Guideline Summary NGC-8961

Guideline Title

Palliative care.

Bibliographic Source(s)

Institute for Clinical Systems Improvement (ICSI). Palliative care. Bloomington (MN): Institute for Clinical Systems Improvement (ICSI); 2011 Nov. 62 p. [85 references]

Guideline Status

This is the current release of the guideline.

This guideline updates a previous version: Institute for Clinical Systems Improvement (ICSI). Palliative care. Bloomington (MN): Institute for Clinical Systems Improvement (ICSI); 2009 Nov. 68 p. [136 references]

Scope

Disease/Condition(s)

Potentially life-limiting, life-threatening, or chronic progressive illnesses that might benefit from palliative care

Guideline Category

Evaluation

Management

Clinical Specialty

Cardiology

Critical Care

Family Practice

Geriatrics

Internal Medicine

Neurology

Oncology

Pulmonary Medicine

Intended Users

Advanced Practice Nurses

Allied Health Personnel

Health Care Providers

Health Plans

Hospitals

Managed Care Organizations

Nurses

Patients

Physician Assistants

Physicians

Psychologists/Non-physician Behavioral Health Clinicians

Social Workers

Guideline Objective(s)

- To increase the identification of patients who are in the early stages of a serious illness who would benefit from palliative care
- To improve the effectiveness and comfort level of the primary care clinicians in communicating the necessity and benefits of palliative care with those patients with a serious illness
- To improve the assessment of the identified patient's palliative care needs utilizing the domains of palliative care
- To increase the percentage of patients in the early stages of a serious illness who have a care plan identified and/or documented
- To improve the ongoing reassessment and adjustment of the patient's plan of care as the condition warrants, utilizing the domains of palliative care
- To increase the completion, documentation and ongoing utilization of advance directives for patients with a serious illness

Target Population

Adult patients with a serious (potentially life-limiting, life-threatening, or chronic, progressive) illness who may benefit from palliative care including patients who still desire curative or life-prolonging treatments and those who are best served by active end-of-life management

Note: This guideline will not assist providers in the identification or care for pediatric patients with life-threatening or chronic progressive illness. See Appendix C, "Pediatrics," in the original guideline for a brief overview of consideration for pediatric patients.

Interventions and Practices Considered

1. Initiation of palliative care discussion
2. Assessment of palliative care needs
3. Management of physical aspects such as 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
4. Management of cultural, psychological and psychiatric, social, spiritual, religious, ethical, and legal aspects of care
5. Development and implementation of palliative care plan and establishment of goals of care through shared decision-making
6. Hospice care
7. Palliative and specialty care referrals and consults as needed
8. Managing imminently dying patients and bereavement process

Major Outcomes Considered

Efficacy of palliative care

Methodology

Methods Used to Collect/Select the Evidence

Searches of Electronic Databases

Description of Methods Used to Collect/Select the Evidence

A literature search of clinical trials, meta-analyses, and systematic reviews is performed.

A consistent and defined process is used for literature search and review for the development and revision of Institute for Clinical Systems Improvement (ICSI) guidelines. Literature search terms for the current revision of this document include palliative care assessments, cultural influence in medical care, depression in serious illness, spiritual influences in medical care, ethics in dying patients, advance care planning, patient and family involvement, care conferences, shared decision-making, early palliative care interventions, advance directives and end-of-life planning from July 2009 through July 2011.

In the Grading of Recommendations Assessment, Development and Evaluation (GRADE) process, evidence is gathered related to a specific question. Systematic reviews are utilized first. Further literature is incorporated including randomized control trials, observational studies, etc. The evidence addresses the same population, intervention, comparisons and outcomes.

