Health Care Guideline:
Palliative Care for Adults

Sixth Edition
January 2020

Text in blue in this algorithm indicates a linked corresponding annotation.
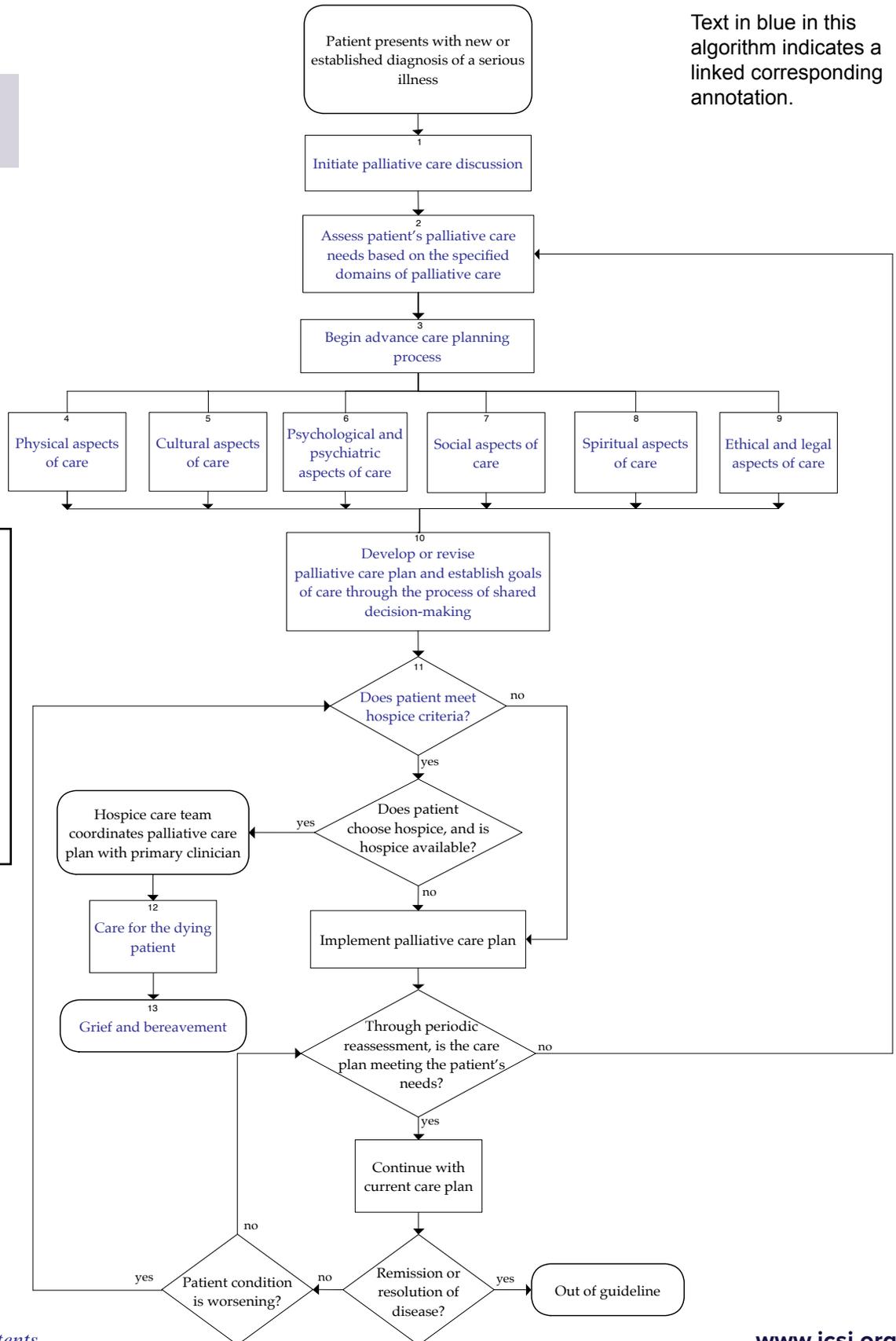
Serious Illness:

- Terminal illness
- Chronic, progressive and probably life-shortening illness
- Severe neurodegenerative diseases
- Life-threatening illness with a chance of full recovery

Patient presents with new or established diagnosis of a serious illness

1 Initiate palliative care discussion

2 Assess patient's palliative care needs based on the specified domains of palliative care

3 Begin advance care planning process

4 Physical aspects of care

5 Cultural aspects of care

6 Psychological and psychiatric aspects of care

7 Social aspects of care

8 Spiritual aspects of care

9 Ethical and legal aspects of care

10 Develop or revise palliative care plan and establish goals of care through the process of shared decision-making

11 Does patient meet hospice criteria? — no

yes

Does patient choose hospice, and is hospice available? — yes → Hospice care team coordinates palliative care plan with primary clinician

no

Implement palliative care plan

12 Care for the dying patient

13 Grief and bereavement

Through periodic reassessment, is the care plan meeting the patient's needs? — no

yes

Continue with current care plan

Patient condition is worsening? — yes / no

Remission or resolution of disease? — no / yes → Out of guideline

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Evidence Grading

Literature Search

A consistent and defined literature search process is used in the development and revision of ICSI guidelines. Literature searches for this guideline were done under the following parameters:

- Time frame: Jan. 1, 2013, through Dec. 1, 2018.

- Types of studies searched for: systematic reviews and meta-analysis, randomized controlled trials, implementation studies and observational studies (case-control, cohort and cross-sectional studies).

- Population: adults.

- All studies were published in English and included humans.

For a detailed list of literature search terms, see Appendix A.

In addition to the literature searches, articles were obtained by work group members and ICSI staff. Those vetted by the work group were included in the guideline when appropriate.

Methodology

ICSI utilizes the Grading of Recommendations Assessment, Development and Evaluation (GRADE) methodology system. GRADE involves systematically evaluating the quality of evidence (high, moderate, low, very low) and developing a strength of recommendation (strong, weak). For more detailed information on GRADE, please visit http://www.gradeworkinggroup.org/. In addition, when GRADE methodology could not be applied, the work group developed consensus recommendations.

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Recommendations Table

The following table is a list of evidence-based recommendations for palliative care.

Note: Other recommendation language may appear throughout the document as a result of work group consensus but not included in this evidence-based recommendations table.

Topic	Quality of Evidence	Recommendation(s)	Strength of Recommendation	Annotation Number	Relevant Resources
Early Intervention	Low	Palliative care can begin at the time of diagnosis of a serious illness regardless of treatment plan and continue throughout the course of a patient's illness.	Strong	1	*Temel, 2010 (Randomized Control Trial); Kass-Bartelmes, 2004 (Summary); Morrison, 2004 (Case Report) Steinhauser, 2000 (Observational Study)*
Early Intervention	Low	Palliative care discussion or referral should be considered whenever a patient develops or presents with a serious or life-threatening illness, in all care settings.	Strong	1	*Kavalieratos, 2016 (Systematic Review/Meta-Analysis); Khandelwal, 2015 (Systematic Review); Lamba, 2014 (Report); Smith, 2014 (Review); Strand, 2013 (Summary); Weissman, 2011 (Consensus Report)*
Assess Domains of Palliative Care	Low	Clinicians should use validated assessment tools, where available, to assess palliative care needs for each of these domains: physical, cultural, psychological, social, spiritual and ethical/legal.	Strong	2	*Aslakson, 2017 (Technical Brief); Bakitas, 2009 (Randomized Control Trial); Pulchaski, 2009 (Report); Smith, 2009 (Case Report); Gries, 2008 (Case Report); Chochinov, 2006 (Summary); Moro, 2006 (Observational Study); Kemp, 2005 (Summary); Searight, 2005 (Summary); Morrison, 2004 (Case Report); Curtis, 2002 (Case Report); Werth, 2002 (Summary); Kagawa-Singer, 2001 (Case Report); Block, 2000 (Case Report); Chang, 2000 (Observational Study); Post, 2000 (Summary); Phillip, 1998 (Observational Study); Reed, 1987 (Observational Study)*
Informed Consent	Low	Informed consent should be obtained for any treatment or plan of care from either a patient with decision-making capacity or an appropriate surrogate decision-maker.	Strong	2	*Silveira, 2010 (Observational Study); Arnold, 2006 (Summary)*

Topic	Quality of Evidence	Recommendation(s)	Strength of Recommendation	Annotation Number	Relevant Resources
Interdisciplinary Care Team	Low	The interdisciplinary care team (IDT) of health care providers should ideally include at a minimum physicians, advance practice providers, nurses, social workers, spiritual counselors, and bereavement staff. Other clinicians may also participate on the IDT.	Strong	2	*Bakitas, 2009 (Randomized Control Trial); Pulchaski, 2009 (Report); Smith, 2009 (Case Report); Gries, 2008 (Case Report); Chochinov, 2006 (Summary); Kemp, 2005 (Summary); Searight, 2005 (Summary); Morrison, 2004 (Case Report); Curtis, 2002 (Case Report); Werth, 2002 (Summary); Kagawa-Singer, 2001 (Case Report); Block, 2000 (Case Report); Post, 2000 (Summary); Reed, 1987 (Observational Study)*
Care Conferences	Low	Care conferences with the patient, family and members of the interdisciplinary team are recommended on an ongoing basis to discuss patient's condition, course of illness, treatment options, possibility of progression to death, goals and plan of care.	Strong	2	*Agar, 2017 (Randomized Control Trial), Gries, 2008 (Case Report); Moneymaker, 2005 (Pamphlet); McDonagh, 2004 (Observational Study); Curtis, 2001(Observational Study)*
Advance Care Planning	Low	Facilitation of advance care planning conversations is appropriate for all adult patients. Regular review of goals and wishes should occur as the patient's condition or life circumstances change.	Strong	3	*Weissman, 2011 (Report); Gries, 2008 (Case Report); Block, 2006 (Case Study); Sinclair, 2006 (Summary); Lee, 2002 (Summary); Vandekieft, 2001(Summary); Balaban, 2000 (Summary)*
Provider's Order for Life-Sustaining Treatment	Low	Adopt the Provider's Order for Life-Sustaining Treatment (POLST) as a community standard to document and communicate the preferences of individual patients with a serious illness as an official medical order written by a provider.	Strong	3	*Wang, 2017 (Systematic Review); Jennings, 2016 (Observational Study); Hickman, 2015 (Systematic Review); Bamba, 2012 (Summary)*

Topic	Quality of Evidence	Recommendation(s)	Strength of Recommendation	Annotation Number	Relevant Resources
Ethical Aspects of Care	Low	As the disease progresses, clinicians should recognize those patients who are receiving nonbeneficial, low-yield therapy and reassess the treatment plan with the patient and family.	Strong	9	*Snyder Sulmasy, 2019 (Manual); Schneiderman, 2003 (Randomized Control Trial)*
Shared Decision Making	Low	Clinicians should engage in shared decision-making with the patient and/or family when establishing or revising goals of care.	Strong	10	*Shay, 2015 (Systematic Review); Stiggelbout, 2015 (Summary); Belanger, 2011 (Systematic Review); Makoul, 2006 (Review)*
Assess for Hospice Referral	Low	In a patient with serious illness, clinicians should recognize the prognosis of less than 6 months, and if in line with the patient goals of care, refer to hospice.	Strong	11	*Joseph, 2016 (Systematic Review); Brinkman-Stoppelenburg, 2014 (Systematic Review); Lamont, 2001 (Observational Study); Brody, 1997 (Summary); SUPPORT, 1995 (Control Trial)*
Care for Dying Patient	Low	Clinicians should identify when a patient is actively dying and communicate that to the patient and family.	Strong	12	*Taylor, 2017 (Observational Study); Kennedy, 2014 (Review); Solloway, 2005 (Observational Study); Ellershaw, 2003 (Report)*
Grief and Bereavement	Low	Clinicians should engage in ongoing assessment of grief and bereavement throughout the illness trajectory and intervene or refer for ongoing bereavement services when warranted.	Strong	13	*Griffin, 2007 (Guideline); Strobe, 2006 (Report); Hollenbeck, 2005 (Guideline); Ellifrit, 2003 (Observational Study); Chochinov, 1989 (Review); Sheldon, 1998 (Clinical Review)*

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Foreword

Introduction

Palliative care is medical care that focuses on relief of the symptoms and stress of a serious illness for people and their families living with a life-threatening condition. The World Health Organization (2018) defines palliative care as "an approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." Derived from the Latin word palliatus, meaning to "cloak or cover," the name is meant to convey care that wraps the patient with another layer of comfort and support. The WHO goes on to elaborate that palliative care:

- provides relief from pain and other distressing symptoms;

- affirms life and regards dying as a normal process;

- intends neither to hasten or postpone death;

- integrates the psychological and spiritual aspects of patient care;

- offers a support system to help patients live as actively as possible until death;

- offers a support system to help the family cope during the patient's illness and in their own bereavement;

- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;

- enhances quality of life and may also positively influence the course of illness;

- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Implicit in this definition is the assertion that palliative care may be provided as the primary focus of treatment, or concurrently with other medical interventions at any stage of a serious illness. By intervening at the onset of a serious illness, health care professionals can assure that appropriate interventions are offered to meet the goal of reducing the burden of disease and maximizing the quality of life.

Working in partnership with the primary physician, the palliative care team provides the following:

- Time to devote to intensive family meetings and patient/family counseling

- Skilled communication about what to expect in the future in order to ensure that care is matched to the goals and priorities of the patient and the family

- Expert management of complex physical and emotional symptoms, including complex pain, depression, anxiety, fatigue, shortness of breath, constipation, nausea, loss of appetite and difficulty sleeping (Center to Advance Palliative Care [CAPC])

- Attention to psychosocial and spiritual care needs

The National Consensus Project (2018), National Quality Forum (2012) and The Joint Commission (2012) have outlined systematic components of palliative care services to support these outcomes. In addition, the Center to Advance Palliative Care (CAPC) provides a wealth of resources to assist in the development of quality palliative services. This guideline aims to help clinicians understand the philosophy and structure of palliative care, as well as provide aims and measures to operationalize palliative care services.

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The Evidence for Palliative Care Programs

Technological advances in medical care have allowed individuals to live longer, but often at the expense of increased symptom burden and quality of life. The need for palliative services is driven by patients' desire for relief of suffering, whether caused by the underlying illness or its treatment. The landmark SUPPORT study (1995) documented the scope and nature of challenges associated with seeking to provide effective, comprehensive care for individuals facing serious illness. A series of reports from the Institute of Medicine (1998, 2002, 2003) provided further documentation of how the burdens of disease and treatment were not being adequately addressed.

Early hospital-based palliative care programs emerged in hospitals like the Cleveland Clinic and Medical College of Wisconsin, and evidence began to accumulate demonstrating it is possible to concurrently provide disease-directed therapies and palliative care. Palliative care teams are shown to facilitate effective communication, identify patient-centered goals, align these with appropriate treatments, improve quality of life for the patient and family, decrease symptom burden and reduce costs. (*Morrison, 2008*) These results supported the ongoing growth of hospital-based palliative care programs, which CAPC reports that as of 2016 can be found in more than 75% of all U.S. hospitals with more than 50 beds.

Outpatient palliative care services evolved to address palliative needs earlier in the disease process. Early palliative care, including outpatient services, can improve quality of life, reduce symptoms, support patient-centered goals and promote increased survival. (*Temel, 2010*)

In addition to the benefits patients derive from palliative services, palliative care programs can support health system efforts to work toward the "Triple Aim" of improved patient experience, improved population health and reduced per capita costs of health care. (*Berwick, 2008*) The comprehensive, systematic approach to serious illness aligns palliative care with efforts to reduce avoidable rehospitalization, facilitate transitions between settings of care, and identify patient- and goal-directed services within the purview of collaborating, accountable care organizations. As this guideline shows, the strengths and benefits of palliative care services apply in various settings and specialties.

Primary and specialty palliative care

Nearly all health care professionals offer palliative care to their patients in some manner. Indeed, there is a presumption that providers will all be able to provide a level of *primary palliative care* for symptoms commonly encountered in their respective practices. There is, however, growing recognition that primary care providers may need more education and training to recognize and evaluate other forms of distress and suffering in patients with serious illness. (*Quill, 2013*) Educational programs have been developed in recent years to assist clinicians in developing the skills needed to address serious illness conversations with their patients. More challenging cases of distressing symptoms or complicated communication systems would be appropriate for referral to *specialty palliative care* services with a multidisciplinary team that includes board-certified specialists where available. These specialists are also responsible for teaching other providers and building systems to guarantee the highest possible level of palliative care expertise for a population of patients.

See the "Implementation Tools and Resources Tables" section for provider education references.

Palliative care and hospice care: Similarities and differences

In America, "palliative care" and "hospice care" are terms often incorrectly used interchangeably. This confusion can reduce willingness to refer patients for palliative care services and limit access to beneficial and appropriate services early in the course of illness and treatment. Hospice care is a form of palliative care for patients with a limited life expectancy of six months or less (according to Medicare hospice coverage criteria) who want to focus on quality of life and comfort rather than life-prolonging care. Most insurance plans provide coverage for hospice. Hospice is a defined Centers for Medicare and Medicaid Services

(CMS) benefit with explicit enrollment criteria, interdisciplinary practice guidelines, and quality assurance and performance improvement requirements. See Annotation #11, "Does Patient Meet Hospice Criteria?"

Ensuring the larger medical community has a thorough understanding of the benefits of both palliative care and hospice has been a challenge.

HOSPICE: The patient has

- a limited life expectancy (specifically six months or less);

- *and* the goals for care are exclusively to optimize quality of life and maintain comfort, regardless of the symptom burden. The patient must elect to forego further life-prolonging therapies such as chemotherapy or surgery.

PALLIATIVE CARE: The patient has

- a serious illness diagnosis;

- *and* a significant symptom burden, *or* significant psychosocial distress, *or* need for assistance with decision-making or delineating goals of care, *or* a need for increased support.

All hospice is palliative care, but not all palliative care is hospice.

Scope and Target Population

By defining appropriate evaluations and outcomes, this guideline attempts to equip the clinician with knowledge of appropriate discussions, clinical interventions, and utilization of palliative care and hospice. This guideline is appropriate for adult patients who still desire curative or life-prolonging treatments, or patients who are best served by active end-of-life management. It will outline key considerations for creating a plan of care to meet patient, family and other caregivers' needs throughout the continuum of care.

This guideline will not assist providers in the identification or care for pediatric patients with life-threatening or chronic progressive illness.

