as appropriate. Again, cultural sensitivity is mandatory in this setting. Consultation with a psychiatrist and/or other mental health professionals to evaluate and treat preexisting psychiatric disorders, substance abuse, and dysfunctional adjustment reactions should be considered for some patients (see the NCCN Distress Management Guidelines; for the most recent version of these guidelines, visit the NCCN Web site at www.nccn.org).

After-Death Care Interventions

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. These guidelines have modified this delineation of the attributes of satisfactory palliative care to include adequate pain and symptom control, reduction of patient/family distress, acceptable sense of control, relief of caregiver burden, strengthened relationships, optimized quality of life, and personal growth and enhanced meaning. A "good death" has been defined as "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 reasonably consistent with clinical, cultural, and ethical standards."¹⁵ Singer et al.²⁸ state that satisfactory palliative care should promote a good death by providing adequate pain and symptom management, reduction of distress to the patient and family, acceptable sense of control, relief of caregiver burden, strengthened personal relationships, and optimized quality of life.

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 implanted devices; 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. Funeral attendance can be considered for individual patients. For family members, grief should be normalized, risk factors for complicated grief identified, and complicated grief identified and treated. 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 and require assistance in identifying community bereavement resources. Health care professionals should 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 patient's death. A well-supported end-of-life care experience

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will facilitate the family's acceptance of appropriate referral for cancer risk assessment and risk modification. Psychosocial support should also be provided for the staff.

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. Patient conditions usually move from ambulatory to sedentary as disease advances and performance status lowers. 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.

Cancer patients' experiences throughout the disease course begin with the diagnosis. 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 have 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 team members will work with them and their family 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. The combined efforts of the oncology team and hospice/palliative care team can improve the overall outcome for patients and their families.

Palliative care applied late in the course of disease is designed 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.^{73,74} This may be a sign that patients do not fully understand the disease. 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 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 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. During the next few years, the panel will complete the details of specific palliative care interventions and will refine the palliative care reassessment outcome measures. The panel will also incorporate information from the institutions that review and implement these guidelines, and will try to address barriers to accessing high-quality end-of-life care. The care outlined in these guidelines provides a different kind of hope than that for cure of

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the disease itself. Palliative care provides hope for dignity, comfort, and closure, and for growth at the end of life.

Palliative care Internet resources for clinicians can be found on the NCCN Web site at www.nccn.org.

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Individual Disclosures for the NCCN Palliative Care Panel					
Panel Member	Clinical Research Support	Advisory Boards, Speakers Bureau, Expert Witness, or Consultant	Patent, Equity, or Royalty	Other	Date Completed
Anthony Back, MD	None	None	None	None	9/12/08
Costantino Benedetti, MD	None	Merck & Co., Inc.	None	None	1/2/09
J. Andrew Billings, MD	None	None	None	None	9/12/08
Susan Block, MD	None	None	None	None	9/12/08
Barry Boston, MD	BEST	Bayer HealthCare; Onyx Pharmaceuticals, Inc.; Pfizer Inc.; and sanofi-aventis U.S.	None	None	12/22/08
Eduardo Bruera, MD	None	None	None	None	1/2/09
Sydney M. Dy, MD	None	None	None	None	6/27/08
Catherine Eberle, MD	None	None	None	None	9/12/08
Kathleen M. Foley, MD	None	None	None	None	1/5/09
Sloan Beth Karver, MD	None	None	None	None	6/30/08
Sara J. Knight, PhD	None	None	None	None	9/14/08
Michael H. Levy, MD, PhD	Wyeth Pharmaceuticals	Purdue Pharma LP; and Wyeth Pharmaceuticals	None	None	10/11/08
Sumathi Misra, MD	None	None	None	None	7/17/08
Christine S. Ritchie, MD, MSPH	Association for Healthcare Research and Quality; Intramural Funding; and National Institute on Aging	None	None	None	9/12/08
David Spiegel, MD	National Cancer Institute	None	None	None	6/30/08
Linda Sutton, MD	None	GW Pharma	None	None	11/24/08
Susan Urba, MD	MGI PHARMA, INC.	Merck & Co., Inc.; and MGI PHARMA, INC.	None	None	7/21/08
Jamie H. Von Roenn, MD	None	None	None	None	9/12/08
Sharon M. Weinstein, MD	None	None	None	None	12/15/08

The NCCN guidelines staff have no conflicts to disclose.