Number of Source Documents

Not stated

Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Quality of Evidence and Strength of Recommendations

Category	Quality Definitions	Strong Recommendation	Weak Recommendation
High Quality Evidence	Further research is very unlikely to change the work group's confidence in the estimate of effect.	The work group is confident that the desirable effects of adhering to this recommendation outweigh the undesirable effects. This is a strong recommendation for or against. This applies to most patients.	The work group recognizes that the evidence, though of high quality, shows a balance between estimates of harms and benefits. The best action will depend on local circumstances, patient values or preferences.
Moderate Quality Evidence	Further research is likely to have an important impact on the work group's confidence in the estimate of effect and may change the estimate.	The work group is confident that the benefits outweigh the risks, but recognizes that the evidence has limitations. Further evidence may impact this recommendation. This is a recommendation that likely applies to most patients.	The work group recognizes that there is a balance between harms and benefit, based on moderate quality evidence, or that there is uncertainty about the estimates of the harms and benefits of the proposed intervention that may be affected by new evidence. Alternative approaches will likely be better for some patients under some circumstances.
Low Quality Evidence	Further research is very likely to have an important impact on the work group's confidence in the estimate of effect and is likely to change. The estimate or any estimate of effect is very uncertain.	The work group feels that the evidence consistently indicates the benefit of this action outweighs the harms. This recommendation might change when higher quality evidence becomes available.	The work group recognizes that there is significant uncertainty about the best estimates of benefits and harms.

Supporting Literature

In addition to evidence that is graded and used to formulate recommendations, additional pieces of literature will be used to direct the reader to other topics of interest. This literature is not given an evidence grade and is instead used as a reference for the associated topic and is found in the references section of the original guideline document.

Methods Used to Analyze the Evidence

Systematic Review

Description of the Methods Used to Analyze the Evidence

Not stated

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

Guideline Development Process

A work group consisting of 6 to 12 members that includes physicians, nurses, pharmacists, and other healthcare professionals relevant to the topic, along with an Institute for Clinical Systems Improvement (ICSI) staff facilitator develops each document. Ordinarily, one of the physicians will be the leader. Most work group members are recruited from ICSI member organizations, but if there is expertise not represented by ICSI members, 1 or 2 members may be recruited from medical groups or hospitals outside of ICSI.

The work group will meet for 7 to 8 three-hour meetings to develop the guideline. A literature search and review is performed and the work group members, under the coordination of the ICSI staff facilitator, develop the algorithm and write the annotations and footnotes and literature citations.

Once the final draft copy of the guideline is developed, the guideline goes to the ICSI members for critical review.

Rating Scheme for the Strength of the Recommendations

See the "Rating Scheme for the Strength of the Evidence" field.

Cost Analysis

The guideline developers reviewed published cost analyses.

Method of Guideline Validation

Internal Peer Review

Description of Method of Guideline Validation

Critical Review Process

Every newly developed guideline or a guideline with significant change is sent to the Institute for Clinical Systems Improvement (ICSI) members for Critical Review. The purpose of critical review is to provide an opportunity for the clinicians in the member groups to review the science behind the recommendations and focus on the content of the guideline. Critical review also provides an opportunity for clinicians in each group to come to consensus on feedback

they wish to give the work group and to consider changes necessary across systems in their organization to implement the guideline.

All member organizations are expected to respond to critical review guidelines. Critical review of guidelines is a criterion for continued membership within ICSI.

After the critical review period, the guideline work group reconvenes to review the comments and make changes, as appropriate. The work group prepares a written response to all comments.

Approval

Each guideline, order set, and protocol is approved by the appropriate steering committee. There is one steering committee each for Respiratory, Cardiovascular, Women's Health, and Preventive Services. The Committee for Evidence-based Practice approves guidelines, order sets, and protocols not associated with a particular category. The steering committees review and approve each guideline based on the following:

- Member comments have been addressed reasonably.
- There is consensus among all ICSI member organizations on the content of the document.
- Within the knowledge of the reviewer, the scientific recommendations within the document are current.
- When evidence for a particular recommendation in the guideline has not been well established, the work group identifies consensus statements that were developed based on community standard of practice and work group expert opinion.
- Either a critical review has been carried out, or to the extent of the knowledge of the reviewer, the changes proposed are sufficiently familiar and sufficiently agreed upon by the users that a new round of critical review is not needed.

Once the guideline, order set, or protocol has been approved, it is posted on the ICSI Web site and released to members for use. Guidelines, order sets, and protocols are reviewed regularly and revised, if warranted.

Revision Process of Existing Guidelines

ICSI scientific documents are revised every 12 to 36 months as indicated by changes in clinical practice and literature. Every 6 months, ICSI checks with the work group to determine if there have been changes in the literature significant enough to cause the document to be revised earlier than scheduled.