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Aims

1. Increase the identification of patients who are in the early stages of a serious illness who would benefit from palliative care. *(Annotations #1, 2)*

2. Improve the effectiveness and comfort level of the clinician in communicating the necessity and benefits of palliative care with those patients with a serious illness. *(Annotation #1)*

3. Increase the completion and documentation of health care directive and health care proxy for patients with a serious illness. *(Annotation #3)*

4. Improve the accessibility and ongoing utilization of the patient's palliative care plan, health care directive, patient values and preferences, and involvement of the health care proxy across the continuum of care (inpatient, ED, outpatient, home care, senior residence, etc.). *(Annotations #3, 9)*

5. Improve the effectiveness of care and the comfort level of the palliative care patients and family. *(Annotation #10)*

Clinical Highlights

*   Planning for palliative care should begin early in the patient's journey of a serious illness. *(Annotations #1, 2; Aim #1)*

    -   Where palliative care consultation is available, referral to this service should be considered early on in the patient's care if there are complex needs. Primary care clinicians should begin palliative care planning early through palliative care conversations with their patients. *(Annotations #1, 2; Aim #1)*

*   Health care providers should complete a systematic review of patients' palliative care needs and document patients' goals for care and advance directives. *(Annotations #2-9; Aims #3, 4)*

*   Suffering is common in this patient population. It commonly presents itself in physical symptoms; thus, controlling symptoms to maximize patient comfort is a cornerstone function of palliative care. Also important are the recognition, assessment and management of nonphysical areas of suffering that are important to the patient. These include cultural, psychological, social, spiritual, financial, ethical and legal issues. Where available, consultation with palliative care specialists should be considered for all of these symptoms. *(Annotations #4-9; Aim #4)*

*   The ability to address these issues depends on the quality of communication with patients and families. Setting realistic goals of care and providing realistic hope are essential. Engaging patients in decisions about their care increases their involvement and satisfaction. Shared decision-making (SDM) is one method to engage patients. *(Annotations #2-4, 9,10; Aims #3, 4)*

*   Palliative care is compatible with all other medical treatments. *(Introduction)*

Implementation Recommendation Highlights

The following system changes were identified by the guideline work group as key strategies for health care systems to incorporate in support of the implementation of this guideline.

*   Develop a process that will allow clinicians to identify and assess patients who would benefit from palliative care services regardless of the setting or location. This process should include recognition of non-beneficial, low-yield or potentially harmful care based on patient condition and preferences. *(Aims #1, 5)*

- Develop a process to provide education to clinicians, patients and families regarding the elements and appropriateness of palliative care. It is important to address the difference between palliative care and hospice. *(Aim #2)*

- Utilize scripts for clinicians that will assist them in initiating and discussing palliative care services. *(Aim #2)*

- Develop a process for timely referral to palliative care consultation for patients with a serious illness. *(Aim #1)*

- Develop workflows and policies to assure that all staff use standardized naming conventions and filing of documents, and are trained in how to retrieve them from the electronic medical record (EMR). *(Aim #4)*

- Develop standard documentation procedures to capture patient wishes and preferences, inclusion of health care proxy, ongoing review, and updates to health care directives during transitions. *(Aims #3, 4)*

- Utilize measurement tools to improve patient engagement and the use of health care directives. *(Aims #3-5)*

Related ICSI Scientific Documents

Guidelines

- Pain: Assessment, Non-Opioid Treatment Approaches and Opioid Management

- Diagnosis and Management of Chronic Obstructive Pulmonary Disease (COPD)

- Adult Depression in Primary Care

Definitions

Clinician: All health care professionals whose practice is based on integration with and/or treatment of a patient.

Patient and Family: The use of "patient and family" implies inclusion of a patient's chosen health care agent such as a surrogate, proxy or durable power of attorney for health care.

Serious Illness: In the context of palliative care, "serious illness" is defined as "a condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress." *(Kelly, 2015)* A serious illness could be a terminal illness; a chronic, progressive, and probably life-shortening illness; or severe neurodegenerative diseases. A serious illness could also be a life-threatening illness that however has a chance of long-term cure and full recovery such as acute critical illnesses in an otherwise healthy person.

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Algorithm Annotations

1. Initiate Palliative Care Discussion

Recommendation	Quality of Evidence and Strength of Recommendation
Palliative care can begin at the time of diagnosis of a serious illness regardless of treatment plan, and continue throughout the course of a patient's illness.	Quality of Evidence: Low Strength of Recommendation: Strong
Benefit: Quality of life throughout the course of the illness is as important as longevity. Palliative care can decrease the symptom burden for patients and families along with appropriate disease-modifying therapies. **Harm:** Opportunity costs of time needed for discussion and limited access to palliative care providers. **Benefit-Harms Assessment:** Early palliative care provides the ability to address stressors early as well as potentially decrease ED and hospital utilization.	
Relevant Resources: *Temel, 2010 (Randomized Control Trial); Kass-Bartelmes, 2004 (Summary); Morrison, 2004 (Case Report) Steinhauser, 2000 (Observational Study)*	

Recommendation	Quality of Evidence and Strength of Recommendation
Palliative care discussion or referral should be considered whenever a patient develops or presents with a serious or life-threatening illness, in all care settings.	Quality of Evidence: Low Strength of Recommendation: Strong
Benefit: Palliative care involvement in patients with serious illness has been shown to improve quality of life and resource utilization. Patients are more likely to receive care that is consistent with their wishes. **Harm:** Opportunity costs of time needed for discussion. If palliative care is misinterpreted, patients, family, and providers may not understand the desired outcome. Access may be an issue. **Benefit-Harms Assessment:** Pausing to consider the patient and family wishes and values in every setting allows clinicians to match preferences to the care received.	
Relevant Resources: *Kavalieratos, 2016 (Systematic Review/Meta-Analysis); Khandelwal, 2015 (Systematic Review); Lamba, 2014 (Report); Smith, 2014 (Review); Strand, 2013 (Summary); Weissman, 2011 (Consensus Report)*	

Palliative care is appropriate for patients of any age and at any stage of a serious illness, and should be made available to patients and families long before the terminal stage of an illness. Unlike hospice care, which is specifically for patients with terminal illnesses in the final months to year of life, palliative care should be provided across the course of a patient's illness, even while receiving curative or disease-directed therapy.

In the context of palliative care, "serious illness" is defined as "a condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress." (*Kelly, 2015*) A serious illness could be a terminal illness like most metastatic solid tumor

cancers; a chronic, progressive, and probably life-shortening illness like heart failure, COPD or cirrhosis; or severe neurodegenerative diseases like most dementias, amyotrophic lateral sclerosis and severe multiple sclerosis. A serious illness could also be a life-threatening illness that however has a chance of long-term cure and full recovery such as some leukemias and acute critical illnesses (e.g., acute respiratory distress syndrome in an otherwise healthy person).

While we recommend palliative care for all patients with serious illnesses early on, what constitutes 'palliative care' will differ based on a patient's needs and local palliative care resources. "Primary" or "generalist" palliative care refers to care that is palliative in its scope and intent, given to patients with serious illness by health care clinicians who are not palliative specialists. (*Quill, 2013*) This includes primary care clinicians or specialists (e.g., oncology care team members, intensive care unit care team members) who care for patients with serious illness. These clinicians routinely should provide primary palliative care such as symptom and quality-of-life assessments and treatments, empathetic and clear discussions of prognosis, options and care goals, and support for patient and family grief, worry, and spiritual distress.

"Specialty palliative care" refers to care delivered by trained, dedicated palliative care interdisciplinary teams that are available in some communities in the hospital, ambulatory and home settings. There is broad research supporting the benefit of early, specialized palliative care for patients with advanced solid cancers, indicating that such early involvement (from near the time of diagnosis) improves patient and family quality of life and coping when compared to usual care. (*Temel, 2017*) The American Society of Clinical Oncology urges early integration of specialty palliative care teams into the care of all patients with advanced cancers (*Aslakson, 2017*), and we strongly recommend organizations implement policies and programs to make specialty palliative care available to all patients with advanced cancers from the time of diagnosis.

Fundamentally, we recommend that if a patient with serious illness has persistent, distressing physical, psychological, informational or spiritual needs after attempts by the primary medical team to meet those needs, the patient should be rapidly connected with specialized palliative care teams if available, regardless of the patient care setting. The table below presents an expert consensus criterion on which patients should be offered specialty palliative care services.

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Debility/Failure to Thrive	• Greater than three chronic conditions in patient over 75 years old • Functional decline • Weight loss • Patient/family desire for low-yield therapy • Increasing frequency of outpatient visits, emergency department visits, hospitalizations
Cancer	• Uncontrolled symptoms due to cancer or treatment • Introduced at time of diagnosis – if disease likely incurable • Introduced when disease progresses despite therapy
Heart Disease	• Stage III or IV heart failure despite optimal medical management • Angina refractory to medical or interventional management • Frequent emergency department visits or hospital admissions • Frequent discharges from implanted defibrillators despite optimal device and antiarrhythmic management
Pulmonary Disease	• Oxygen-dependent, O_2 sats less than 88% on room air • Unintentional weight loss • Dyspnea with minimal to moderate exertion • Other pulmonary diagnoses, e.g., pulmonary fibrosis, pulmonary hypertension
Dementia	• Refractory behavioral problems • Feeding problems – weight loss • Caregiver stress – support needed • Frequency of emergency department visits • Increased safety concerns
Liver Disease	• Increased need for paracentesis for removal of ascitic fluid • Increased confusion (hepatic encephalopathy) • Symptomatic disease
Renal Disease	• Dialysis • Stage IV or Stage V kidney disease
Neurologic	• Stroke • Parkinson's • ALS – amyotrophic lateral sclerosis • MS – multiple sclerosis

Trajectories of late-life illness (see following graphs)

The natural history of most cancers, without treatment, is generally marked by a period, which may be prolonged, when patients enjoy good functional status and symptoms are readily treated. At some point, as the disease advances, function begins to decline, and from there the trajectory of the illness tracks steadily downward. It was this model of late life trajectories that informed the inclusion of a limited life expectancy as a criterion for hospice services. Other chronic medical conditions, however, manifest different patterns. Patients with conditions such as congestive heart failure and chronic obstructive pulmonary disease have periodic exacerbations where they may become quite ill. Medical treatment may successfully improve their status, although functional recovery may not return quite to the pre-episode level. A graph would show a sawtooth pattern, with the sharp downward inflections marking the acute illnesses, during which death may occur, with an overall slow downward slope in the curve. Progressive neurologic illnesses, such as Parkinson's and Alzheimer's diseases, generally show a slow overall decline in slope, which may occur over years, with occasional downward spikes marking episodes of infection (e.g., pneumonia) during which a patient might die. (*Lorenz, 2008*)

High

Mostly cancer

Function

Low → Time

Death

Short Period of Evident Decline

High

Function

Mostly heart and lung failure

Low → Time

Death

Long-Term Limitations with Intermittent Serious Episodes

High

Function

Mostly frailty and dementia

Low → Time

Death

Prolonged Dwindling
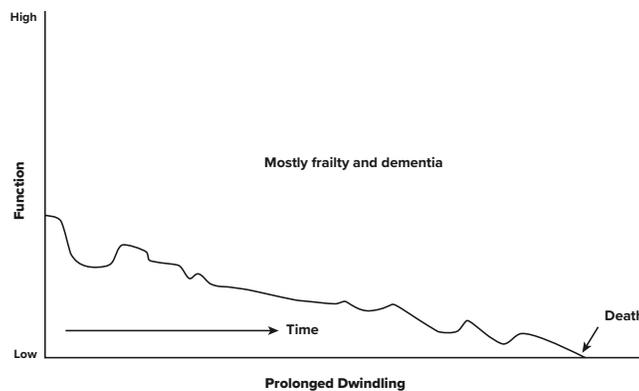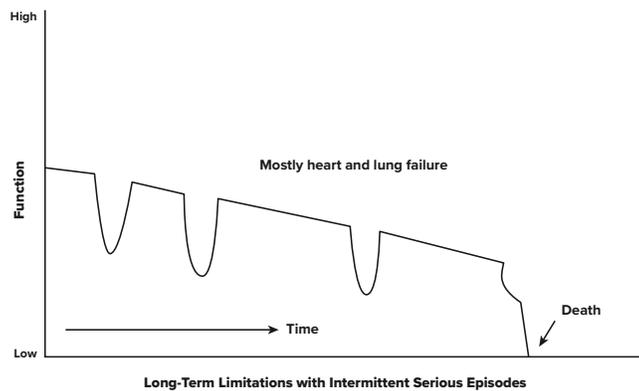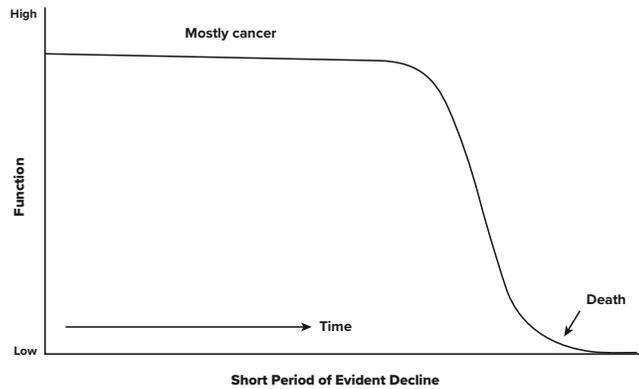
Used with permission 2011-2013. *Annals of Internal Medicine*, Jan. 2008.

For *Choosing Wisely®* recommendations related to early identification of potential benefit from palliative care, see Appendix D.

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Identify hospitalized patients who can benefit from early palliative care

Palliative care involvement in hospitalized patients with serious illness has been shown to improve quality of life and resource utilization in multiple studies. (*Kavalieratos, 2016; Smith, 2014*) Hospitals should proactively create policies and procedures to identify hospitalized patients who would benefit from palliative care, and provide them primary or specialized palliative care early on (depending on local resources). Clinicians should not wait until a patient is actively dying, or can no longer receive restorative/disease-directed therapy to provide palliative care.

While there are no precise, evidence-based guidelines as to the exact patient characteristics defining who should receive palliative care in the hospital, we endorse the following expert-opinion parameters. Hospitals should use these as a starting points when designing programs and policies to provide palliative care to their patients.

See Appendix B: How to Discuss Serious Illness.

*Criteria for a Palliative Care Assessment at the Time of Admission

A potentially life-limiting or life-threatening condition *and*…

Primary Criteria[a]
- The "surprise question": *You would not be surprised if the patient died within 12 months*
- Frequent admissions (e.g., more than one admission for same condition within several months)
- Admission prompted by difficult-to-control physical or psychological symptoms (e.g., moderate-to-severe symptom intensity for more than 24–48 hours)
- Complex care requirements (e.g., functional dependency; complex home support for ventilator/antibiotics/feedings)
- Decline in function, feeding intolerance, or unintended decline in weight (e.g., failure to thrive)

Secondary Criteria[b]
- Admission from long-term care facility or medical foster home
- Elderly patient, cognitively impaired, with acute hip fracture
- Metastatic or locally advanced incurable cancer
- Chronic home oxygen use
- Out-of-hospital cardiac arrest
- Current or past hospice program enrollee
- Limited social support (e.g., family stress, chronic mental illness)
- No history of completing an advance care planning discussion/document

[a]Primary Criteria are global indicators that represent the minimum that hospitals should use to screen patients at risk for unmet palliative care needs.

[b]Secondary Criteria are more-specific indicators of a high likelihood of unmet palliative care needs and should be incorporate into a systems-based approach to patient identifications if possible.

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*Criteria for a Palliative Care Assessment During Each Hospital Stay

A potentially life-limiting or life-threatening condition *and…*

Primary Criteria[a]
- The "surprise question": *You would not be surprised if the patient died within 12 months*
- Difficult-to-control physical or psychological symptoms (e.g., more than one admission for same condition within several months)
- Intensive Care Unit length of stay ≥ 7 days
- Lack of Goals of Care clarity and documentation
- Disagreements or uncertainty among the patient, staff, and/or family concerning…
  - major medical treatment decisions
  - resuscitation preferences
  - use of nonoral feeding or hydration

Secondary Criteria[b]
- Awaiting, or deemed ineligible for, solid-organ transplantation
- Patient/family/surrogate emotional, spiritual, or relational distress
- Patient/family/surrogate request for palliative care/hospice services[c]
- Patient is considered a potential candidate, or medical team is considering seeking consultation, for:
  - feeding tube placement
  - tracheostomy
  - initiation of renal replacement therapy
  - ethics concerns
  - LVAD[d] or AICD[e] placement
  - LTAC[f] hospital or medical foster home disposition
  - bone marrow transplation (high-risk patients)

[a] Primary Criteria are global indicators that represent the minimum that hospitals should use to screen patients at risk for unmet palliative care needs.

[b] Secondary Criteria are more-specific indicators of a high likelihood of unmet palliative care needs and should be incorporate into a systems-based approach to patient identifications if possible.

[c] These matters are included based on a consensus panel opinion.

[d] LVAD = Left ventricular assist device.

[e] AICD = Automated implantable cardioverter-defibrillator.

[f] LTAC = Long-term acute care hospital.

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2. Assess Patient's Palliative Care Needs Based on the Following Domains of Palliative Care

Recommendation	Quality of Evidence and Strength of Recommendation
Clinicians should use validated assessment tools, where available, to assess palliative care needs for each of these domains: physical, cultural, psychological, social, spiritual, and ethical/legal.	Quality of Evidence: Low Strength of Recommendation: Strong
Benefit: Thorough assessment is less likely to miss symptoms in need of management. The consistent use of tools creates reliability in assessment over time and potentially with different providers.	
Harm: Nonstandardized assessment may lead to specific needs going unaddressed.	
Benefit-Harms Assessment: Assessment tools used in conjunction with clinical assessment can identify new and changing symptoms and needs, leading to early intervention.	
Relevant Resources: *Aslakson, 2017 (Technical Brief); Bakitas, 2009 (Randomized Control Trial); Pulchaski, 2009 (Report); Smith, 2009 (Case Report); Gries, 2008 (Case Report); Chochinov, 2006 (Summary); Moro, 2006 (Observational Study); Kemp, 2005 (Summary); Searight, 2005 (Summary); Morrison, 2004 (Case Report); Curtis, 2002 (Case Report); Werth, 2002 (Summary); Kagawa-Singer, 2001 (Case Report); Block, 2000 (Case Report); Chang, 2000 (Observational Study); Post, 2000 (Summary); Phillip, 1998 (Observational Study); Reed, 1987 (Observational Study)*	

Recommendation	Quality of Evidence and Strength of Recommendation
Informed consent should be obtained for any treatment or plan of care from either a patient with decision-making capacity or an appropriate surrogate decision-maker.	Quality of Evidence: Low Strength of Recommendation: Strong
Benefit: Patients have the right to understand the treatment plan. Engaging patients and family in decisions respects the autonomy of the patient.	
Harm: There are no harms to obtaining informed consent in a nonemergent situation.	
Benefit-Harms Assessment: Informed consent is an integral tenet of medical care.	
Relevant Resources: *Silveira, 2010 (Observational Study); Arnold, 2006 (Summary)*	

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Recommendation	Quality of Evidence and Strength of Recommendation
The interdisciplinary care team (IDT) of health care providers should ideally include at a minimum physicians, advance practice providers, nurses, social workers, spiritual counselors, and bereavement staff. Other clinicians may also participate on the IDT.	Quality of Evidence: Low Strength of Recommendation: Strong

Benefit:
Multidimensional sources of medical expertise across disciplines have the ability to identify and mitigate symptoms, and address needs of the patient and family.

Harm:
Some geographic/rural/resource-scarce regions may lack expertise, and hiring may be prohibitive.

Benefit-Harms Assessment:
Even partially staffed IDT is better than none if gaps in the team are recognized and other resources are consulted.