Prior to the work group convening to revise the document, ICSI members are asked to review the document and submit comments. During revision, a literature search of clinical trials, meta-analyses, and systematic reviews is performed and reviewed by the work group. The work group will meet for 1 to 2 three-hour meetings to review the literature, respond to member organization comments, and revise the document as appropriate.

If there are changes or additions to the document that would be unfamiliar or unacceptable to member organizations, it is sent to members to review prior to going to the appropriate steering committee for approval.

Recommendations

Major Recommendations

Note from the National Guideline Clearinghouse (NGC) and the Institute for Clinical Systems Improvement (ICSI): For a description of what has changed since the previous version of this guidance, refer to Summary of Changes Report -- November 2011. In addition, in 2011 ICSI began its transition to the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system as a method of assessing the quality of evidence and writing recommendations.

The recommendations for palliative care are presented in the form of a table with a list of evidence-based recommendations and an algorithm with 19 components, accompanied by detailed annotations. The table and algorithm are provided in the original guideline document at the ICSI Web site for Palliative Care. Clinical highlights and selected annotations (numbered to correspond with the algorithm) follow.

Quality of evidence (Low Quality, Moderate Quality, and High Quality) and strength of recommendation (Weak or Strong) definitions are provided at the end of the "Major Recommendations" field.

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 #3, 4 to 9; Aims #3, 6)*
- 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 non-physical 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 to 9; Aim #3)*
- 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, 3, 10; Aim #2)*
- Palliative care is compatible with all other medical treatments. *(See the Introduction section in the original guideline document.)*

- Health care providers play an important role in the grief and bereavement processes by supporting the patient and family throughout the course of illness and following the patient's death. *(Annotation #19)*

Palliative Care Algorithm Annotations

1. **Patient Presents with New or Established Diagnosis of a Serious Illness and/or Is Actively Dying**

Recommendations:

- Palliative care should begin at the time of diagnosis of a serious condition and continue through cure, or until death and then into the family's bereavement period (*low quality evidence, strong recommendation*).
- Clinicians should recognize patients with signs of imminent death or those patients who are receiving non-beneficial or low-yield therapy (*low quality evidence, strong recommendation*).
- Clinicians should discuss the likelihood of disease progression to death with patients and/or their families (*low quality evidence, strong recommendation*).

General considerations clinicians should use to identify patients who would benefit from palliative care planning include:

- Disease progression, especially with functional decline
- Pain and/or other symptoms not responding to optimal medical treatment
- Need for advance care planning

Conditions that may prompt the initiation of palliative care discussions include debility/failure to thrive, cancer, heart disease, pulmonary disease, dementia, liver disease, renal disease, and neurologic diseases such as stroke, Parkinson's, amyotrophic lateral sclerosis (ALS), and multiple sclerosis (MS). For more information on these conditions refer to the original guideline document.

Many residents in long-term care facilities and patients with poor social support have these symptoms and should be assessed for palliative care.

The work group offers a comparison of conditions and symptoms appropriate for palliative care and hospice. See Appendix D in the original guideline document.

Unfortunately, accurately predicting death can only be identified by retrospective measures. Multiple studies have shown that physicians overestimate prognosis by a factor of two or more. The medical literature also shows that patients with terminal illness often don't recognize that they are dying, or are unable to acknowledge the fact even to themselves until very late. Life-limiting illness is usually defined as the question "*Would you be surprised if your patient died within the next two years?*" This definition significantly broadens the identified population associated with hospice care to those who would benefit from palliative care. Appropriate medical interventions need to address suffering that occurs due to pain, and other physical symptoms, and psychological issues. Other domains that should be addressed by an interdisciplinary team include cultural, spiritual, ethical, legal, and social issues. The care plan created includes the caregivers and family. Palliative care can occur simultaneously with curative therapies, or may be the sole focus of care.

Actively Dying Patient

Diagnosing dying is a complex process. Physicians are frequently inaccurate about the length of time left to a patient before he/she dies. Each individual patient is different. Physicians are trained to cure patients and will often continue aggressive, invasive procedures and treatments at the expense of making the patient comfortable. There is often a reluctance to make the diagnosis of dying if any hope of improvement exists and even more so if no definite diagnosis has been made. When recovery is uncertain, it is better to discuss this rather than giving false hope to the patient and family.