Relevant Resources:
Bakitas, 2009 (Randomized Control Trial); Pulchaski, 2009 (Report); Smith, 2009 (Case Report); Gries, 2008 (Case Report); Chochinov, 2006 (Summary); Kemp, 2005 (Summary); Searight, 2005 (Summary); Morrison, 2004 (Case Report); Curtis, 2002 (Case Report); Werth, 2002 (Summary); Kagawa-Singer, 2001 (Case Report); Block, 2000 (Case Report); Post, 2000 (Summary); Reed, 1987 (Observational Study)

Recommendation	Quality of Evidence and Strength of Recommendation
Care conferences with the patient, family and members of the interdisciplinary team are recommended on an ongoing basis to discuss patient's condition, course of illness, treatment options, possibility of progression to death, goals and plan of care.	Quality of Evidence: Low Strength of Recommendation: Strong

Benefit:
Team members can listen for opportunities to assist the patient and respond in a timely manner to patient and family needs. Care conferences allow the whole team to hear directly from the patient/family.

Harm:
Opportunity costs and time constraints.

Benefit-Harms Assessment:
Engaging the patient and family together with the IDT prevents dis-synchronous conversations and strengthens relationships with caregivers. This communication saves time and improves care.

Relevant Resources:
Agar, 2017 (Randomized Control Trial), Gries, 2008 (Case Report); Moneymaker, 2005 (Pamphlet); McDonagh, 2004 (Observational Study); Curtis, 2001(Observational Study)

Needs Assessment

Using validated assessment tools, perform a thorough assessment grounded in the domains of palliative care. Address these identified needs, based upon the patient's values and resources of the patient, family and community.

Patient autonomy is paramount to the development of the care plan that includes the patient's identified needs. Clinicians must create an environment in which the needs of the patient, based on a comprehensive assessment, are fully considered and values honored. Only then can a reasonable determination be made of what services are required to meet the needs of patients and their families in these domains:

- Physical

- Psychological

- Social

- Cultural

- Ethical

- Spiritual

An interdisciplinary team approach is crucial to addressing these domains. Repeated assessments have been shown to identify symptoms that may otherwise have been overlooked or unreported, facilitate treatment and treatment planning, and enhance patient and family satisfaction.

Assessment Tools

Electronic medical records may have built-in tools that make it easy to document your assessment of the patient and easy for the entire interdisciplinary team to access the information. The Edmonton Symptom Assessment System (ESAS) is one such tool. ESAS is thorough yet simple in clinical application; it has a robust evidence-based foundation for validation in various clinical settings, and is readily available via the Internet. Other tools that are useful for determining function or prognosis include Palliative Performance Scale (PPS) and Mitchell Mortality Index. These tools can help teams identify when a hospice referral may be appropriate. See the Implementation Tools and Resources Tables for more assessment tools.

Informed Consent and Decision-Making Capacity

Informed consent is based on the principle that patients should be allowed to make decisions for themselves. Informed consent for any treatment or plan of care requires a patient with decision-making capacity or an appropriate surrogate decision-maker. When a patient lacks this ability, a surrogate is needed.

For patients to make informed choices regarding palliative care, it is necessary for the patient to have decision-making capacity. Then it is important for both the patient and the clinicians to have a realistic understanding of the options available. The patient must have the capacity to understand the choices available, especially when some of the choices are not likely to benefit the patient to any great extent. Further, it should be recognized by clinicians and communicated to patients that the realistic choices available for care may change as the patient's medical condition changes. Accordingly, assessment of palliative care needs will be ongoing and may require, if the patient's decision-making capacity is impaired, the assistance of family or other well-informed surrogates to provide the information needed to assess the patient's ever-changing palliative care needs.

Competency is a legal term referring to a decision made by a judge, although a clinician's opinion carries a large amount of weight in a competency hearing. In contrast, **decision-making capacity** refers to a clinician's determination, based on clinical examination, whether a patient is able to make medical decisions for himself/herself relative to the discussion. Most state power of attorney for health care documents require a clinician to document that a patient has lost decision-making capacity for the surrogate to become the legal agent for medical decisions.

To be deemed **decisional**, a clinician must be satisfied that a patient is able to:

- receive information (e.g., must be awake, but not necessarily oriented);

- evaluate, deliberate and mentally manipulate information; and

- communicate a treatment preference (e.g., the comatose patient by definition is not decisional).

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Decision-making capacity is:

Understanding. Does the patient truly understand the information about the risks, benefits and alternatives of what is being proposed? The patient does not have to agree with your interpretation but should be able to repeat what you have said. Ask, "Can you repeat to me the options for treatment I have just discussed with you?" "Can you explain to me why you feel that way?"

Task specific. Deciding if the patient is decisional means weighing the degree to which the patient has decision-making capacity against the objective risks and benefits to the patient. Some decisions are more complex than others, requiring a higher level of decision-making capacity. Thus, a moderately demented patient may be able to make some decisions (e.g., antibiotics for pneumonia) but not others (e.g., chemotherapy for colon cancer). This sliding scale view of decision-making capacity holds that it is proper to require a higher level of certainty when the decision poses greater risk.

Logical. Is the logic the patient uses to arrive at the decision "not irrational"? One wants, as much as possible, to make sure the patient's values are speaking, rather than an underlying mental or physical illness. Note: Severe depression or hopelessness may make it difficult to interpret decision-making capacity; consult psychiatry for assistance with this or other complex cases.

Time specific. When encephalopathic, a patient may not be decisional; after treatment, decisional capacity may be regained.

Consistent. Is the patient able to make a decision with some consistency? This means not changing one's mind every time one is asked. Is the decision consistent with the patient's values? If there is a change in the patient's values, can the patient explain the change?

(*Arnold, 2006*)

The role of surrogate and identification of such surrogate should be anticipated at the time of initial assessment and care planning. Bringing together, as much as possible, those who may impact decision-making is integral to the initial plan of care development. Careful clarification for all present at initial care planning will help anticipate and prevent discord as the patient and surrogate(s) make future care choices. The initial meeting for care planning is also useful for identifying availability and limitations of caregivers and other resources for meeting patient needs in implementing the plan of care.

When discussing goals of care or a patient's end-of-life wishes, the *"ask – tell – ask"* model provides a useful and effective structure for such conversations. In this model, clinicians can do any of the following:

- Ask patients and/or family members what they already know about the clinical situation (e.g., "What have the doctors told you about your illness?")

- Clarify any misconceptions, remembering to use plain, everyday language instead of "medicalese" (e.g., say "The cancer has spread" rather than "The cancer has metastasized"). Clinicians should always assume patients and family member have questions instead of asking whether they do (e.g., don't ask "Do you have any questions?" but rather ask "What questions do you have?")

- Ask the patient and/or family to restate the information discussed to assess their understanding. This can be normalized by saying "To make sure I did a good job explaining everything, can you tell me, in your own words, what we just talked about [or decided]?" (*Smith, 2009*)

Using the determined goals of care informs the care plan, utilizing the principles of shared decision-making by introducing choice, describing options and exploring patient preferences. (*Elwyn, 2014*)

Patient and family expectations, goals for care and understanding of the disease and prognosis, as well as preferences for the type and setting of care, should be assessed and documented. This assessment needs to

be reviewed on a regular basis, with consideration given to the patient's capacity to represent himself/herself. Documentation of the goals of care, patient preferences and advance directive in an electronic medical record promotes accessibility and portability across care settings. Also see Annotation #10, "Develop or Revise Palliative Care Plan and Establish Goals of Care through the Process of Shared Decision-Making."

As patient conditions change, there may be need for change of setting or clinicians of care. It is helpful in care planning if the community has a uniform system to communicate patient wishes so that the continuity of care makes a smooth transition between clinicians in these circumstances. In this regard, community-wide agreement on recognition of particular advance directive forms and Clinician/Provider Orders for Life-Sustaining Therapy (POLST) enhances the quality of care available. See Annotation #9, "Ethical and Legal Aspects of Care."

Assessing palliative care needs requires a knowledgeable team familiar with needs assessment and access to resources. This is best performed by an interdisciplinary team (IDT) made up of specifically trained professionals. Typical IDT membership includes but is not limited to an RN, a social worker, a chaplain, and an advance practice provider (APP) or MD. Other members may include therapists, behavioral health specialists and pharmacists. Accessing this IDT and thus palliative care is variable throughout the health care systems, with palliative care services being much more prevalent in larger hospitals (e.g., more than 300 beds). *(CAPC 2019 Palliative Care Report Card)* In the past few years the focus of leading palliative care organizations (CAPC and National Quality Forum) has shifted from developing hospital-based services to developing community-based services, but continued expansion is needed in this area.

See the Implementation Tools and Resources Tables for searchable resources.

Care conferences

Patient and family meetings or care conferences allow the IDT an opportunity to meet with the patient and/or family to discuss the patient's diagnosis, condition, course of illness and treatment options, and to answer questions and establish both the goals and plan of care. The level of formality of these conferences is likely to vary depending on the focus or goals. These conferences may involve the primary clinician and part of the care team or the entire team.

Use a consistent approach for care conferences by focusing on four goals for a family meeting or conference. These goals focus on:

- gaining knowledge of the person experiencing the illness and understanding this person's goals,

- promoting communication between the care team and patient/family,

- decreasing stress and suffering by reviewing realistic goals and establishing a realistic plan that aligns with these goals, and

- establishing trust and support to work with the patient/family throughout the course of illness.

Incorporating time for this assessment can be done in the inpatient, outpatient or home setting and can be done over multiple encounters. Documentation of such meetings and any changes in the goals of care or care plans are necessary to complete closed-loop communication among the interdisciplinary team, patient and family.

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3. Begin Advance Care Planning Process

Recommendation	Quality of Evidence and Strength of Recommendation
Facilitation of advance care planning (ACP) conversations is appropriate for all adult patients. **Regular review of goals and wishes should occur as the patient's condition or life circumstances change.**	Quality of Evidence: Low Strength of Recommendation: Strong
Benefit: Regular review of ACP ensures patient wishes for treatment are accurately documented and family understands the benefits and burdens of available treatment options.	
Harm: Opportunity costs and limited available resources may be a barrier. Systems may have difficulty capturing, storing and accessing ACP documents when needed.	
Benefit-Harms Assessment: Although it is difficult to have this detailed discussion with all adult patients, it is extremely helpful to patients, family and clinicians in the event that the patient cannot express his/her desires.	
Relevant Resources: *Weissman, 2011 (Report); Gries, 2008 (Case Report); Block, 2006 (Case Study); Sinclair, 2006 (Summary); Lee, 2002 (Summary); Vandekieft, 2001(Summary); Balaban, 2000 (Summary)*	

Recommendation	Quality of Evidence and Strength of Recommendation
Adopt the Provider's Order for Life-Sustaining Treatment (POLST) as a community standard to document and communicate the preferences of individual patients with a serious illness as an official medical order written by a provider.	Quality of Evidence: Low Strength of Recommendation: Strong
Benefit: POLST documents are recognized by most institutions, are usually easily accessible and convey specific orders designed for use during urgent situations. The information is clear, unambiguous, flexible, portable, available across all sites of care and likely to be honored by all clinicians when needed.	
Harm: If a POLST is completed and a patient's condition changes, the POLST may be outdated and care may not be consistent with the patient's wishes. Without a POLST, clinicians will provide care using their standard orders and protocol, which may conflict with patient wishes.	
Benefit-Harms Assessment: POLST or similar documents are a recognized method of rapidly communicating critical information about the patient wishes.	
Relevant Resources: *Wang, 2017 (Systematic Review); Jennings, 2016 (Observational Study); Hickman, 2015 (Systematic Review); Bamba, 2012 (Summary)*	

Begin Advance Care Planning Process

Advance care planning refers to the process whereby a person identifies his or her specific goals and preferences related to health care in general, and in particular the care received when that person is seriously ill or at the end of life. Those are situations where a person may no longer able to communicate those choices. Documenting them and having them available to family members and health care providers are critical to ensure that the person receives the care desired.

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Systematic literature reviews also show that individuals who receive advance care planning or palliative care interventions are less likely to be admitted to intensive care units, and, if admitted, have shorter lengths of stay. (*Khandelwal, 2015*)

The process of advance care planning should result in the completion of a written health care directive based on the discussion between the patient and the health care agent regarding the patient's wishes. Written health care directives are legal in every state; however, laws and forms vary from state to state. It is important to remember that travelers should be aware of differing laws in whichever state they plan to travel within, and bring a copy of their document so that they may present it to a facility where they intend to receive medical care.

Advance care planning always consists of conversations among patient, family and clinician about who should make decisions if the patient is unable to do so, and what type of care the patient desires. It is recommended to document that plan with a legal health care directive and/or Provider's Order for Life-Sustaining Treatment (POLST).

A legal advance directive consists of:

- Designation of a **health care agent** (aka surrogate, proxy, durable power of attorney for health care, etc.). The patient appoints someone to make decisions about his/her medical care if he/she cannot make those decisions. Ongoing communication between the patient and his/her health care agent is imperative so that the agent can participate fully as an advocate when the patient is no longer able to communicate. In Minnesota, an individual can authorize an agent to make decisions even if the individual remains decisional.

- A formal **health care directive** is a written document in which a patient's wishes regarding the type or extent of medical treatment to be administered or withheld are described. A Do Not Resuscitate (DNR) form is not a health care directive. Generally, a health care directive goes into effect only when the patient becomes unable to communicate his/her preferences.

Some studies show that the use of advance care planning improved agreement in stated treatment preferences between individuals and their surrogates, and those who participate in advance care planning programs have a higher rates of completion of formal health care directive and POLST documents. (*MacKenzie, 2018, Huang, 2016*)

Advance care planning is an iterative process and not linear. It should begin before it is needed and should be reassessed and reviewed regularly as conditions and life circumstances change.

See the Implementation Tools and Resources Tables for more information on health care directives.

Provider's Order for Life-Sustaining Treatment (POLST)

Patients create a health care directive, ideally in consultation with family members and their primary care providers. While health care directives can provide rich information about an individual's overarching goals for medical treatments as well as preferred surrogate decision-makers, they can be difficult to locate and challenging to interpret in specific clinical situations. As a result, they may be overlooked or disregarded at the very time of need. Further, they do not carry the force of an official "order" written by a provider. They are also not recognized by emergency medical providers. To overcome these limitations, the POLST has become an increasingly used instrument to ensure that an individual's specific preferences can be honored. It consists of a document (there are many acronyms for similar tools) designed to capture a patient's preferences for specific interventions, especially cardiopulmonary resuscitation, intubation and ventilatory support, and hospitalization. These decisions are extremely time-sensitive, and the presence of an order signed by an authorized physician or advance practice provider improves the likelihood that a patient will receive the type of care desired. Other types of treatments, such as antibiotic use or nutritional support, can be addressed as well. The POLST is designed to be portable and in most locations is recognized and followed as medical orders.

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The process of completing a POLST should optimally include discussions between a patient and family with the provider, inclusion in the patient's medical record, and periodic revision, including at the time of significant changes in health status, to ensure that the instructions continue to accurately reflect the patient's wishes.

In actuality, evidence of high-quality discussions is often lacking, systems ensuring rapid access to POLST documents are fragmented, and information regarding patient satisfaction with these documents is scarce. Nonetheless, this guideline strongly recommends using the POLST process as the best means available at this time to document and communicate the preferences of individual patients with serious illness for medical care. (*Bomba, 2012; Hickman, 2015*)

The major advantage of the POLST form is that it puts into action your advance directive. When adopted as the community standard, the information is clear, unambiguous, flexible, portable, available across all sites of care and likely to be honored by all clinicians when needed. One observational study showed a marked increase in the rate of completion of POLST documents among long-term care residents in California, and no racial differences were identified. (*Jennings, 2016*) And while ultimately clinicians should be the principal individuals completing POLST documents with patients, nonclinicians such as trained lay facilitators can help educate individuals and their agents in understanding and clarifying goals of care. (*Wang, 2017*)

See the Implementation Tools and Resources Tables for more information on the POLST.

Potential barriers to completing an advance directive:

- Discussions with patients and families are time-consuming, and clinicians in fee-for-service practices can lack direction for billing of this professional service. In 2016 CMS implemented specific advance planning codes (CPT codes 99497 and 99498) to support reimbursement). See the Implementation Tools and Resources Tables for more information.

- Many clinicians believe it is not appropriate to begin advance care planning on an outpatient basis.

  Overcoming this barrier: When beginning a discussion of advance care planning, simply ask, "Do you know what an advance directive is? Do you have one?" Normalizing this conversation, e.g., "I ask all of my patients this question, sick or well," and introducing the topic early in the therapeutic relationship can reassure patients.

- Many people believe that if a loved one has financial power of attorney, he/she doesn't need a separate medical power of attorney. This is not true. **Most often these are separate legal roles.**

  Overcoming this barrier: When discussing power of attorney with your patient, assess his/her understanding. Have literature and information about online resources in your office to clear up discrepancies.

- Many clinicians and patients feel that having an advance directive means "Don't treat." Unfortunately, advance directives can be a trigger for disengagement by the clinicians.

  Overcoming this barrier: Make sure your patients and staff understand that advance directives don't mean "Don't treat me" but **instead "Treat me the way I want to be treated."**

- Patients often fear that once they name a health care agent in an advance directive, they lose control of their own care.

  Overcoming this barrier: When explaining advance directives to your patients, make sure they understand that as long as they retain decision-making capacity, they retain control of their medical care. Advance directives become active only when an individual cannot speak for himself/herself, unless he/she specifically indicates otherwise.

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- Many people believe that only elderly people need advance directives.

    Overcoming this barrier: The stakes may actually be higher for younger people if tragedy strikes. Use the example of the Terri Schiavo case (a young person who had a tragic accident and was left in a persistent vegetative state with no directives) as a trigger to enlighten the discussion. Ask, "What would you want if you were in a similar situation?"

See the Implementation Tools and Resources Tables for resources on advance care planning.

Eliciting values

Because of the diversity of backgrounds – cultural, educational, other differences – that patients represent, clinicians cannot assume that a patient shares their values.

If an individual has not discussed and documented goals and preferences before he/she has become incapacitated, he/she forfeits autonomy, and the surrogate must then make a decision that is authentic to the individual's values. (*Scheunemann, 2012*) Even a thoughtfully crafted health care directive or POLST may be difficult to interpret in a clinical setting, and a surrogate can help clinicians apply a patient's values to the decisions at hand.

Facilitated values history

Scheunemann, et al. have proposed a framework for eliciting a patient's values from surrogates:

- Attend to surrogates' emotions. Respect the time surrogates need to process their emotions. The authors cite the NURSE acronym:

    - **N**ame emotion

    - **U**nderstand the emotion

    - **R**espect the family

    - **S**upport the family

    - **E**xplore the emotion

- Help surrogates understand their contribution to decision-making

    - Difference between substituted judgment and best interests

- Understand the patient as a person

- Explore specific values and value conflicts

    - Help surrogates prioritize conflicting values

- Summarize the patient's values relevant to the discussion

- Bridge from the patient's values to specific treatment pathways

- Give permission to follow the patient's wishes

Such an approach may assist in resolving misunderstandings and conflicts surrounding difficult decision-making or applying an existing health care directive in complex clinical circumstances.

For *Choosing Wisely®* recommendations related to understanding patient goals of care in palliative care, see Appendix D.

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4. Physical Aspects of Care

The control of physical symptoms is an important part of the palliative care plan. Common symptoms include, but are not limited to, pain, anorexia and cachexia, constipation, delirium, diarrhea, dyspnea and secretion, fatigue, agitation, nausea and vomiting, cough, fever, gastroesophageal reflux disease, hiccups, ascites and pleural effusions, skin and wound care, pruritus, sleep disturbances and insomnia, urinary incontinence and urinary retention.