This portion of the guideline is meant to aid providers in identifying those patients actively dying or those to whom aggressive therapy is no longer the best option. These patients may not have been previously identified as palliative care patients. Also see Annotation #10, "Develop or Revise Palliative Care Plan Including Care of the Actively Dying Patient and Establish Goals of Care through the Process of Shared Decision-Making," for care of the dying patient.

The following signs and symptoms may indicate that death is approaching. Not all individuals will show all of these signs.

- 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 persons 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 to 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 and 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

2. **Initiate Palliative Care Discussion**

Recommendations:

- Clinicians should initiate or facilitate advance care planning for all adult patients and their families with regular review as the patient's condition changes (*low quality evidence, strong recommendation*).
- Palliative care discussion or referral should be considered whenever a patient develops a serious illness (*low quality evidence, strong recommendation*).

A recent consensus panel convened by the Center to Advance Palliative Care developed primary and secondary criteria for two checklists – one upon admission and one for daily rounds – to be used to screen patient for unmet palliative care needs (see the original guideline document). The hope is that a checklist approach combined with educational initiatives and other system-change work will allow hospital staff and clinicians engaged in day-to-day patient care to identify and begin to address palliative care needs themselves while reserving specialty palliative care services for more complex problems.

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.

There are several excellent mnemonics available to help providers 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)

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 given 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 understand, 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 providers 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 provider 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.

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. 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 and 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 care provider 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.

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 wanted 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.)."

See Appendix A, "Myths about Palliative Care," in the original guideline document.

Refer to the original guideline document for additional considerations pertaining to palliative care discussion.

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

Recommendations:

- Clinicians should use a validated assessment tool to assess palliative care needs (*low quality evidence, strong recommendation*).
- Care conferences with the patient, family and an interdisciplinary team are recommended on an ongoing basis to discuss patient's condition, course of illness, treatment options, goals and plan of care (*low quality evidence, strong recommendation*).

Perform a thorough assessment based on the domains of palliative care and address needs, values and resources of the patient and family.

It is important, especially in the development of recommendations for care of patients' palliative care and end-of-life needs, that there is recognition of patient autonomy in choosing care. One goal of this annotation is to discuss how clinicians can create an environment in which the needs of the patient, based on a comprehensive assessment, are fully considered. Only then can a reasonable determination be made of what services are required to meet the physical, psychological, social, cultural, legal/ethical, and spiritual needs of patients and their families. Clinicians recognize that assessment of these domains of care is important to a patient's care but, in a busy practice, may find it difficult to address all domains. The work group recognizes this and suggests that clinicians could incorporate key aspects of palliative assessment with existing assessment processes. They also encourage using a team approach. Routine assessment has been shown to identify symptoms that may otherwise have been overlooked or unreported, facilitate treatment and treatment planning, and enhance patient and family satisfaction.

For patients to make informed choices regarding palliative care, it is important for both patient and providers 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 providers 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 necessarily be ongoing and may require at some point, 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. The role of a surrogate for assessment of patient condition and expression of patient wishes should be anticipated at the time of initial assessment and care planning. Bringing together, as much as possible, those who may impact decision-making should be 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. See the original guideline document for specific information on how to utilize this model.

Patient and family expectations, goals for care and for living (quality of life), understanding of the disease and prognosis, as well as preferences for the type and site 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. Also see Annotation #10, "Develop or Revise Palliative Care Plan Including Care of the Actively Dying Patient and Establish Goals of Care Through the Process of Shared Decision-Making."

Among the available assessment tools, it was the decision of this work group to recommend the Edmonton Symptom Assessment System (ESAS) because it is thorough yet simple in clinical application, and it has a robust evidence-based foundation for validation in various clinical settings and is readily available via the Internet.

As patient and clinician conditions change, there may be need for change of site 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, communitywide agreement on recognition of particular advance directive forms and Physician/Provider Orders for Life-Sustaining Therapy (POLST) enhances the quality of care available. See Annotation #9, "Ethical and Legal Aspects of Care."