Covering all the potential symptoms or physical needs of a palliative care patient is out of the scope of this guideline. We have highlighted a few common symptoms for which opioids are commonly used. For more resources around the management of symptoms please see the Implementation Tools and Resources Tables.

Each patient should be frequently evaluated for these issues. We encourage the use of validated assessment tools, where feasible, to optimize the consistency of assessments for symptoms across various observers and sites of care. Therapy should be individualized for each patient's unique circumstances.

The preferred location of the provided services may vary among patients. Many prefer to avoid hospitals and minimize trips to clinics. However, some symptoms cannot be successfully managed outside of the hospital, and medical emergencies occur that may require transfer to emergency departments for definitive care. Decisions to transport patients for treatment must be informed by the patient-specified goals of care. (*Green, 2017*)

Patients may fear that accepting palliative care interventions will shorten their lives. Numerous studies have shown that in patients with a life expectancy of less than six months, palliative care is not associated with decreased life expectancy when compared with disease-directed treatment, and patients receiving palliative interventions experience improved quality of life (*Temel, 2010, 2017; Reljik, 2017*).

Dyspnea

Dyspnea is present in the majority of patients at the end of life and can be a troublesome symptom even when lung disease is not the patient's primary diagnosis. Opioids have been well studied and can be useful in relieving air hunger. Oxygen may be useful for patients who are hypoxic, but the presence of dyspnea does not always correspond to oxygen saturation levels. When they can be identified, treating specific underlying factors such as fluid overload can be useful when those treatments correspond to the individual's specified goals (*Barnes, 2016; Kamal, 2012*).

Pain

Control of pain in order to improve quality of life is an important aspect of palliative care. However, the prognoses and goals of care for patients receiving palliative care can vary widely depending on the individual. Someone with serious illness may have a condition that can be cured or remitted, with the potential for a long period of survival. For that patient, pain management strategies must include careful weighing of the potential risks of treatment side effects such as complications of prolonged opioid use, addiction or tissue damage from radiation treatments. The ICSI Pain: Assessment, Non-Opioid Treatment Approaches and Opioid Management guideline presents background information and recommendations that can be appropriately employed for these patients.

Patients whose disease trajectories suggest a shorter life expectancy, such as those with end-stage illnesses who prioritize comfort and optimal symptom control over longevity, may be less concerned with long-term side effects of various treatments.

Pain is a subjective symptom; there is no test to measure pain. Pain is what the patient says it is, and it needs to be addressed adequately in order to improve quality of life. The patient, along with family members, should be actively involved in establishing the goals of palliative pain management. Offering education support and providing communication tools can improve their ability to contribute to the process of achieving pain control. (*Chi, 2017; Cagle, 2015*)

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Pharmacological approach/Opioids

Opioid use has become more controversial as the national incidence of opioid addiction and opioid-related deaths has increased, and long-term adverse effects of opioid use have become better understood. It is generally accepted that opioids are not first-line therapy for chronic pain. (*ICSI Pain Guideline, 2017*) For patients with serious illness, it is critical for the clinician to discuss benefits and risks, as well as nonopioid therapies, with patients and families, and utilize shared decision-making in evaluating the role of opioids in achieving safe pain control.

Opioids have a unique and special role in palliative care. There will be circumstances when opioid use is justified by the clinical situation. The clinician must measure goals for pain and function. Short-acting opioids are suggested, starting with low doses and increasing slowly. Small quantities of opioids should be prescribed at a time. There is no role for long-acting opioids in managing acute pain. (*ICSI Pain Guideline, 2017*)

When a patient is nearing end of life, the risks of opioid use may be outweighed by the need for optimal symptom management. However, for patients who improve or recover, there needs to be shared decision-making with the patient about reducing or eliminating opioids to avoid unnecessary complications from long-term opioid use. Follow and reevaluate the patient closely, with dose reduction or discontinuation as needed.

The clinician must evaluate risk factors for opioid-related harms. Checking state prescriber databases for monitoring opioid use should be done upon initiation and periodically during the duration of treatment. Urine drug testing may be considered. Avoiding concurrent opioid and benzodiazepine prescribing is highly recommended (*ICSI Pain Guideline, 2017*), although there may be circumstances when this is clinically indicated. The clinician must arrange for treatment of opioid use disorder if needed.

See the Implementation Tools and Resources Tables for more pain management resources.

Nonpharmacological approaches

Palliative radiation can be an important tool for pain from metastatic lesions. Particularly for individuals with limited life expectancy, high dose-low fraction regimens can provide significant pain relief with minimal disruption. (*Lutz, 2017*)

Peripheral nerve blocks can be useful for pain that can be localized to an appropriate anatomic location. They are safe and often very effective in improving comfort and allowing reduction of medications. (*Chambers, 2008*)

Physical modalities such as physical therapy, massage and manipulative therapy can be highly effective with minimal risk for adverse effects when delivered by trained providers. (*ICSI Pain Guideline, 2017*) Caregivers can be trained to administer some of these modalities as well. Interventions that address nonphysical suffering can also be useful for relief of pain.

For *Choosing Wisely®* recommendations related to symptom management in palliative care, see Appendix D.

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5. Cultural Aspects of Care

Culture has been defined as "the learned and shared beliefs, values, and life ways of a designated or particular group which are generally transmitted inter-generationally and influence one's thinking and action modes." (*Leininger, 1985*) The cultural assessment promotes patient/family-centered decision-making and offers the opportunity to identify care preferences. Cultural decisions affecting palliative care also include attention to gender, age, generation, education level, diet/food and ritual. Clinicians should ask the patient/family about these considerations, and keep in mind that every patient conversation is a *cultural conversation*.

For many individuals seeking health care, the vocabulary, structure and process of decision-making in medicine is complex to understand and integrate. Clinicians may underestimate the striking differences between the culture of medicine and the distinct beliefs and traditions that patients may value.

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As palliative care providers, clinicians must evaluate their services, policies and procedures to maximize cultural and linguistic accessibility and responsiveness to changing multicultural populations. (*NCP, 2013*)

Cultural Humility:

A cultural humility framework is recommended for all clinicians engaged in all health care. "Cultural humility" is defined as "a lifelong process of self-reflection and self-critique whereby the individual not only learns about another's culture, but one starts with an examination of her/his own beliefs and cultural identities. This critical consciousness is more than just self-awareness, but requires one to step back to understand one's own assumptions, biases and values." (*Yeager, 2013*)

Clinicians caring for patients with serious illness should examine their own cultural values and assumptions about what constitutes "good" care for patients nearing the end of life, recognizing not all patients will share these same values, and ensure goals and decisions remain centered around the patient's values/beliefs.

Core principles of the cultural aspects for care:

- Culture plays a significant role in shaping the way people make meaning of illness, suffering and dying. Culture helps guide decisions about what kind of care a patient chooses to receive, who it should be provided by and under what conditions. It is important to avoid stereotyping. There are, in fact, wide variations in beliefs, attitudes and behaviors within and between every cultural group *(Smith, 2009)*.

- Literacy plays a critical role in cultural competency. Many individuals do not read or write in their spoken language. Therefore, using easily understood videos with clear verbal messages and actions may be effective when confronting literacy barriers.

- Among many populations, factors outside of medical technology such as a divine plan and personal coping skills may be more important for survival than physician intervention. (*Smith, 2009*) Identifying current spiritual or other leaders to help navigate patient/family beliefs and values is often helpful when exploring culture-based decision-making. Conversations with these trusted individuals may help give perspective and bridge gaps in trust between the medical community and the patient/family.

Guidelines for multicultural patient/family communications

The following are work group suggestions for clinicians in patient/family communications:

- Use nonverbal forms of education such as drawing, showing pictures or easily understood videos.

- Understand that not all tools (such as pain scales) are universal and that clinicians should use terms that are culturally relevant.

- Avoid using jokes or humor because they may be misunderstood or considered offensive.

- Be sensitive to the roles that gender, age, generation and education play in patient-to-clinician communications.

- Always ask if there are other family/extended family members who should be included in the conversation. It's important to have the necessary people present in health care discussions.

- Address adults formally (Mr., Mrs., or Ms.) rather than by their first name. This action demonstrates respect. Individuals can later ask you to use their first name if they prefer.

- Ask open-ended questions that engage and provide clues about patient beliefs and understanding. "Tell me what you believe about your illness" rather than "Do you have any questions about your illness?"

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- Review patient education materials for cultural diversity and awareness. Do resources include professionals and persons of color? Are persons of different generations included? Are extended families depicted that include members other than a simplistic "nuclear" family?

- Address dietary/food preferences.

- Address preferences regarding physical care of the deceased, including funeral and burial rituals.

Guidelines for using professional medical interpreters

Clinicians should also follow the established best practices of utilizing professional medical interpreters when English is not a patient's first language or when there are gaps in understanding English. (*Norris, 2004; Searight, 2005*) The following recommendations are suggested for clinicians utilizing professionally trained medical interpreters:

- Meet briefly with interpreters prior to and after delivery of bad news or difficult discussions to help prepare the interpreter and to allow the interpreter to provide information about the patient, family and culture.

- Establish with the interpreter, patient and family members at the outset of a conversation or care conference that everything spoken will be translated word for word.

- After making a complete statement, clinicians should pause to allow for the translation.

- Clinicians should speak to and look at the patient/family rather than the translator. "Where is your pain?" rather than "Can you ask him where he hurts?"

- Consider meeting with the interpreter after health care discussions to allow for any necessary debriefing.

See the Implementation Tools and Resources Tables for more cultural resources.

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6. Psychological and Psychiatric Aspects of Care

Psychological and emotional distress is present in serious illness, but too often these issues and their symptoms go undetected and untreated. Routine ongoing assessment of a patient's psychological status is critical to provide quality palliative care. Psychosocial issues are more difficult to evaluate and address if the patient has distressing or poorly controlled physical symptoms. (*Strickland, 2004*) Psychological symptoms may also present as physical symptoms such as pain, constipation, nausea and vertigo. Difficulty in improving physical symptoms should lead one to look at psychological or other causes. Clinicians must be aware of psychological symptoms of depression and anxiety, and use of standardized assessments (e.g., PHQ-9, GAD-7) may be helpful.

Refer to the ICSI Adult Depression in Primary Care guideline for more information about depression and the depression assessment tool (PHQ-9).

Simply asking the following questions can be a starting point:

- How are you coping?

- What are you doing to cope?

- Are you having trouble thinking?

- Are you depressed?

- Do you think about ending your own life?

- Do you feel your situation is hopeless?

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Affective disorders such as anxiety and depression are common in seriously ill patients, and they adversely affect quality of life. (*Periyakoil, 2012*) Undertreated pain can exacerbate psychological distress, and undertreated psychological distress can exacerbate pain. Recent data suggest that depression is associated with a higher risk of death in cancer patients, as well as decreased treatment adherence, longer hospital stays, reduced quality of life and requests to hasten death. (*Sherrill, 2017*)

Anxiety may result in insomnia, gastrointestinal upset, dysphagia, fatigue, palpitations, diaphoresis, fear and isolation, and may escalate as disease progresses. Causes of anxiety should be identified and treated if possible. Frank discussions of fears may help alleviate anxiety. Short-term psychotherapy modalities such as dignity therapy (DT) can provide reduction in depression and anxiety symptoms. (*Julião, 2013*) DT is a brief individualized psychotherapy developed for patients with advance illness aimed at relieving psychological, emotional and existential distress through life reflection and review. (*Vuksanovic, 2017*) DT aims to increase the patient's sense of meaning, purpose and dignity and can include creation of a legacy document.

Grief versus depression

It is important to differentiate grief from depression. Grieving is an appropriate response to loss, but persistence of the symptoms mandates consideration of depression. Normal grief is an adaptive process and often responds well to counseling and ongoing support. Grief can manifest as physical symptoms (insomnia, loss of appetite) or emotional, cognitive and behavioral changes. Normal grief manifestations can mirror depressive symptoms, but the patient may fluctuate between days with few or no manifestations of grief and days with significant manifestations.

In contrast, clinical depression is a state that causes clinically significant distress and impairment for the patient. Persistent dysphoria, anhedonia, a sense of hopelessness, helplessness and/or worthlessness, and/or an active and persistent desire for an early death could be signs of depression. (*Periyakoil, 2012*) Undermanaged depression diminishes quality of life and can impact palliation of other symptoms. Depression often needs to be treated with a combination of nonpharmacological and pharmacological modalities. The Palliative Grief Depression Scale (PDGS) has been validated with hospice and palliative patients to assess grief and depression. (*Periyakoil, 2012*)

Education about the difference between clinical depression and grief/loss can be helpful with serious illnesses and provide a construct to understand what the patient has been experiencing. The clinicians must inquire if the patient is at risk for suicide.

See the Implementation Tools and Resources Tables for more psychological resources.

For *Choosing Wisely®* recommendations related to treatment of mental health in palliative care, see Appendix D.

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7. Social Aspects of Care

A comprehensive assessment includes the social aspects of care, which are complex and interconnected, and often impact the plan of care. The interdisciplinary team of professionals needs patient-population-specific skills in assessment and development of a plan of care that includes social domains influencing the individual that include but are not limited to:

Family system:

- Whom do they identify as family? Where is family geographically located?

- What is the state of the relationship? Are there dynamics to the system that will impact care?

- Are there areas of added support/need?

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Support network:

- What is the perceived social/cultural/spiritual support network?

- Is the support network engaged? Is assistance needed to engage the support network?

Communication preferences:

- How does the patient prefer to receive or give information (e.g., direct, indirect, need time to process/reflect, written format)?

- How does the family prefer to receive or give information? Is there a family spokesperson?

Decision-making:

- How are decisions made within the family system?

- What experiences/beliefs/values influence decisions regarding medical interventions?

Goals of care/advance care plan:

- What are the stated or understood goals of care? Do the goals change with the current medical state?

- How is quality of life defined for the individual? For the family?

- Is there a health care directive or POLST completed? Are there named agents/surrogate decision-makers? Are they engaged if the patient is unable to guide his/her own care?

Adjustment to illness/coping:

- How is the patient/family coping with the illness?

- How has it impacted relationships? Sexuality and intimacy?

- What is the impact on roles including caregiving?

- Is there need for counseling?

Education/employment:

- What impact has the illness had on the patient/family's ability to attend school or work?

- Does the patient/family need assistance with Family Medical Leave Act paperwork?

Financial/legal:

- Are there legal matters that need to be addressed now? Or in the future?

- Are there concerns with finances? Concerns with ability to pay for medications, treatments or equipment?

- Is assistance needed with filing for disability or other paperwork?

- Are there concerns with medical insurance/coverage?

Concurrent stressors/mental health/chemical health:

- Are there concurrent stressors that are impacting coping (e.g., housing, transportation, other commitments, limited caregiver availability)?

- Are there known mental health/chemical health histories for the patient or family? Does this need to be addressed or referred to appropriated resources?

Serious illness can impact financial stability, relationships, emotional well-being, coping with new demands/caregiving, and create the need for conversations about decision-making and treatment plans. Lack of knowledge or understanding of the social domains can significantly impact engagement in the plan of care and create frustration within the medical team. Poor communication among patient, family and clinicians undermines effective decision-making.

In situations where family/surrogate decision-makers are electing to remove life-sustaining treatment a care conference is helpful. Family members/surrogate decision-makers feel more supported and satisfied in the decision-making process when the care conference explores the patient's wishes, clinician recommendations, and assessment of the spiritual care needs of the family.

See the Implementation Tools and Resources Tables for more social resources.

Also see Annotation #2, "Assess Patient's Palliative Care Needs Based on the Following Domains of Palliative Care."

- Make referrals to meet identified social needs and to remove barriers to care. This includes but is not limited to transportation for treatment and appointments, caregiver service options to meet patient's needs at home, caregiver support needs, counseling, financial resources and community clubs/services for support.

- Understand that advance care planning is rarely fixed in time with specific treatment decisions but rather a dynamic process emerging from the clinical context of the disease and the social context of the patient. (*Prendergast, 2001*) Clear and honest communication, trust over time, and working within the patients' most important relationships are needed to improve the quality and outcome of this process.

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8. Spiritual Aspects of Care

Spirituality is recognized as an integral part of the palliative care plan. Clinicians should screen for spiritual beliefs and practices and respond respectfully. (*Pulchaski, 2009; NCP, 2018*) Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred. (*Puchalski, 2009*)

Illness and the prospect of dying can impact meaning, purpose, and connections in an individual's life. Thus, illness and dying have a spiritual dimension and are often perceived by patients as spiritual experiences. (*Balboni, 2018*) As people face serious illness, dying, and death, they often ask questions of meaning, value and relationships such as:

Meaning:

- Why is this happening to me? Why now?

- What is the meaning of my illness, my suffering, my death?

- What will happen to me after I die?

Value:

- Do I still have value despite changes in my appearance, productivity, independence?

- Is there anything valuable about me that will persist beyond death?

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Relationships:

- Do I need to forgive or be forgiven by anyone?

- Am I loved? By whom?

- Will I be remembered after I die? Will I be missed?

Other spiritual issues and concerns encountered in palliative care include life review, concerns or fears especially of dying/death, beliefs about afterlife, guilt, forgiveness, concerns about relationships, spiritual practices, legacy, and life completion tasks. (See also Annotation #6, "Psychological Aspects of Care.")

Patients often draw on their spirituality as they make health care decisions and to help them cope with illness and the experience of dying. (*Balboni, 2018*) Spiritual and religious concerns can also at times create distress and increase the burden of illness. Support of patient's spiritual needs at end of life is associated with better quality of life, increased hospice use and decreased use of intensive care. (*Zhang, 2012; Balboni, 2010*) Attending to a patient's spirituality can deepen the relationship between patient and clinician, and build trust. (*Ehman, 1999*)

All palliative care patients should receive a spiritual screening upon admission and regularly, especially at times of high need such as transitions in care and changes in condition. Spiritual screening is a quick determination of a patient's spiritual resources and concerns. Models of spiritual screening use a few simple questions that can be asked in the course of an overall patient and family interview. Examples of such questions include "Are spirituality or religion important in your life?'" and "How well are those resources working for you at this time?'" and "Do you currently have what you would describe as religious or spiritual struggles?" (*King, 2017*)

There are a number of spiritual assessment tools created for use by clinicians in the clinical setting. Some of these tools include:

H: Sources of hope, meaning, comfort, strength, peace, love, connection?
O: Member of an organized religion?
P: Personal spirituality, practices?
E: Effects of beliefs on medical care and end-of-life issues?

(Anandarajah, 2001)

F: Do you have spiritual beliefs or faith that has helped you cope with difficult times in the past?
I: Are these beliefs important to you, and how do they influence the way you care for yourself?
C: Are you involved in a spiritual or religious community or church?
A: How would you like your health care clinicians help you address spiritual issues and concerns?

(Puchalski, 2000)

S: Spiritual belief system
P: Personal spirituality
I: Integration with a spiritual community
R: Ritualized practices and restrictions
I: Implications for medical care
T: Terminal events planning

(Maugans, 1996)

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Based on information from the spiritual screening, clinicians can identify the presence of spiritual issues (including spiritual distress or spiritual resources of strength) and make the appropriate referrals to chaplains in the inpatient setting or to other spiritual care providers in an outpatient setting.

In addition, clinicians can attend to patient's spiritual needs and concerns in the following ways:

- Offer compassionate presence – strive to be present with and attentive to patients.

- Listen to the patient's fears, hopes, pain and concerns.

- Ask about hope and peace – this can be a simple, brief yet effective way to assess spiritual concerns. *(Steinhauser, 2006)*

    - Do you have hope?

    - Where does your hope come from?

    - What are you hoping for now as you look ahead?

    - Are you at peace with the care decisions you've made?

    - Do you feel at peace – in your heart, your spirit?

    - Where does peace come from for you?

    - Does that peace come from a spiritual or religious source?

Utilize clinically trained chaplains as members of the interdisciplinary health care team to provide patient-centered spiritual care and support. (*Astrow, 2001; Balboni, 2007; NCP, 2018*) They offer interfaith support to all who are in need and have specialized education to mobilize spiritual resources to help patients cope more effectively. (*VanderCreek, 2001*)

Clinicians should always respect the spiritual beliefs and practices of patients and families, should keep spiritual discussions patient/family-centered, and should never proselytize or impose beliefs onto a patient/family. Clinicians should be respectful when patients and families decline to discuss their beliefs or accept spiritual support. (*NCP, 2018*)

9. Ethical and Legal Aspects of Care

Recommendation	Quality of Evidence and Strength of Recommendation
As the disease progresses, clinicians should recognize those patients who are receiving nonbeneficial, low-yield therapy and reassess the treatment plan with the patient and family.	Quality of Evidence: Low Strength of Recommendation: Strong

Benefit: As needs change and providers engage the patient and family, it can save time by identifying changes in the patient wishes. It can avoid preventable harm.
Harm: Conflicts may arise with family members as the patient changes their wishes.
Benefit-Harms Assessment: When the patient and family understands the proposed treatment, and the patient's wishes, it is more likely that they will avoid nonbeneficial or low-yield therapy.
Relevant Resources: *Snyder Sulmasy, 2019 (Manual); Schneiderman, 2003 (Randomized Control Trial)*

Nonbeneficial/Low-Yield Therapy (formerly named Medical Futility)

The term "medical futility" has previously been used by clinicians to discuss the appropriateness of a medical treatment option. The public, policy-makers, ethicists and the medical profession have been unable to agree on a clear, concise definition of futility that can be applied to all medical situations. One general definition is that a futile intervention is one that:

a) is unlikely to be of any benefit to a particular patient in a particular medical situation, and

b) will not achieve the patient's intended goals. The sticking point in all futility definitions is the concept of **benefit**, as the perception of benefit is highly subjective.

Nonbeneficial Intervention: We recognize that patients, surrogates and members of the health care team may have different perceptions and values as to the usefulness of certain interventions. Nonbeneficial treatment is an intervention that the health care team determines:

a. will not achieve its intended short or long term treatment goal,

b. will not appreciably extend the patient's life span,

c. has no realistic chance of achieving the medical goal of returning the patient to the level of health that permits survival outside of the acute care setting,

d. prolongs an inevitable and imminent dying process, or

e. is based on the achievement of a goal that the patient who permanently lacks awareness will never be able to experience or appreciate.

Clinicians, patients and families often have very different views on what is potentially beneficial. Medical futility can be easily misunderstood as health care rationing. While economic issues may impact shared decision-making, the ultimate question is not "How much does this therapy cost?" but rather "Do the advantages of this therapy outweigh the disadvantages in a given patient?"

Clinicians are not legally, professionally or ethically required to offer medically futile treatments, **as defined by the standard of care of the medical community**. Ethics committees, hospitals and local/state medical organizations can provide resources to understand nonbeneficial/low-yield therapy and professional responsibilities in one's practice area. For critically ill patients who ultimately died during hospitalization, Schneiderman has shown lower utilization of ICU resources in patients when ethics consultation occurred. (*Schneiderman, 2003*)

Most literature on futility is based on the perspective of clinicians. Patients and families may have different perspectives that must be recognized and acknowledged. A multicenter qualitative study, based on semi-structured interviews with surrogate decision-makers for critically ill patients, found that 64% of the surrogates did not fully accept the clinicians' determinations of physiologic futility. They were equally divided between those with religious objections and those who either doubted the ability of clinicians to make these predictions or who needed more information from other sources. (*Zier, 2009*)

Reframing the discussion from "futility" or nonbeneficial/low-yield therapy to a clarification of goals of care allows the clinician to identify potential disagreement and customize discussions to address these areas.

Suggestions:

- Check with your health care institution about the presence of an existing futility policy.

- Avoid using the term "futility" in discussion with patients/families; rather, speak in terms of benefits/ burdens of treatment and patient- or family-specific goals of care.

- Involve a palliative care and/or ethics consultant in any situation where "futility" will be invoked as a process step in formulating decisions.

(*Cuezze, 2006*)

For *Choosing Wisely®* recommendations related to ethical treatment and nonbeneficial care in palliative care, see Appendix D.

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10. Develop or Revise Palliative Care Plan and Establish Goals of Care through the Process of Shared Decision-Making

Recommendation	Quality of Evidence and Strength of Recommendation
Clinicians should engage in shared decision-making (SDM) with the patient and/or family when establishing or revising goals of care.	Quality of Evidence: Low Strength of Recommendation: Strong
Benefit: SDM improves patient satisfaction and decreases decisional conflict. **Harm:** Patients or family may feel uncomfortable or burdened with difficult choices. Physicians may struggle to find options where few choices are available. **Benefit-Harms Assessment:** SDM remains the preferred method of conducting goals of care conversations in palliative care.	
Relevant Resources: *Shay, 2015 (Systematic Review); Stiggelbout, 2015 (Summary); Belanger, 2011 (Systematic Review); Makoul, 2006 (Review)*	

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The model of shared decision-making has been promoted in medicine both for the purpose of honoring the ethical obligation to support patient autonomy and to reduce variation in care introduced by physician preferences for treatments. (*Stiggelbout, 2015*) Evidence shows that when patients report they have participated in shared decision-making, they also report improved satisfaction and less decisional conflict, but thus far, links to other health outcomes are weak. (*Shay, 2015*)

Eliciting patient goals of care is an essential component of palliative care. Shared decision-making (SDM) has been the preferred method for conducting goals of care conversations in palliative care. However, a systematic review of the literature (*Belanger, 2011*) addressing SDM in palliative care revealed a relatively sparse research base that encompasses heterogenous approaches. The studies reveal that, similar to healthier patients, the majority of palliative care patients prefer to participate to some degree in treatment decision-making, while a substantial minority prefers to delegate the decision-making role. Clinicians are strongly encouraged to elicit each patient's decision-making preferences as part of the shared decision-making process.

Within the framework of SDM, the palliative clinician should ensure that the patient/family:

- are provided with accurate knowledge about the patient's condition and available treatments,

- have an understanding of prognosis associated with each treatment option,

- have an opportunity to express their decision-making preference,

- express the patient's beliefs and values regarding the treatments,

- receive a recommendation about treatment based on the clinican's knowledge of the medical condition as well as patient's expressed wishes and values, and

- understand the implementation of the agreed-upon decision.

Many authors have attempted to define the important steps of shared decision-making. Makoul (2006) identified nine essential elements of shared decision-making:

1. Define or explain problem.

2. Present options.

3. Discuss pros and cons.

4. Assess patients' values or preferences.

5. Discuss patient ability or self-efficacy.

6. Provide doctor knowledge or recommendations.

7. Check or clarify understanding.

8. Make or explicitly defer decision.

9. Arrange follow-up.

More recently, Stiggelbout (2015) delineated four steps:

1. The professional informs the patient that a decision is to be made and that the patient's opinion is important.

2. The professional explains the options and the pros and cons of each relevant option.

3. The professional and patient discuss the patient's preferences; the professional supports the patient in deliberation.

4. The professional and patient discuss the patient's decisional role preference, make or defer the decision, and discuss possible follow-up.

Regardless of the steps involved, all share the common elements that the decision-making involves at least two participants — clinician and patient; both parties share information; and consensus is reached on how to move forward. Various training programs and models are available to guide SDM, and at this time there is no clear advantage to utilizing one over the others.

See the Implementation Tools and Resources Tables for more information on SDM.

For *Choosing Wisely®* recommendations related to shared decision-making in palliative care, see Appendix D.

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11. Does Patient Meet Hospice Criteria?

Recommendation	Quality of Evidence and Strength of Recommendation
In a patient with serious illness, clinicians should recognize the prognosis of less than 6 months, and if in line with the patient goals of care, refer to hospice.	Quality of Evidence: Low Strength of Recommendation: Strong
Benefit: Earlier referral provides a better chance of relieving symptoms, improved quality of life, and addressing patient and family needs. **Harm:** The patient's choice may cause conflict among family and providers. Access to hospice may be limited. **Benefit-Harms Assessment:** The patient may not seek life-prolonging care; however, patients can always chose to resume it.	
Relevant Resources: *Joseph, 2016 (Systematic Review); Brinkman-Stoppelenburg, 2014 (Systematic Review); Lamont, 2001 (Observational Study); Brody, 1997 (Summary); SUPPORT, 1995 (Control Trial)*	

Hospice is a specialized form of palliative care dedicated to caring for the patient and family in the last months of life. It is both a philosophy of care and a specific insurance benefit. To qualify for hospice enrollment a patient must have a terminal diagnosis and is likely to die in the next six months if the disease runs its usual course. Hospice enrollment requires that two physicians (one being the hospice medical director) agree that the prognosis is less than six months. The patient must also elect to forego further life-prolonging therapies such as chemotherapy or surgery. Hospice seeks to support the patient at the end of life, neither prolonging life nor hastening death. Studies have shown that those who die at home and those enrolled in hospice programs have improved quality of life and symptom control. (*Brinkman-Stoppelenburg, 2014*)

Currently the median length of stay in hospice before death is about 17 days. (*Baxter, 2018*) This is despite the fact that the hospice benefit is at least six months or longer if needed. This short length of stay means that the patient, family and IDT have limited time to get a plan of care in place before death and that the focus tends to be more on the care of the imminently dying patient than living life to the fullest before the final decline in function. Early referral to hospice increases the likelihood that pain and other symptoms will be managed more aggressively and therefore there will be less anxiety and distress at the end of life. It allows the IDT to prepare the patient and family for death, and more thoroughly address concerns and aid in coping.

Another unique aspect of hospice is the bereavement benefit. For 13 months following a death the family is assessed and guided through the mourning process. (See also Annotation #13, "Grief and Bereavement.")

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Though patients may die of natural causes in their home peacefully and surrounded by family without hospice services, this specialized form of care ensures a more proactive approach to symptom management and crisis prevention. See the comparisons below:

	Palliative Care	**Hospice Care**
Timing of referral	Anytime after diagnosis of serious illness	Likely prognosis of < 6 months
Care focus	Symptoms *and* cure if possible; offered concurrently with active disease treatment if indicated	Symptoms only; life-prolonging care not typically covered e.g., chemotherapy, surgery
Venue of care	Hospital, home, long-term care, assisted living, clinic	Hospital, home, long-term care, assisted living, residential hospice house
Payment	Traditional insurance, including Medicare, covers professional fees, medications as usual through insurance, copays apply.* Social services and chaplain services typically not covered but may be waived, or paid for by grants or cash	Medicare covers all expenses related to the terminal diagnosis including medications, durable medical equipment and professional services; most insurances cover similarly
Bereavement	Varies	13 months
24/7 access	Possible – varies with venue of care	RN, MD/NP by phone 24/7
At time of home death	Notification of law enforcement	Preregistered, no law enforcement

*Currently insurers/payors define and cover palliative care services inconsistently. Inpatient palliative care services are covered as any inpatient service and generally are not an issue. Outpatient/clinic-based or home care-based palliative care services are more variably covered. Provider services by MDs and PA/NPs are covered in the usual fashion. RN, spiritual care and social services may not be covered, depending on payor.

- Early referral and admission into hospice services allows the patient and family time to get symptoms under control and time to plan with the entire IDT for the next stage of life, reduce the risk for complicated grief and improve overall quality of life. Some patients even experience improved life expectancy. (*Joseph, 2016*)

- A patient may revoke hospice at any time and may be readmitted if criteria are met again.

- A patient may be discharged from hospice if he/she improves or stabilizes and the prognosis is no longer less than six months.

- A patient may remain on hospice services longer than six months as long as the likely prognosis is still less than six months.

- Patients can continue working with their usual physicians as they would like, and the hospice interdisciplinary team will coordinate care with all team members.

- Each hospice IDT is required to meet every 15 days to review care plans and will meet more frequently if the patient's status dictates. (See also Annotation #11, "Assess for Hospice Referral.")

See the Implementation Tools and Resources Tables for more hospice resources.

For *Choosing Wisely®* recommendations related to limited life expectancy in palliative care, see Appendix D.

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12. Care for the Dying Patient

Recommendation	Quality of Evidence and Strength of Recommendation
Clinicians should identify when a patient is actively dying and communicate that to the patient and family.	Quality of Evidence: Low Strength of Recommendation: Strong
Benefit: Early communication decreases preventable harm and increases appropriate care. Engaging everyone allows time for preparation, closure, grief and bereavement.	
Harm: Prognosis is hard to predict.	
Benefit-Harms Assessment: It is important to respect the patient's and family's need for preparation, closure, grief and bereavement.	
Relevant Resources: *Taylor, 2017 (Observational Study); Kennedy, 2014 (Review); Solloway, 2005 (Observational Study); Ellershaw, 2003 (Report)*	

Diagnosing dying is complex and at times, uncertain. The clinical indicators of dying can be variable between patients and in progression rate. There are, however, benefits to both patients and families to acknowledging the dying phase. Avoiding provision of difficult and painful medical treatments to dying patients results in a higher likelihood of a peaceful death. Agreement between care team members that the patient is dying and communicating this to the patient and family fosters trust and improves satisfaction. Preparing and supporting the family and loved ones has also been shown to be a strong influence on how they cope with and adapt to bereavement. (*Kennedy 2014; Ellershaw, 2003*)

Care of the actively dying patient focuses on comfort and dignity while avoiding futile and invasive interventions that prevent a peaceful death. Despite barriers, it is important to have this plan available at the point of care, regardless of the site of care (inpatient, long-term care, home care, assisted living, ED, etc.). (*Solloway, 2005*)

Attention to adequate symptom management allays fears and allows comfort during the dying process. See also Annotation #4, "Physical Aspects of Care."

Patient and family wishes regarding the site of death should be discussed. Studies show that from 70% to 90% of people indicate that they prefer to die at home; despite this, about 75% of all deaths in the United States occur in hospitals or nursing homes. Referral to a hospice program may be appropriate. See Annotation #11, "Does Patient Meet Hospice Criteria?"

Spiritual assessment should be an integral part of the plan of care, and spiritual support patients should be offered to all patients. It has been shown that spiritual care can contribute to dying patients' quality of life and is an important domain of quality of medical and nursing care. (*Norris, 2005; Balboni, 2007; Richardson, 2014*) See also Annotation #8, "Spiritual Aspects of Care."

Education for the patient and family should be an early and ongoing part of the plan of care. Explanation of the signs and symptoms of imminent death should be provided, along with education about the interventions being used to provide comfort. It is important to understand the patient's cultural preferences regarding communication of negative health information; in some cultures, informing a dying patient directly might be considered harmful.

See the Implementation Tools and Resources Tables for more on death and dying resources.

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Also see Appendix C: "Signs and Symptoms That Indicate Death."

Death

At the time of death many things happen simultaneously. Families are actively grieving, other family members need to be contacted, professionals need to be notified, and all of this is influenced by the raw emotions of death. The following are some typical things families need to be aware of at the time of death.

Frequently Asked Question

Management of the body after death:

- Death in the home: The funeral home is notified to pick up the body in the home. State laws vary, but typically a body may remain in the home for 24 hours.

- Death in the hospital: Staff will contact the funeral home of choice for transportation. Many hospitals have policies about how long a body may remain on the unit before being transported to the morgue or funeral home. Staff may also contact state agencies regarding organ donation.

- Cremation: All licensed funeral homes offer cremation services.

- Federal law requires funeral homes to accept caskets that families have purchased from another vendor. Families/patients may also build their own casket.

- Most bodies are buried in established cemeteries, but burial on private property is possible in Minnesota. Check with the funeral home.

- Minnesota requires embalming or refrigeration in more circumstances than most states. A body must be embalmed or packed in dry ice if:

  - it will be shipped by public transportation,

  - burial or cremation will not occur within 72 hours after death, or

  - the body will be viewed publicly (by people other than family). Most funeral homes have a policy requiring embalming if the body is to be publicly viewed, but this is not required by Minnesota law. Ask if the funeral home offers private family viewing without embalming. If some form of preservation is a practical necessity, ask the funeral home if refrigeration is available.

  - A body may not be kept in refrigeration for more than six days – or packed in dry ice for more than four days – from the time the body is released from the place of death or from a medical examiner.

  - Scattering ashes on private land in MN is allowed. Regulations apply to public lands, federal lands, bodies of water and by air.

Reporting a death:

- Law enforcement must be notified of every death in the home except if preregistered while enrolled in hospice. Expected deaths that are not preregistered with the county will require a death investigation before release of the body to the funeral home. This is usually done by law enforcement and takes only a short time.

Death certificate:

- Must be registered within five days of death and before a body is buried or cremated

Organ donation:

- Register with the Minnesota Donor Registry

- No cost to patient or family

- What can be used is determined at the time of death

Body donation:

- Must preregister with either medical school (e.g., http://www.mayoclinic.org/body-donation) or http://www.bequest.umn.edu

- Both the University of Minnesota and the Mayo Clinic will cremate the remains and inter them at their own facilities or return them to the donor's family upon the family's request.

Cultural considerations:

- Proactively ask these questions on admission to hospice.

- Many ethnic and religious cultures have specific rituals practiced at the time of death and regarding the care of the body after death. Honoring tradition is usually possible. See Annotation #5, "Cultural Aspects of Care."

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13. Grief and Bereavement

Recommendation	Quality of Evidence and Strength of Recommendation
Clinicians should engage in ongoing assessment of grief and bereavement throughout the illness trajectory and intervene or refer for ongoing bereavement services when warranted.	Quality of Evidence: Low Strength of Recommendation: Strong
Benefit: Effective assistance for patients and family regarding anticipatory grief and intervention. Ongoing assessment allows for engagement, intervention and referral linkage to address patient and family needs.	
Harm: Patients or family may feel it is an undesired intrusion into the grief process and may not engage in or be open to the support offered.	
Benefit-Harms Assessment: In general this is often overlooked and can be of significant help through clear communication, bereavement risk/protective factors, and referral to resources.	
Relevant Resources: *Griffin, 2007 (Guideline); Strobe, 2006 (Report); Hollenbeck, 2005 (Guideline); Ellifrit, 2003 (Observational Study); Chochinov, 1989 (Review); Sheldon, 1998 (Clinical Review)*	

Grief is the normal emotional/affective process of reacting to a significant loss. It can include physiologic, psychologic and emotional reactions. Bereavement is the period after the loss in which grief is experienced. Every person is unique and will have individual differences in how he/she experiences grief and length of bereavement. The bereaved will use both cognitive and affective strategies in adapting to bereavement that is influenced by internal and external pressures. (*Doughty, 2009*) Grief is not on a linear continuum and does not follow a specific time frame.