See the Quality Improvement Support Resources Table section in the original guideline document for the POLST and ESAS Web sites.

Documentation of the goals of care, patient preferences, and advance directive in an electronic medical record promotes accessibility and portability across care settings.

Clinicians should be aware of their individual state, provincial or national forms and requirements.

Care Conferences

Patient and family meetings or care conferences allow the treatment team 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 provider and part of the care team or the entire team.

Most guidelines for care conferencing are based on expert recommendations. Family counseling literature and studies of giving bad news and end-of-life discussions form the basis for these expert recommendations.

A step-by-step model for care conferences outlines four goals for a family meeting or conference. These goals focus on:

- Gaining knowledge of the person experiencing 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
- Establishing trust and support to work with the patient/family throughout the course of illness

Incorporating time for this assessment can be done in either the inpatient, outpatient or home settings. In the inpatient setting, this assessment may be done by the palliative care team or by the physician during daily rounds. In the outpatient setting, this assessment can be accomplished over a series of visits or during an extended visit. In the home setting, this can be accomplished in one or more home visits.

See Appendix C, "Pediatrics," in the original guideline document for special considerations for pediatric patients.

4. **Physical Aspects of Care**

Recommendation:

- The physical aspects of the patient's serious illness should be an integral component of the palliative care plan (*low quality evidence, strong recommendation*).

The control of physical symptoms is an important part of palliative care. 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.

Each patient should be frequently evaluated for these issues. Therapy should be individualized for each patient's unique circumstances.

The work group recognizes that there is not a single order set that covers all patient situations. Multiple sources are available to assist in symptom management. Some possible resources include but are not limited to:

Pal-Med Connect: http://www.palmedconnect.org; 1-877-PAL-MED4, 1-877-725-6334

http://www.hospicecare.com/resources/emedicine.htm

http://www.stoppain.org/palliative_care/content/symptom/pain.asp

Fast Facts: http://www.EPERC.mcw.edu/EPERC/FastFactsandConcepts

Pain

Control of pain in order to improve quality of life is an important aspect of palliative care. However, the approach toward pain management in palliative care is different from those of chronic pain and acute pain management. While cures of underlying disease may still be possible, they may no longer be the primary goal, because of life-limiting illness. Disease progression may necessitate increased dosing of opioids to control pain; this should not be confused with "tolerance." In fact, when a patient with previously well-controlled pain develops the need for increasing opioid doses to achieve comfort, advancing illness is almost always the cause.

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.

Opioid rotation, especially for patients with cancer, should be considered when opioid side effects are difficult to manage or if inadequate analgesia is present. If symptoms of delirium and confusion are present and are attributable to opioids, a switch to a different opioid may be advisable.

5. **Cultural Aspects of Care**

Recommendations:

- A cultural assessment should be an integral component of the palliative care plan (*low quality evidence, strong recommendation*).
- The clinician should utilize professional medical interpreters whenever possible (*low quality evidence, strong*

recommendation)

Patient and family reactions to serious illness and decisions about end-of-life care are influenced by cultural factors. Cultural assessment should be an integral component of the palliative care plan. The assessment should include:

- Locus of decision-making
- Preferences regarding disclosure of information
- Truth telling and decision-making
- Dietary preferences
- Language, family communication
- Perspectives on death, suffering and grieving
- Physical care of the deceased, funeral and burial rituals

Specific cultural assessment promotes patient/family-centered decision-making and offers the opportunity to identify care preferences.

With this in mind, clinicians should respect the important role culture plays in shaping the way people make meaning of illness, suffering, and dying and in guiding decisions people make about health care. Clinicians should avoid stereotyping and the assumption that they know what any one individual thinks or does because they assume they know what people of that group tend to think. There is, in fact, wide variation in beliefs, attitudes and behaviors within every cultural group.

Several key clinical recommendations that providers should consider have been identified:

- Many ethnic groups prefer not to be directly informed of a life-threatening diagnosis.
- In cultural groups in which patients are not directly informed about a serious prognosis, family members may want the clinician to discuss the patient's condition with family members only.
- When considering therapeutic options, clinicians should consider that members of many cultural groups prefer that family members, rather than patients, make treatment decisions.
- Direct discussions of advance directives and therapeutic support levels may be undesirable in situations in which they are viewed as potentially harmful to a patient's well-being.