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Grief can be anticipatory, such as that experienced by the patient or a loved one prior to the expected death of the patient. (*Hallenbeck, 2005*) Bereavement interventions can begin prior to and in anticipation of the actual loss. (*Chochinov, 1989*) When the intense initial reactions of grief continue for a prolonged period, grief can be considered complicated or a prolonged grief response. (See also Annotation #6, "Psychological Aspects of Care.") Some individuals will experience disenfranchised grief when society has denied their need, right, role or capacity to grieve. By assessing the grief response prior to death, it is possible to identify risk of complicated grieving and to provide early intervention. (*Ellifrit, 2003*) Assessment of bereavement risk should include risk and protective factors.

Several factors may predispose an individual to complicated grief. These include:

- Dependent or ambivalent relationship

- Multiple previous bereavements

- Previous psychiatric history, especially depression

- Sudden and unexpected death

- Death of a young person

- Stigmatized deaths such as suicide or AIDS (disenfranchised grief)

- Culpable deaths

- Inability to carry out valued religious rituals

- Perceived lack of social support

- Survivor under age 45 whose partner died suddenly, or over 65 whose partner had illness of five years or more

- Multiple life crises

- Gender of bereaved person – e.g., elderly male widower

(Sheldon, 1998; Chochinov, 1989)

Several factors may provide a protective factor in grief or ameliorate bereavement risk. These are:

- Belief in own ability to cope

- Strong social support

- Optimism

- Spiritual/religious coping or connections

- Resiliency

(*Stroebe, 2006*)

Clinicians play an important role in facilitating healthy grief and bereavement processes. Honesty at the end of life is essential and allows patients to review their life and assist loved ones in future plans. Providing information and education on normal grief responses can assist in bereavement.

Following the death of the patient, it is essential to allow the patient's loved ones to perform customs or rituals that are important to them, within the policy guidelines of the facility. Failure to do so may lead to complicated grieving. (*Lebrocq, 2003*) Clinicians should be available to answer questions and offer support. This may be done informally or through a formal debriefing.

Contact by clinicians after the death of a patient can be comforting for the patient's loved ones. (*Griffin, 2007*) Clinicians may wish to offer emotional support by sending a card expressing their condolences. Clinicians should also offer practical support by completing death certificates in a timely manner, filling out necessary forms or writing letters for the family as needed.

Many resources are available for children, including storybooks, workbooks and camps for grieving children. For confused elders or survivors with learning disabilities, repeated explanations and participation in important events, such as the funeral, may help. (*Sheldon, 1998*)

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The intent of this section is to provide resources, strategies and measurement to help close the gap between current clinical practice and the recommendations set forth in the guideline.

Measurement is one of the key components of quality improvement. It evaluates the impact of clinical evidence-based recommendations on current clinical practice, and can assure that new practices are being implemented. The measures are recommended by each guideline workgroup and confirmed through consensus. ICSI's Committee for Evidence-Based Practice provides oversight and final approval for the measures as part of the guideline revision process.

As part of the process, local and national resources for measures are searched and relevant measures are included if aligned with the workgroup recommendations. These resources include: National Quality Forum (NQF), Joint Commission, National Committee for Quality Assurance (NCQA), MN Community Measurement (MNCM), CMS MACRA-MIPS measures and resources specific to the guideline topic.

ICSI work groups focus on quality improvement measures, not measures for accountability. Our goal is to help organizations understand how closely practice mirrors guideline recommendations and monitor this over time as quality improvement changes are implemented.

Types of measures included are measures of process, experience, and outcomes; each measure is labeled accordingly. Measurement data should be tracked and compared over time to help gain insight into effectiveness of interventions. Measurement definitions and data collection frequency need to be consistent to ensure validity of data comparisons over time.

The subdivisions of this section are:
- Aims and Measures
- Implementation Recommendations
- Implementation Tools and Resources
- Implementation Tools and Resources Tables

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Aims and Measures

The ICSI work group conducted a search of local and national resources on measures of palliative care and was unable to find measures relevant to the recommendations in this guideline. Therefore, the measures below are suggestions by ICSI Palliative Care Guideline Work Group.

Population of interest for Aims 1-4: Patients with a serious illness.

In the context of palliative care, a "serious illness" could be defined as:

- a terminal illness (metastatic solid tumor cancers)

- a chronic, progressive, and probably life-shortening illness (e.g., heart failure, COPD, cirrhosis)

- severe neurodegenerative diseases (e.g., dementia, amyotrophic lateral sclerosis, severe multiple sclerosis)

- a life-threatening illness with a chance of full recovery (some leukemias, acute critical illnesses)

1. Increase the identification of patients who are in the early stages of a serious illness who would benefit from palliative care. *(Annotations #1, 2)*

   Measure for accomplishing this aim:

   a. Percentage of adult patients with a serious illness who have been screened for palliative care. (process measure)

2. Improve the effectiveness and comfort level of the clinician in communicating the necessity and benefits of palliative care with those patients with a serious illness. (*Annotation #1*)

   Population of interest: Patients with a serious illness. (See definition above.)

   Measures for accomplishing this aim:

   a. Percentage of clinicians who have education and training regarding palliative care concepts. (process measure)

3. Increase the completion and documentation of health care directive and health care proxy for patients with a serious illness. *(Annotation #3)*

   Population of interest: Patients with a serious illness. (See definition above.)

   Measures for accomplishing this aim:

   a. Percentage of adult patients with a serious illness who have documentation in the medical record of a designated health care proxy. (process measure)

   b. Percentage of adult patients with a serious illness who have documentation in the medical record of a completed health care directive. (process measure)

   c. Percentage of adult patients with a serious illness who have a completed POLST form documented in the medical record. (process measure)

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4. Improve the accessibility and ongoing utilization of the patient's palliative care plan, health care directive, patient values and preferences, and involvement of the health care proxy across the continuum of care (inpatient, ED, outpatient, home care, senior residence, etc.). *(Annotations #3-9)*

    Population of interest: Patients with a serious illness. (See definition above.)

    Measure for accomplishing this aim:

    a. Percentage of adult patients with a serious illness who have documentation in the medical record that the health care directive were reviewed with the patient and their proxy and are readily accessible within the medical record. (process measure)

    b. Percentage of adult patients with a serious illness who have documentation in the medical record that the health care directive were reviewed and updated with the patient and their proxy when the patient's condition or life circumstances changed (including transitions of care). (process measure)

5. Improve the effectiveness of care and the comfort level of the palliative care patients and family. *(Annotation #10)*

    Population of interest: Patients in palliative care

    Measures for accomplishing this aim:

    a. Percentage of palliative care patients who experience care beyond or against their wishes. (outcome measure of care efficacy; decrease in the rate suggests improvement)

    b. Percentage of palliative care patients who died who were offered hospice care at any time. (outcome measure of care efficacy; increase in the rate suggests improvement)

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Implementation Recommendations

Prior to implementation, it is important to consider current organizational infrastructure that address the following:

- System and process design

- Training and education

- Culture and the need to shift values, beliefs and behaviors of the organization.

The following system changes were identified by the guideline work group as key strategies for health care systems to incorporate in support of the implementation of this guideline:

- Develop a process that will allow clinicians to identify and assess patients who would benefit from palliative care services regardless of the setting or location. This process should include recognition of nonbeneficial, low-yield or potentially harmful care based on patient condition and preferences. *(Aims #1, 5)*

- Develop a process to provide education to clinicians, patients and families regarding the elements and appropriateness of palliative care. It is important to address the difference between palliative care and hospice. *(Aim #2)*

- Utilize scripts for clinicians that will assist them in initiating and discussing palliative care services. *(Aim #2)*

- Develop a process for timely referral to palliative care consultation for patients with a serious illness. *(Aim #1)*

- Develop workflows and policies to assure that all staff use standardized naming conventions and filing of documents, and are trained in how to retrieve them from the electronic medical record. *(Aim #4)*

- Develop standard documentation procedures to capture patient wishes and preferences, inclusion of health care proxy, ongoing review, and updates to health care directive during transitions. *(Aims #3, 4)*

- Utilize measurement tools to improve patient engagement and the use of health care directive:

    - Use of a patient engagement/satisfaction tool for palliative care (such as *collaboRATE ™* instrument: (http://www.glynelwyn.com/collaborate.html) *(Aim #5)*

    - Use a retroactive chart audit tool or discussion during a care team meeting using a tool such as the "*Conversation Ready Respect Measurement tool*" to generate dialogue around improving how well the elements of advance care planning are addressed with a given patient. *(Aims #3-5)*

    (http://www.ihi.org/resources/Pages/IHIWhitePapers/ConversationReadyEndofLifeCare.aspx)

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Implementation Tools and Resources

Criteria for Selecting Resources

The following tools and resources specific to the topic of the guideline were selected by the work group. Each item was reviewed thoroughly by at least one work group member. It is expected that users of these tools will establish the proper copyright prior to their use. The types of criteria the work group used are:

- The content supports the clinical and the implementation recommendations.

- Where possible, the content is supported by evidence-based research.

- The author, source and revision dates for the content are included where possible.

- The content is clear about potential biases and when appropriate conflicts of interests and/or disclaimers are noted where appropriate.

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Implementation Tools and Resources Tables

Assessment Tools

Assessment Tool	Audience	Web Sites/Order Information
Edmonton Symptom Assessment System (ESAS)	Health Care Providers	https://pallipedia.org/edmonton-symptom-assessment-system-esas/
Palliative Performance Scale (PPS)	Health Care Providers	http://npcrc.org/files/news/palliative_performance_scale_PPSv2.pdf
Mitchell Mortality Index	Health Care Providers	https://eprognosis.ucsf.edu/mitchell.php

Physician Education Resources (Fast Facts)

Domain	Fast Fact Title/Description	Audience	Web Link
Palliative Care Network of Wisconsin (PCNOW)	Palliative Care Network of Wisconsin (PCNOW) Fast Fact resources, including symptom management. Enter symptom into search box for resources.	Health Care Provider	https://www.mypcnow.org/fast-facts
Advance Directives	#12 Myths about Advance Directives	Health Care Provider	https://www.mypcnow.org/fast-fact/myths-about-advance-directives/
Spiritual Domain	#318 Existential Suffering – Part 1: Definition and Diagnosis	Health Care Providers	https://www.mypcnow.org/fast-fact/existential-suffering-part-1-definition-and-diagnosis/
Cultural Domain	#216 Asking About Cultural Beliefs in Palliative Care	Health Care Providers	https://www.mypcnow.org/fast-fact/asking-about-cultural-beliefs-in-palliative-care/
Psychological Domain	#07 Depression in Advanced Cancer	Health Care Providers	https://www.mypcnow.org/fast-fact/assessing-depression-in-advanced-cancer/
Psychological Domain	#186 Anxiety in Palliative Care- Causes and Diagnosis	Health Care Providers	https://www.mypcnow.org/fast-fact/anxiety-in-palliative-care-causes-and-diagnosis/
Psychological Domain	#59 Dealing with the Angry Dying Patient	Health Care Providers	https://www.mypcnow.org/fast-fact/dealing-with-the-angry-dying-patient/

Domain	Fast Fact Title/Description	Audience	Web Link
Psychological Domain	#29 Responding to patient emotion	Health Care Providers	https://www.mypcnow.org/fast-fact/responding-to-patient-emotion/
Psychological Domain	#186 Anxiety in Palliative Care – Causes and Diagnosis	Health Care Providers	https://www.mypcnow.org/fast-fact/anxiety-in-palliative-care-causes-and-diagnosis/
Grief and Bereavement Domain	#254 Complicated Grief	Health Care Providers	https://www.mypcnow.org/fast-facts/quiz/complicated-grief/

General Tools and Resources

Author/Organization	Title/Description	Audience	Web Sites/Order Information
Agency for Health care Research and Quality (AHRQ)	Effective Health Care Programs for Palliative Care includes assessment tools, quality improvement, care interventions and integrating palliative care with chronic disease management.	Health Care Providers	https://effectivehealthcare.ahrq.gov/health-topics/palliative-care
Aging with Dignity	"5 Wishes" and "My Wishes." The documents address medical, personal, emotional and spiritual needs that should be addressed when an adult or child is seriously ill and unable to speak for themselves.	Patients and Families	http://www.agingwithdignity.org
American Academy of Hospice and Palliative Medicine	A professional organization specializing in hospice and palliative care medicine. Tools to Address Opioid Prescribing.	Health Care Providers	http://www.aahpm.org http://aahpm.org/education/opioid-resource-hub
American Academy of Hospice and Palliative Medicine	An excellent resource for clinicians to share with patients and families. It has been developed by the American Academy of Hospice and Palliative Medicine.	Health Care Providers	http://www.palliativedoctors.org
American Academy of Hospice and Palliative Medicine	Essential practices of hospice and palliative medicine learning modules.	Health Care Providers	http://aahpm.org/self-study/essentials
American Academy of Family Physicians	Symptom management resources and education.	Health Care Providers	https://www.aafp.org/afp/topicModules/viewTopicModule.htm?topicModuleId=57

Author/Organization	Title/Description	Audience	Web Sites/Order Information
American Board of Hospice and Palliative Medicine (ABHPM)	ABHPM promotes excellence in the care of all patients with advanced, progressive illness through the development of standards for training and practice in palliative medicine. The board is an independent, nonprofit organization whose certificate is recognized as signifying a high level of clinician competence in the discipline of palliative medicine.	Health Care Providers	http://www.aahpm.org/ certification/default/index.html
American Hospital Association	Resources include Put It In Writing brochure, wallet ID, advertisements and links.

The website provides information about advance directive, as well as educational resources to raise awareness regarding this issue. | Patients and Families; Health Care Providers | http://www.putitinwriting.org |
| Ariadne Labs | Serious Illness Conversation Guide

Ariadne Labs: A joint Center for Health Systems Innovation (www.ariandelabs.org) and Dana-Farber Cancer Institute. | Health Care Providers | https://www.ariadnelabs. org/wp-content/uploads/ sites/2/2015/08/Serious-Illness-Conversation-Guide-5.22.15.pdf |
Association of Professional Chaplains	Resources for chaplains in palliative care.	Chaplains	http://www. professionalchaplains.org/ content.asp?pl=86&contentid=86
Caring Connections	Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer and community engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation.	Patients and Families	http://www.caringinfo.org
Center to Advance Palliative Care (CAPC)	CAPC searchable database	Health Care Providers	http://getpalliativecare.org/ provider-directory/
Center to Advance Palliative Care (CAPC)	Tools for Palliative Care Programs.

A collection of tools assembled by CAPC to assist in designing, strengthening, maintaining and defending Palliative Care programs.

CAPC Palliative Care Report findings | Health Care Providers | https://www.capc.org/ search/?q=Palliative+care+tools

https://reportcard.capc.org/ findings/ |

Author/Organization	Title/Description	Audience	Web Sites/Order Information
Center to Advance Palliative Care (CAPC)	Comfort during the dying process. There are several example order sets and nursing care plans.	Health Care Providers	https://www.capc.org/search/?q=Palliative+care+tools
Center to Advance Palliative Care (CAPC)	CAPCconnect Forum: A free resource for health care professionals who want to share information, exchange ideas, and get advice from their colleagues on operational issues affecting their palliative care programs.	Health Care Providers	http://www.capc.org/forums/
Center to Advance Palliative Care (CAPC)	Symptom management online training modules.	Health Care Providers	https://www.capc.org/training/symptom-management/
CMS Medicare Learning Network	Education on Advance Care Planning use and billing for Medicare patients.	Health Care Providers	https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf
CMS Medicare Hospice Benefit information	CMS site with Medicare hospice benefit criteria.	Health Care Providers	https://www.cms.gov/Center/Provider-Type/Home-Health-Agency-HHA-Center.html?redirect=/center/hospice.asp
GetPalliativeCare.org The site is provided by the Center to Advance Palliative Care (CAPC)	The website provides clear, comprehensive palliative care information for people coping with serious, complex illness. Information includes description of what palliative care is, how it is different from hospice care and information on advance directive.	Patients and Families	http//www.getpalliativecare.org
Hank Dunn Hard Choices	Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-Threatening Illness, Fourth Edition. Book: (ISBN 1-928560-30-2)	Patients and Families	To order: http://www.hardchoices.com To download or read online: http://hardchoices.com/about_hc.html
Honoring Choices Minnesota	A large-scale, community-based initiative that introduces advance care planning conversations to all individuals over 18 years of age.	Health Care Providers; Patients, Families and Caregivers	https://www.honoringchoices.org/
Hospice and Palliative Nurses Association (HPNA)	A professional organization for nurses within hospice and palliative care to advance expert care in serious illness.	Health Care Providers	https://advancingexpertcare.org/
Hospice Patients Alliance	Signs & Symptoms of Approaching Death	Health Care Professionals; Patients and Families	http://www.hospicepatients.org/hospic60.html

Author/Organization	Title/Description	Audience	Web Sites/Order Information
Institute for Clinical Systems Improvement (ICSI)	Shared Decision-Making Model	Health Care Providers	https://www.icsi.org/guideline/palliative-care/
Institute for Healthcare Improvement Conversation Ready	"Conversation Ready": A Framework for Improving End-of-Life Care (Second Edition) "How to Talk to Your Patients about End-of-Life Care: A Conversation Ready Toolkit for Clinicians"	Health Care Providers	http://www.ihi.org/resources/Pages/IHIWhitePapers/ConversationReadyEndofLifeCare.aspx
Barbara Karnes	Gone from My Sight; The Dying Experience	Patients and Families	Bookstores
Minnesota Network of Hospice & Palliative Care (MNHPC)	MNHPC has developed a database palliative care programs in the stae of Minnesota that is searchable by zip code. Resources for health care professionals as well as patients and families.	Health Care Professionals; Patients and Families	www.mnhpc.org
National Consensus Project	Clinical Practice Guidelines for Quality Palliative Care (2018) This includes updated references for each of the eight domains, exemplars illustrating implementation of the guidelines, and the relationship of the guideline domains with the National Quality Forum's Preferred Practices.	Health Care Provider	http://www.nationalconsensusproject.org
National Hospice and Palliative Care Organization	NHPCO is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people in America and their loved ones. This website provides information about end-of-life care, with resources, facts and figures, news briefs, patient advocacy, conferences and education.	Health Care Provider; Patients and Families	http://www.nhpco.org

Author/Organization	Title/Description	Audience	Web Sites/Order Information
Palliative.org (Regional Palliative Care Program in Edmonton, Alberta)	The website provides clinical information to health care professionals regarding palliative care. The assessment tools include including various tools such as the Edmonton Symptom Assessment System (ESAS). The site also includes a link to the American Academy of Hospice and Palliative Medicine Fast Facts.	Health Care Provider	http://www.palliative.org/newPC/professionals/tools/tools.html
POLST.org is sponsored by the Center for Ethics in Health Care and Oregon Health & Science University	POLST (Physician Orders for Life-Sustaining Treatment) is designed to help health care professionals honor the end-of-life treatment desires of their patients. The form includes clinician orders that follow patient wishes and treatment intentions, and enhances the appropriateness and quality of patient care. The Minnesota Medical Association has adopted a version of POLST for statewide use (see link). Indiana has made a POLST video suitable for patients and family explaining its use (see YouTube link).	Health Care Providers; Patients and Families	http://www.polst.org https://www.mnmed.org/advocacy/improving-health-of-minnesotans/POLST-Communications https://www.youtube.com/watch?v=ci7KlDJQpFU
Social Work Hospice and Palliative Care Network	A professional organization/network of psychosocial hospice and palliative care professionals dedicated to advancing best practices in caring for those with serious illness.	Health Care Providers	https://www.swhpn.org/
University of Wisconsin	Best Case/Worst Case Shared decision-making instructional YouTube video. A communication tool developed by researchers at the University of Wisconsin to help surgeons discuss difficult treatment decisions.	Health Care Providers	http://www.youtube.com/watch?v=FnS3K44sbu0
VitalTalk	VitalTalk provides evidence-based training to clinicians on communication skills for serious illness shared decision-making.	Health Care Providers	https://www.vitaltalk.org/

The subdivisions of this section are:

- References
- Appendices

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Appendix A: Literature Search Terms

Date range: Jan. 1, 2013, through Dec. 1, 2018

English, Human studies

Types of literature: Systematic reviews/meta-analysis, Randomized controlled trial, Observational studies (cohort, case-control and cross-sectional) and Implementation studies

Search terms:

- End of life care

- Hospice

- Palliative care

- Supportive care

- Symptom management

- Existential distress

- Demoralization

- Terminal illness

- Moral distress

- Ethics in palliative care and hospice

- Physician aid in dying

- Access to palliative care

- Financing and payment for palliative care

- Privatization of palliative care

- Suffering

- Death and dying

- Staff roles in palliative care

- Community-based palliative care

- Opioid addiction in palliative care and cancer

- Pain management in palliative care or cancer

- Implementation of palliative care

- Life-limiting diagnoses

- Chronic care management and palliative care and intensive team care model

- Advanced care planning

- POLST (physician order for life-sustaining treatment)

- Rural palliative care programs

- Assessment of palliative care

- Assessing well-being and emotional health

- Counseling

- Quality of life

- Health services accessibility

- Health care disparities

- Payment model

- Pain

- Stress, psychological

- Patient care team

- Nursing staff

- Medical staff

- Primary care

- Cancer pain

- Palliative care/methods

- Palliative care/organization and administration

- Opioid-related disorders

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Appendix B: How to Discuss Serious Illness

Many clinicians believe they lack confidence and experience in discussing with patients the issues and decisions that come with having a serious illness – specifically recommendations about palliative care and hospice services. This may involve delivering "bad news," as well as answering questions that may not have specific answers. A useful definition of "bad news" is information that "results in a cognitive, behavioral, or emotional deficit in the person receiving the news that persists for some time after the news is received." (*Ptacek, 1996*) Another definition of bad news is "any news that drastically and negatively alters the patient's view of her or his future." (*Buckman, 1984*) Implicit in these definitions is that a terminal diagnosis is not the only form of bad news; it may also refer to disclosing the diagnosis of a serious chronic condition such as multiple sclerosis, ultrasound-verified fetal demise to a pregnant woman, and other scenarios.