Whenever possible the clinician should utilize professional medical interpreters. If medical interpreters are not available, the clinician may need to use bilingual health care workers or family members. This, however, is less desirable due to misinterpretation of medical phrases, censorship of sensitive or taboo topics, and the tendency to filter or summarize discussions rather than translate them directly. See the original guideline document for specific suggestions to clinicians utilizing interpreters.

A learning module on cultural and spiritual sensitivity and a quick guide to cultural and religious traditions can be found at this Web address: http://www.professionalchaplains.org/uploadedFiles/pdf/learning-cultural-sensitivity.pdf.

The University of Washington's "Culture Clues" tip sheets contain information for clinicians about the needs and preferences of patients from diverse cultures: http://depts.washington.edu/pfes/CultureClues.htm.

National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS Standards), 2001 are directed at health care organizations and individual clinicians to make their practices more culturally and linguistically accessible. This includes sign language: http://minorityhealth.hhs.gov/templates/ browse.aspx?lvl=2&lvlID=15.

6. **Psychological and Psychiatric Aspects of Care**

Recommendation:

- A psychological assessment should be an integral component of the palliative care plan (*low quality evidence, strong recommendation*).

Routine ongoing assessment of a patient's psychological status is critical to provide quality palliative care.

Pain and other physical symptoms are commonly the initial focus of treatment. Psychosocial issues are more difficult to evaluate and address if the patient has distressing or poorly controlled physical symptoms.

Patients come to advanced illness with issues of worry, insomnia, panic, anxiety, nervousness, paranoia and lack of energy. 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. Use of standardized assessments to diagnose (e.g., Patient Health Questionnaire [PHQ-9]) may be helpful; however, no screening tool for depression has been validated for palliative care. Questions like "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?" or "Do you feel your situation is hopeless?" are good questions. Refer to the NGC summary of the ICSI guideline Major Depression in Adults in Primary Care for more information about depression and the depression assessment tool (PHQ-9).

Anxiety can contribute to suffering and decreased quality of life. The anxiety may be due to medications, social, psychological or unidentifiable reasons, fears or pain. Anxiety may result in insomnia, gastrointestinal upset, dysphagia, fatigue, palpitations, diaphoresis, fear and isolation, and may escalate as disease progresses. Patients with a history of panic disorder, phobia, obsessive-compulsive disorder or other anxiety disorders will have an increased risk of symptoms of anxiety. Causes of anxiety should be identified and treated if possible. Physical and emotional issues should be addressed. Social and spiritual resources should be utilized. Frank discussions of fears may help alleviate anxiety.

It is important to differentiate grief from depression. Grieving can be an appropriate response to loss, but persistence of the symptoms mandates consideration of depression. Simply asking a patient, "Are you depressed?" can be a useful screening tool and provides a reasonably sensitive and specific assessment of depression in

patients with terminal illnesses. This may be preceded by educating the patient about the difference between clinical depression and appropriate reactive feelings to the situation.

The clinicians must inquire if the patient is at risk for suicide. There is no evidence that asking the patient about suicide increases the risk that the patient will carry out his or her plan.

More information can be found in the following Fast Facts at the Web site www.eperc.mcw.edu. #07 Depression in Advanced Cancer, #59 Dealing with the Angry Dying Patient, #145 Panic Disorders at the End of Life, and #186 Anxiety in Palliative Care-Causes and Diagnosis provide up-to-date easy to access references for psychological aspects of palliative care.

7. **Social Aspects of Care**

Recommendation:

- A social assessment should be an integral component of the palliative care plan (*low quality evidence, strong recommendation*).

The comprehensive assessment should include family structure and geographic location; relationships and family dynamics; lines of communication and need for counseling for self and family; existing social and cultural network; perceived social support; medical decision-making/advance directives and quality of life; work and school settings; finances including filing for disability and ability to pay for medications and treatments; sexuality; intimacy; living arrangements; caregiver availability; access to transportation, medications, needed equipment and nutrition; community resources; and legal issues.