In the absence of more formal education, the more a clinician prepares for discussions surrounding palliative care and puts that preparation into practice, the more skilled and comfortable that clinician can become in this aspect of medical care.

There are several excellent mnemonics available to help clinicians increase their knowledge, practice examples of these discussions, and generally obtain a better understanding of the emotions, questions and problems that may arise with patients and families at this time in their lives.

One mnemonic found useful for this guideline includes:

- ABCDE (Advance preparation, Build a therapeutic environment/relationship, Communicate well, Deal with patient and family reactions, Encourage and validate emotions) (*Vandekieft, 2001*)

Advance preparation: Obtain the patient's medical information and test results, if possible, so that you are fully aware of the situation. Mentally rehearsing the way you wish to present the information and options can give you a sense of how the conversation may go. Remember to individualize your approach for each patient and family based on how much they know at that point and how they prefer to receive information. Make sure that you have an appropriately private location in which to have the discussion, and that the session will be free of interruptions, including setting the pager to silent or leaving it with a colleague.

Build a therapeutic environment/relationship: Try to find out how much the patient and family understands, how they want to be told (bluntly, gently, etc.), and how much they want to know at that time.

- "If this condition turns out to be something serious, are you the kind of person who likes to know what is going on?"

- "Would you like me to tell you the full details of the diagnosis?"

- "If your condition is serious, how much would you like to know?" If the patient indicates that he/she does not want any information, it is important to "leave the door open." For example, you may say, "That's OK. If you change your mind, at any time, please feel free to talk to me or one of my colleagues."

- Have family members or friends present as per the patient's preference, and take time to learn names and relationships of each support person present. Use touch and humor where appropriate, taking into consideration your relationship with the patient. Reassure the patient of your availability, set up follow-up appointments, and contact other clinicians about the situation where appropriate.

Communicate well: Ask the patient for any questions. Speak truthfully but compassionately and avoid using medical terms or euphemisms. Say the words "cancer," "dying," "death," etc. Although a care clinician may be uncomfortable with these terms, they help with clarity of communication and accurate understanding by the patient and family of what is being said.

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Adapt the communication style to the education level and personal preference of the patient and family. For example, if the patient is a company executive who is used to calling the shots, this person may benefit more if provided with several different options to choose from rather than being told what to do. If the education level and preferred style are unknown, a good rule of thumb is to present information at a sixth through eighth grade level.

Don't rush the process; allow time for silence, tears and questions. This allows the patient and family (if present) time to react to the news and to discuss concerns of the patient, and allows the patient to receive the news at his or her own pace. (*Ellis, 1999*) Remember that the patient may not retain much of the information given beyond that of the diagnosis or prognosis, and may have to wait to "digest" what information can be absorbed. Strong emotions elicited in difficult conversations may distract the patient from hearing the full communication. Repeat important points, write things down and periodically assess the patient's understanding of the information and reactions to what was heard. Think out loud; help the patient and family feel they are part of the team. Visual aids, written question prompts (suggesting possible questions that a patient or family may want to ask), and the provision of audio tapes of the conversations may aid communication and recall of important points.

Communicate any bad news to the patient and family. The clinician may want to deliver a "warning" statement prior to the bad news itself to prepare the patient (and family if present) for the communication that follows. For example, "I'm afraid I have [difficult/bad] news to share on [your/his/her] condition." Additionally, it may be advisable to ask a few open-ended questions prior to delivering the actual bad news to assess what the patient and family already know and their readiness to hear the news. (*Baile, 2000*)

The following questions are examples of inquiries that should be utilized in every palliative assessment to ensure cultural awareness:

- "Some people want to know everything about their medical condition, and others do not. What is your preference?" (Identifies preferences regarding disclosure of information)

- "Do you prefer to make medical decisions about future tests or treatments for yourself, or would you prefer that someone else make these decisions for you?" (Identifies locus of decision-making)

- "What do you think caused this illness to happen?" "Why do you think it started when it did?" (Identifies perspectives on death, suffering and grieving)

- "What do you fear about this sickness?" (Identifies perspectives on death, suffering and grieving)

- "What kind of treatment would you prefer to receive at this point?" (Perspectives on physical care)

- "What are the most important results you hope to receive from this treatment?"

- "Do you have other hopes or fears related to your illness?"

Deal with patient and family reactions: Be sensitive to the emotional reactions of the patient and family. Recognize that denial, blame, intellectualization, disbelief and acceptance may be present to varying degrees and time frames. Watch for signs of depression and suicidality in subsequent visits. Be empathetic. Crying may occur, but make sure that your tears are empathic in nature and not reflective of personal issues on your part. There may be anger from the patient and family about care received from you or another colleague; resist becoming defensive or argumentative about these issues. Try to deal with that particular patient's and family's cultural and ethnic norms.

- "I was probably raised differently than you. Can you tell me how your family deals with these situations?"

Encourage and validate emotions: During the discussion, periodically ask the patient and family how and what they are feeling, and respond with empathy. If the patient (and family if present) is ready, discuss treatment options and arrange for follow-up to put those options into action. Talk with the patient about what this means for him/her, and what needs outside of the traditional medical scope he/she may have. It is important that the patient and family do not lose their sense of hope. Offer realistic hope. Communicating hope, even though a "cure" may not be possible, may be done by redirecting the focus of hope to keep the patient comfortable and as symptom-free as possible. Reassure the patient that every effort will be made to promote comfort, dignity and quality of life as defined by the patient.

- "I know this is not what you were hoping to hear."

- Don't say, "*There is nothing more we can do*"; instead say, "What we are going to focus on now is___[comfort, pain relief, etc.]." (*Baile, 2000*)

Additional considerations pertaining to the initial discussion between clinician, patient and family (based on expert consensus) include the following:

- Discussing prognosis is a difficult issue, and little attention is given to this issue in most training programs, leaving clinicians relatively unprepared to handle this task. The prognosis for a patient is based on multiple factors with complex interactions, including diagnoses, medications and therapeutics, social issues, functional status, patient preferences, and clinician knowledge and experience. The communication of prognosis should be individualized to the needs and desires of the particular patient and family. As mentioned elsewhere, clinicians tend to significantly overestimate prognosis, which may lead to delays in palliative treatments in favor of unnecessary curative or invasive treatments. Clinicians may build additional trust by acknowledging limitations in providing a prognosis. It may be best to provide a range of dates or times, or tie prognoses to hypothetical situations.

- Encourage continual communication for status updates, to assess comprehension of information, and to respond and empathize with new emotions as they come up.

- Coordination of communication is essential among clinicians, especially when there is a change in care setting or a transfer to another facility such as skilled nursing or home care, as patient preferences may not be known to the clinicians in the new setting.

- Document details of all discussions in the medical record.

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Appendix C: Signs and Symptoms That Indicate Death

The following signs and symptoms may indicate that death is approaching. Not all individuals will show all of these signs; however, these are signs that death is likely to occur in hours to days.

- Delirium, often manifested by increased restlessness, confusion, agitation, inability to stay content in one position and insisting on changing positions frequently.

- Withdrawal from active participation in social activities.

- Increased periods of sleep, lethargy.

- Decreased intake of food and liquids.

- Periods of pausing in breathing (apnea) whether awake or sleeping. Very rapid breathing or cyclic changes in the patterns of breathing (Cheyne-Stokes respirations). Other abnormal breathing patterns.

- Patient reports seeing people who have already died.

- Patient states that he or she is dying.

- Patient requests family visit to settle unfinished business and tie up loose ends.

- Inability to heal or recover from wounds or infections.

- Increased swelling (edema) of either the extremities or the entire body.

- Inability to arouse patient at all (coma) or ability to arouse patient only with great effort, but patient quickly returns to severely unresponsive state (semicoma).

- Severe agitation in patient, hallucinations, acting "crazy" and not in patient's normal manner or personality.

- Increased respiratory congestion or fluid buildup in the lungs. Shortness of breath.

- Inability to swallow any fluids at all. Not taking food by mouth. Vomiting.

- Patient breathing through wide-open mouth continuously and no longer can speak even if awake.

- Urinary or bowel incontinence in a patient who was not incontinent before.

- Marked decrease in urinary output and darkening color of urine or very abnormal color of urine, such as red or brown.

- Blood pressure dropping dramatically from patient's normal blood pressure range (more than a 20-30 point drop).

- Systolic blood pressure below 70. Diastolic blood pressure below 50.

- Patient's extremities feel very cold to the touch.

- Fever.

- Patient complains that his or her legs/feet are numb or cannot be felt at all.

- Cyanosis, or a blue or purple coloring to the patient's arms and legs, especially the hands and feet (mottling).

- Patient's body is held in a rigid, unchanging position.

Appendix D: *Choosing Wisely*® Recommendations Regarding Palliative Care

The following *Choosing Wisely*® recommendations are in alignment with and further support the content of this guideline. For references, please click on the links below each society's name. Where applicable, links for patient materials are also included.

From the American Academy of Hospice and Palliative Medicine:
http://www.choosingwisely.org/doctor-patient-lists/american-academy-of-hospice-palliative-medicine/

1. **Don't recommend percutaneous feeding tubes in patients with advanced dementia; instead, offer oral assisted feeding.** In advanced dementia, studies have found feeding tubes do not result in improved survival, prevention of aspiration pneumonia, or improved healing of pressure ulcers. Feeding tube use in such patients has actually been associated with pressure ulcer development, use of physical and pharmacological restraints, and patient distress about the tube itself. Assistance with oral feeding is an evidence-based approach to provide nutrition for patients with advanced dementia and feeding problems; in the final phase of this disease, assisted feeding may focus on comfort and human interaction more than nutritional goals.

For patient-friendly materials regarding this recommendation:

http://consumerhealthchoices.org/wp-content/uploads/2013/05/ChoosingWiselyFeedingTubeAGS-ER.pdf

2. **Don't delay palliative care for a patient with serious illness who has physical, psychological, social or spiritual distress because they are pursuing disease-directed treatment.** Numerous studies – including randomized trials – provide evidence that palliative care improves pain and symptom control, improves family satisfaction with care and reduces costs. Palliative care does not accelerate death, and may prolong life in selected populations.

3. **Don't leave an implantable cardioverter-defibrillator (ICD) activated when it is inconsistent with the patient/family goals of care.** In about a quarter of patients with ICDs, the defibrillator fires within weeks preceding death. For patients with advanced irreversible diseases, defibrillator shocks rarely prevent death, may be painful to patients and are distressing to caregivers/family members. Currently there are no formal practice protocols to address deactivation; fewer than 10% of hospices have official policies. Advance care planning discussions should include the option of deactivating the ICD when it no longer supports the patient's goals.

4. **Don't recommend more than a single fraction of palliative radiation for an uncomplicated painful bone metastasis.** As stated in the American Society for Radiation Oncology (ASTRO) 2011 guideline, single-fraction radiation to a previously un-irradiated peripheral bone or vertebral metastasis provides comparable pain relief and morbidity compared to multiple-fraction regimens while optimizing patient and caregiver convenience. Although it results in a higher incidence of later need for retreatment (20% vs. 8% for multi-fraction regimens), the decreased patient burden usually outweighs any considerations of long-term effectiveness for those with a limited life expectancy.

5. **Don't use topical lorazepam (Ativan), diphenhydramine (Benadryl), haloperidol (Haldol) ("ABH") gel for nausea.** Topical drugs can be safe and effective, such as topical non-steroidal anti-inflammatory drugs for local arthritis symptoms. However, while topical gels are commonly prescribed in hospice practice, anti-nausea gels have not been proven effective in any large, well-designed or placebo-controlled trials. The active ingredients in ABH are not absorbed to systemic levels that could be effective. Only diphenhydramine (Benadryl) is absorbed via the skin, and then only after several hours and erratically at subtherapeutic levels. It is therefore not appropriate for "as needed" use. The use of agents given via inappropriate routes may delay or prevent the use of more effective interventions.

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From the American Geriatrics Society

http://www.choosingwisely.org/doctor-patient-lists/american-geriatrics-society/

1. **Don't recommend percutaneous feeding tubes in patients with advanced dementia; instead offer oral assisted feed.** Careful hand feeding for patients with severe dementia is at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort. Food is the preferred nutrient. Tube feeding is associated with agitation, increased use of physical and chemical restraints, and worsening pressure ulcers.

2. **Don't use antipsychotics as the first choice to treat behavioral and psychologic symptoms of dementia.** People with dementia often exhibit aggression, resistance to care and other challenging or disruptive behaviors. In such instances, antipsychotic medicines are often prescribed, but they provide limited and inconsistent benefits, while posing risks, including over sedation, cognitive worsening and increased likelihood of falls, strokes and mortality. Use of these drugs in patients with dementia should be limited to cases where non-pharmacologic measures have failed and patients pose an imminent threat to themselves or others. Identifying and addressing causes of behavior change can make drug treatment unnecessary.

3. **Don't use benzodiazepines or other sedative-hypnotics in older adults as first choice for insomnia, agitation or delirium.** Large-scale studies consistently show that the risk of motor vehicle accidents, falls and hip fractures leading to hospitalization and death can more than double in older adults taking benzodiazepines and other sedative-hypnotics. Older patients, their caregivers and their providers should recognize these potential harms when considering treatment strategies for insomnia, agitation or delirium. Use of benzodiazepines should be reserved for alcohol withdrawal symptoms/delirium tremens or severe generalized anxiety disorder unresponsive to other therapies.

4. **Don't recommend screening for breast, colorectal, prostate of lung cancer without considering life expectancy and the risks of testing, overdiagnosis and overtreatment.** Cancer screening is associated with short-term risks, including complications from testing, overdiagnosis and treatment of tumors that would not have led to symptoms. For prostate cancer, 1,055 older men would need to be screened and 37 would need to be treated to avoid one death in 11 years. For breast and colorectal cancer, 1,000 older adults would need to be screened to prevent one death in 10 years. For lung cancer, much of the evidence for benefit from low dose CT screening for smokers is from healthier, younger patients under age 65. Further, although screening 1,000 persons would avoid four lung cancer deaths in six years, 273 persons would have an abnormal result requiring 36 to get an invasive procedure with eight persons suffering complications.

5. **Avoid using prescription appetite stimulants of high-calorie supplements for treatment of anorexia or cachexia in older adults; instead, optimize social supports, discontinue medications that may interfere with eating, provide appealing food and feeding assistance, and clarify patient goals and expectations.** Unintentional weight loss is a common problem for medically ill or frail elderly. Although high-calorie supplements increase weight in older people, there is no evidence that they affect other important clinical outcomes, such as quality of life, mood, functional status or survival. Use of megestrol acetate results in minimal improvements in appetite and weight gain, no improvement in quality of life or survival, and increased risk of thrombotic events, fluid retention and death. In patients who take megestrol acetate, one in 12 will have an increase in weight and one in 23 will have an adverse event leading to death. The 2012 AGS Beers criteria lists megestrol acetate and cyproheptadine as medications to avoid in older adults. Systematic reviews of cannabinoids, dietary polyunsaturated fatty acids (DHA and EPA), thalidomide and anabolic steroids have not identified adequate evidence for the efficacy and safety of these agents for weight gain. Mirtazapine is likely to cause weight gain or increased appetite when used to treat depression, but there is little evidence to support its use to promote appetite and weight gain in the absence of depression.

From the American Society of Clinical Oncology

http://www.choosingwisely.org/doctor-patient-lists/american-society-of-clinical-oncology/

1. **Don't use cancer-directed therapy for solid tumor patients with the following characteristics: low performance status (3 or 4), no benefit from prior evidence-based interventions, not eligible for a clinical trial, and no strong evidence supporting the clinical value of further anti-cancer treatment.** Studies show that cancer-directed treatments are likely to be ineffective for solid tumor patients who meet the above stated criteria. Exceptions include patients with functional limitations due to other conditions, resulting in a low performance status or those with disease characteristics (e.g., mutations) that suggest a high likelihood of response to therapy. Implementation of this approach should be accompanied with appropriate palliative and supportive care.

For patient-friendly materials regarding this recommendation:

http://consumerhealthchoices.org/wp-content/uploads/2013/02/Choosing-WiselyCancerTreatmentsASCO-ER.pdf and

http://consumerhealthchoices.org/wp-content/uploads/2012/10/ChoosingWiselyCancerASCO.pdf

2. **Don't perform PSA testing for prostate cancer screening in men with no symptoms of the disease when they are expected to live less than 10 years.**

   ■ Since PSA levels in the blood have been linked with prostate cancer, many doctors have used repeated PSA tests in the hope of finding "early" prostate cancer in men with no symptoms of the disease. Unfortunately, PSA is not as useful for screening as many have hoped because many men with prostate cancer do not have high PSA levels, and other conditions that are not cancer (such as benign prostate hyperplasia) can also increase PSA levels.

   ■ Research has shown that men who receive PSA testing are less likely to die specifically from prostate cancer. However when accounting for deaths from all causes, no lives are saved, meaning that men who receive PSA screening have not been shown to live longer than men who do not have PSA screening. Men with medical conditions that limit their life expectancy to less than 10 years are unlikely to benefit from PSA screening as their probability of dying from the underlying medical problem is greater than the chance of dying from asymptomatic prostate cancer.

From the American Society of Nephrology

http://www.choosingwisely.org/doctor-patient-lists/american-society-of-nephrology/

1. **Don't perform routine cancer screening for dialysis patients with limited life expectancies without signs or symptoms.** Due to high mortality among end-stage renal disease (ESRD) patients, routine cancer screening – including mammography, colonoscopy, prostate-specific antigen (PSA) and Pap smears – in dialysis patients with limited life expectancy, such as those who are not transplant candidates, is not cost effective and does not improve survival. False-positive tests can cause harm: unnecessary procedures, overtreatment, misdiagnosis and increased stress. An individualized approach to cancer screening incorporating patients' cancer risk factors, expected survival and transplant status is required.

2. **Don't initiate chronic dialysis without ensuring a shared decision-making process between patients, their families, and their physicians.** The decision to initiate chronic dialysis should be part of an individualized, shared decision-making process between patients, their families, and their physicians. This process includes eliciting individual patient goals and preferences and providing information on prognosis and expected benefits and harms of dialysis within the context of these goals and preferences. Limited observational data suggest that survival may not differ substantially for older adults with a high burden of comorbidity who initiate chronic dialysis versus those managed conservatively.

For patient-friendly materials regarding these recommendations:

http://consumerhealthchoices.org/wp-content/uploads/2012/10/ChoosingWiselyKidneyDiseaseASN.pdf

From the American Society for Radiation Oncology
http://www.choosingwisely.org/clinician-lists/#parentSociety=American_Society_for_Radiation_Oncology

1. **Don't routinely use extended fractionation schemes (>10 fractions) for palliation of bone metastases.**

   • Studies suggest equivalent pain relief following 30 Gy in 10 fractions, 20 Gy in 5 fractions, or a single 8 Gy fraction.

   • A single treatment is more convenient but may be associated with a slightly higher rate of retreatment to the same site.

   • Strong consideration should be given to a single 8 Gy fraction for patients with a limited prognosis or with transportation difficulties.

2. **Don't initiate non-curative radiation therapy without defining the goals of treatment with the patient and considering palliative care referral.**

   • Well-defined goals of therapy are associated with improved quality of life and better understanding on the part of patients and their caregivers.

   • Palliative care can be delivered concurrently with anti-cancer therapies.

   • Early palliative care intervention may improve patient outcomes, including survival.

From the College of Emergency Physicians
http://www.choosingwisely.org/clinician-lists/#parentSociety=American_College_of_Emergency_Physicians

1. **Don't delay engaging available palliative and hospice care services in the emergency department for patients likely to benefit.** Palliative care is medical care that provides comfort and relief of symptoms for patients who have chronic and/or incurable diseases. Hospice care is palliative care for those patients in the final few months of life. Emergency physicians should engage patients who present to the emergency department with chronic or terminal illnesses, and their families, in conversations about palliative care and hospice services. Early referral from the emergency department to hospice and palliative care services can benefit select patients resulting in both improved quality and quantity of life.

From the Critical Care Societies Collaborative-Critical Care
http://www.choosingwisely.org/clinician-lists/#parentSociety=Critical_Care_Societies_
Collaborative_%u2013_Critical_Care

1. **Don't continue life support for patients at high risk for death or severely impaired functional recovery without offering patients and their families the alternative of care focused entirely on comfort.** Patients and their families often value the avoidance of prolonged dependence on life support. However, many of these patients receive aggressive life-sustaining therapies, in part due to clinicians' failures to elicit patients' values and goals, and to provide patient-centered recommendations. Routinely engaging high-risk patients and their surrogate decision makers in discussions about the option of foregoing life-sustaining therapies may promote patients' and families' values, improve the quality of dying and reduce family distress and bereavement. Even among patients pursuing life-sustaining therapy, initiating palliative care simultaneously with ongoing disease-focused therapy may be beneficial.

From the Society of General Internal Medicine

http://www.choosingwisely.org/clinician-lists/#parentSociety=Society_of_General_Internal_Medicine

1. **Don't recommend cancer screening in adults with life expectancy of less than 10 years.** Screening for cancer can be lifesaving in otherwise healthy at-risk patients. While certain screening tests lead to a reduction in cancer-specific mortality, which emerges years after the test is performed, they expose patients to immediate potential harms. Patients with life expectancies of less than 10 years are unlikely to live long enough to derive the distant benefit from screening. Furthermore, these patients are more likely to experience the harms since patients with limited life expectancy are more likely to be frail and more susceptible to complications of testing and treatments. Therefore, the balance of potential benefits and harms does not favor cancer screening in patients with life expectancies of less than 10 years.

2. **Don't place, or leave in place, peripherally inserted central catheters for patient or provider convenience.** Peripherally inserted central catheters (or "PICCs") are commonly used devices in contemporary medical practice that are associated with costly and potentially lethal health care-acquired complications: most commonly central-line associated bloodstream infection and venous thromboembolism. Given the clinical and economic consequences of these complications, placement of PICCs should be limited to acceptable indications (e.g., long-term peripherally compatible infusions, non-peripherally compatible infusions, chemotherapy, palliative care and frequent blood draws). PICCs should be promptly removed when acceptable indications for their use ends.

From the Society of Gynecologic Oncology

http://www.choosingwisely.org/clinician-lists/#parentSociety=Society_of_Gynecologic_Oncology

1. **Don't delay basic level palliative care for women with advanced or relapsed gynecologic cancer, and when appropriate, refer to specialty level palliative medicine.** There is now an evidence-based consensus among physicians who care for cancer patients that palliative care improves symptom burden and quality of life. Palliative care empowers patients and physicians to work together to set appropriate goals for care and outcomes. Palliative care can and should be delivered in parallel with cancer directed therapies in appropriate patients.

From the Society of Hospital Medicine-Adult Hospital Medicine

http://www.choosingwisely.org/clinician-lists/#parentSociety=Society_of_Hospital_Medicine_%u2013_Adult_Hospital_Medicine

1. **Don't place, or leave in place, urinary catheters for incontinence or convenience or monitoring of output for non-critically ill patients (acceptable indications: critical illness, obstruction, hospice, perioperatively for <2 days for urologic procedures; use weights instead to monitor diuresis).** Catheter Associated Urinary Tract Infections (CAUTIs) are the most frequently occurring health care acquired infection (HAI). Use of urinary catheters for incontinence or convenience without proper indication or specified optimal duration of use increases the likelihood of infection and is commonly associated with greater morbidity, mortality and health care costs. Published guidelines suggest that hospitals and long-term care facilities should develop, maintain and promulgate policies and procedures for recommended catheter insertion indications, insertion and maintenance techniques, discontinuation strategies and replacement indications.

From the Society of Hospital Medicine

http://www.choosingwisely.org/doctor-patient-lists/society-of-hospital-medicine-adult-hospital-medicine/

1. **Don't place, or leave in place, urinary catheters for incontinence or convenience or monitoring of output for non-critically ill patients (acceptable indications: critical illness, obstruction, hospice, perioperatively for < 2 days for urologic procedures; use weights instead to monitor diuresis).** Catheter Associated Urinary Tract Infections (CAUTIs) are the most frequently occurring health care-

acquired infection (HAI). Use of urinary catheters for incontinence or convenience without proper indication or specified optimal duration of use increases the likelihood of infection and is commonly associated with greater morbidity, mortality and health care costs. Published guidelines suggest that hospitals and long-term care facilities should develop, maintain and promulgate policies and procedures for recommended catheter insertion indications, insertion and maintenance techniques, discontinuation strategies and replacement indications.

From the AMDA – The Society for Post-Acute and Long-Term Care Medicine™

http://www.choosingwisely.org/clinician-lists/#parentSociety=AMDA_%u2013_The_Society_for_Post-Acute_and_Long-Term_Care_Medicine

1. **Don't insert percutaneous feeding tubes in individuals with advanced dementia. Instead, offer oral assisted feedings.** Strong evidence exists that artificial nutrition does not prolong life or improve quality of life in patients with advanced dementia. Substantial functional decline and recurrent or progressive medical illnesses may indicate that a patient who is not eating is unlikely to obtain any significant or long-term benefit from artificial nutrition. Feeding tubes are often placed after hospital-ization, frequently with concerns for aspirations, and for those who are not eating. Contrary to what many people think, tube feeding does not ensure the patient's comfort or reduce suffering; it may cause fluid overload, diarrhea, abdominal pain, local complications, less human interaction and may increase the risk of aspiration. Assistance with oral feeding is an evidence-based approach to provide nutrition for patients with advanced dementia and feeding problems.

2. **Don't prescribe antipsychotic medications for behavioral and psychological symptoms of dementia (BPSD) in individuals with dementia without an assessment for an underlying cause of the behavior.** Careful differentiation of cause of the symptoms (physical or neurological versus psychiatric, psychological) may help better define appropriate treatment options. The therapeutic goal of the use of antipsychotic medications is to treat patients who present an imminent threat of harm to self or others, or are in extreme distress – not to treat nonspecific agitation or other forms of lesser distress. Treatment of BPSD in association with the likelihood of imminent harm to self or others includes assessing for and identifying and treating underlying causes (including pain; constipation; and environmental factors such as noise, being too cold or warm, etc.), ensuring safety, reducing distress and supporting the patient's functioning. If treatment of other potential causes of the BPSD is unsuccessful, antipsychotic medica-tions can be considered, taking into account their significant risks compared to potential benefits. When an antipsychotic is used for BPSD, it is advisable to obtain informed consent.

3. **Don't routinely prescribe lipid-lowering medications in individuals with a limited life expectancy.** There is no evidence that hypercholesterolemia, or low HDL-C, is an important risk factor for all-cause mortality, coronary heart disease mortality, hospitalization for myocardial infarction or unstable angina in persons older than 70 years. In fact, studies show that elderly patients with the lowest cholesterol have the highest mortality after adjusting other risk factors. In addition, a less favorable risk-benefit ratio may be seen for patients older than 85, where benefits may be more diminished and risks from statin drugs more increased (cognitive impairment, falls, neuropathy and muscle damage).

4. **Don't place an indwelling urinary catheter to manage urinary incontinence.** The most common source of bacteremia in the post-acute and long-term care (PA/LTC) setting is the bladder when an indwelling urinary catheter is in use. The federal Healthcare Infection Control Practices Advisory Committee (HICPAC) recommends minimizing urinary catheter use and duration of use in all patients. Specifically, HICPAC recommends not using a catheter to manage urinary incontinence in the PA/LTC setting. Appropriate indications for indwelling urinary catheter placement include acute retention or outlet obstruction, to assist in healing of deep sacral or perineal wounds in patients with urinary incon-tinence, and to provide comfort at the end of life if needed.

5. **Don't recommend screening for breast, colorectal or prostate cancer if life expectancy is estimated to be less than 10 years.** Many patients residing in the LTC setting are elderly and frail, with multi-morbidity and limited life expectancy. Although research evaluating the impact of screening for breast, colorectal and prostate cancer in older adults in general and LTC residents in particular is scant, available studies suggest that multimorbidity and advancing age significantly alter the risk-benefit ratio. Preventive cancer screenings have both immediate and longer term risks (e.g., procedural and psychological risks, false positives, identification of cancer that may be clinically insignificant, treatment-related morbidity and mortality). Benefits of cancer screening occur only after a lag time of 10 years (colorectal or breast cancer) or more (prostate cancer). Patients with a life expectancy shorter than this lag time are less likely to benefit from screening. Discussing the lag time ("When will it help?") with patients is at least as important as discussing the magnitude of any benefit ("How much will it help?"). Prostate cancer screening by prostate-specific antigen testing is not recommended for asymptomatic patients because of a lack of life-expectancy benefit. One-time screening for colorectal cancer in older adults who have never been screened may be cost-effective; however, it should not be considered after age 85 and for most LTC patients older than 75 the burdens of screening likely outweigh any benefits.

6. **Don't recommend aggressive or hospital-level care for a frail elder without a clear understanding of the individual's goals of care and the possible benefits and burdens.** Hospital-level care has known risks, including delirium, infections, side effects of medications and treatments, disturbance of sleep, and loss of mobility and function. These risks are often more significant for patients in the PA/LTC setting, who are more likely to be frail and to have multimorbidity, functional limitations and dementia. Therefore, for some frail elders, the balance of benefits and harms of hospital-level care may be unfavorable. To avoid unnecessary hospitalizations, care providers should engage in advance care planning by defining goals of care for the patient and discussing the risks and benefits of various interventions, including hospitalization, in the context of prognosis, preferences, indications, and the balance of risks and benefits. Advance directive such as the Physician Orders for Life Sustaining Treatment (POLST) paradigm form and Do Not Hospitalize (DNH) orders communicate a patient's preferences about end-of-life care. Patients with DNH orders are less likely to be hospitalized than those who do not have these directives. Patients who opt for less-aggressive treatment options are less likely to be subjected to unnecessary, unpleasant and invasive interventions and the risks of hospitalization.

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ICSI has long had a policy of transparency in declaring potential conflicting and competing interests of all individuals who participate in the development, revision and approval of ICSI guidelines and protocols.

In 2010, the ICSI Conflict of Interest Review Committee was established by the Board of Directors to review all disclosures and make recommendations to the board when steps should be taken to mitigate potential conflicts of interest, including recommendations regarding removal of work group members. This committee has adopted the Institute of Medicine Conflict of Interest standards as outlined in the report, Clinical Practice Guidelines We Can Trust (2011).

Where there are work group members with identified potential conflicts, these are disclosed and discussed at the initial work group meeting. These members are expected to recuse themselves from related discussions or authorship of related recommendations, as directed by the Conflict of Interest committee or requested by the work group.

The complete ICSI policy regarding Conflicts of Interest is available at http://bit.ly/ICSICOI.

Funding Source

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Programmatic Relationships: None
Financial/Nonfinancial Conflicts of Interest: None

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ICSI seeks review from members and the public during the revision process.

Member Review

All ICSI documents are available for member review at two points in the ICSI revision process. The ICSI Response Report is sent to members at the beginning of a document revision. The goal of this report is to solicit feedback about the guideline, including but not limited to the algorithm, content, recommendations and implementation. Members are also welcome to participate in the public comment period (see below).

The work group would like to thank the following organizations for participating in the Palliative Care for Adults prerevision review:
- *Hudson Physicians*
- *Natalis Counseling & Psychology Solutions*

Public Comment

ICSI makes a draft of the guideline available to the public on the ICSI website. The public is invited to comment in an effort to get feedback prior to its finalization. All comments will be reviewed by the ICSI facilitator and work group members when needed. ICSI work group may or may not make changes to the guideline based on public comment responses.

The work group would like to thank all those who took time to thoughtfully and thoroughly review our draft and submitted comments for the Palliative Care for Adults Health Care Guideline.

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◀ The next revision will be no later than November 2024.

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Document History

The original guideline document was drafted in 2006 by a work group of 14 clinicians. It was approved for release early in 2007. In that year a subgroup of the work group was commissioned to develop an order set for symptom management for patients with a life-limiting, progressive illness. This order set was approved and released in December 2007. It contained numerous symptoms – both physical and psychological. Many options for treatment were described incorporating pharmacological, nonpharmacological and complementary/supportive therapies.

Controlling physical and psychological symptoms for patients with a serious illness is core to palliative care. Therapy should be individualized for each patient's unique circumstances. In 2011 the work group made the decision to discontinue revision of the order set. It recognizes that there is not a single order set that covers all symptoms and possible therapies. The guideline contains some resources that are available to assist the clinician in symptom management.

In 2009, ICSI formed a strategic initiative to integrate palliative care into routine care delivery, recognizing that a palliative care specialty may not be available in all health care settings. This initiative was designed to create a more efficient model for the delivery of pain and symptom management, care coordination and shared decision-making from the moment the patient was diagnosed with a serious illness.

A palliative care model and a communication plan were developed for introducing elements of palliative care at the time a patient was identified with a life-limiting illness. Goals included identifying metrics to evaluate the model and creating a plan to ensure the model's financial sustainability. The design team identified what palliative care might look like in primary care, long-term care, home care and specialty care settings by applying the agreed-upon elements of palliative care. In 2011 the specific work on the initiative was halted. Instead, the elements plus other principles learned through the effort were incorporated into other health care redesign efforts, such as health care home, reducing avoidable readmissions to hospitals, and shared decision-making.

The GRADE system as a method of assessing evidence and writing recommendations was implemented in 2011.

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ICSI Document Development and Revision Process

Overview
Since 1993, the Institute for Clinical Systems Improvement (ICSI) has developed more than 60 evidence-based health care documents that support best practices for the prevention, diagnosis, treatment or management of a given symptom, disease or condition for patients.

Audience and Intended Use
The information contained in this ICSI Health Care Guideline is intended primarily for health professionals and other expert audiences.

This ICSI Health Care Guideline should not be construed as medical advice or medical opinion related to any specific facts or circumstances. Patients and families are urged to consult a health care professional regarding their own situation and any specific medical questions they may have. In addition, they should seek assistance from a health care professional in interpreting this ICSI Health Care Guideline and applying it in their individual case.

This ICSI Health Care Guideline is designed to assist clinicians by providing an analytical framework for the evaluation and treatment of patients, and is not intended either to replace a clinician's judgment or to establish a protocol for all patients with a particular condition.

Document Development and Revision Process
The development process is based on a number of long-proven approaches and is continually being revised based on changing community standards. The ICSI staff, in consultation with the work group and a medical librarian, conduct a literature search to identify systematic reviews, randomized clinical trials, meta-analysis, other guidelines, regulatory statements and other pertinent literature. This literature is evaluated based on the GRADE methodology by work group members. When needed, an outside methodologist is consulted.

The work group uses this information to develop or revise clinical flows and algorithms, write recommendations, and identify gaps in the literature. The work group gives consideration to the importance of many issues as they develop the guideline. These considerations include the systems of care in our community and how resources vary, the balance between benefits and harms of interventions, patient and community values, the autonomy of clinicians and patients and more. All decisions made by the work group are done using a consensus process.

ICSI's medical group members and sponsors review each guideline as part of the revision process. They provide comment on the scientific content, recommendations, implementation strategies and barriers to implementation. This feedback is used by and responded to by the work group as part of their revision work. Final review and approval of the guideline is done by ICSI's Committee on Evidence-Based Practice. This committee is made up of practicing clinicians and nurses, drawn from ICSI member medical groups.

Implementation Recommendations and Measures
These are provided to assist medical groups and others to implement the recommendations in the guidelines. Where possible, implementation strategies are included that have been formally evaluated and tested. Measures are included that may be used for quality improvement as well as for outcome reporting. When available, regulatory or publicly reported measures are included.

Document Revision Cycle
Scientific documents are revised every 12-24 months as indicated by changes in clinical practice and literature. ICSI staff monitors major peer-reviewed journals every month for the guidelines for which they are responsible. Work group members are also asked to provide any pertinent literature through check-ins with the work group midcycle and annually to determine if there have been changes in the evidence significant enough to warrant document revision earlier than scheduled. This process complements the exhaustive literature search that is done on the subject prior to development of the first version of a guideline.

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