The impact of a chronic progressive disabling disease extends beyond the patient to the "family," defined in its broadest sense. Children, spouses, parents, co-workers, friends, neighbors, employers and even health care providers are all affected by an individual patient's condition. Financial concerns, caregiver coping, communication with family and friends and discussion/decision-making on advance treatment plans all fall under the domain of social aspects of care. Lack of knowledge about the social aspects of care influencing the patient can frustrate clinicians regarding decisions or lack thereof that the patient makes. Poor communication among patient, family and clinicians undermines effective decision-making.

The interdisciplinary team of professionals including social workers should have patient-population specific skills in assessment and development of a social care plan. Often the social worker is involved in coordinating this conference and its attendees. In situations where loved ones are making decisions regarding withdrawal of life support for patients, there are reports that suggest that family members feel more satisfied and supported in the decision-making process where there is a family conference exploring patient's wishes, clinicians' recommendations for withdrawing life support, and assessment of the spiritual care needs of family members. Further information and documents of support can be found at http://www.capc.org/. Also see Annotation #3, "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, 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. 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.

8. **Spiritual Aspects of Care**

Recommendations:

- A spiritual assessment should be an integral part of the palliative care plan (*low quality evidence, strong recommendation*).
- Clinicians should utilize clinically trained chaplains as members of the interdisciplinary health care team to provide patient-centered spiritual care and support (*low quality evidence, strong recommendation*).

Illness and the prospect of dying can impact the meaning and purpose of a person's life. Thus, illness and dying have a spiritual dimension and are often perceived by patients as spiritual experiences. As people face serious illness or 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?

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, assessment of hopes and fears, meaning, purpose, beliefs about afterlife, guilt, forgiveness, legacy, and life completion tasks.

It is important for clinicians to attend to patients' spirituality, especially any spiritual concerns, questions or distress. Attending to a patient's spirituality can deepen the relationship between patient and clinician and build trust.

All palliative care patients should receive a simple spiritual screening on admission. 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?'' 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.

Clinicians can attend to a patient's spiritual needs and concerns in the following ways:

- Offer compassionate presence—strive to be present with and attentive to patients. Relate to patients not only as a professional expert but also as a fellow human being.
- Listen to the patient's fears, hopes, pain and concerns—listening is a powerful healing tool.
- Asking about hope and peace can be a simple, brief, yet effective way to assess spiritual concerns.

Utilize clinically trained chaplains as members of the interdisciplinary health care team – chaplains are experts in spiritual care. They offer interfaith support to all who are in need and have specialized education to mobilize spiritual resources to help patients cope more effectively. Working with and making referrals to these spiritual care providers are important aspects of holistic care.

Clinicians should always be respectful of a patient's spiritual beliefs, should keep spiritual discussions patient centered, and should never proselytize or impose beliefs onto a patient.

There are a number of spiritual assessment tools created for use by clinicians in the clinical setting. See the original guideline document for examples of some of these tools.

9. **Ethical and Legal Aspects of Care**

Recommendations:

- An advance care plan that includes the designation of a health care agent and completion of a health care directive with the preferences and goals of the patient and family should be created and used (*low quality evidence, strong 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 (*low quality evidence, strong recommendation*).

The patient's goals, preferences and choices should form the basis for the plan of care. They should be respected within the limits of applicable state and federal laws. Informed consent for any treatment or plan of care requires a patient with decision-making capacity or an appropriate surrogate decision-maker. Informed consent is based on the principle that patients should be allowed to make decisions for themselves. When a patient lacks this ability, a surrogate is needed.

Note: **Competency** is a legal term referring to a decision made by a judge, although a physician's opinion carries a large amount of weight in a competency hearing. In contrast, **decision-making capacity** (a.k.a., decisional) refers to a clinician's determination, based on clinical examination, that a patient is able to make medical decisions relative to the discussion for themselves. 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
- Communicate a treatment preference (i.e., the comatose patient by definition is not decisional)

Refer to the original guideline document for more information on "decision-making capacity" and "non-beneficial/low-yield therapy."

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 non-beneficial/low-yield therapy and professional responsibilities in one's practice area.

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.

Advance Care Planning

While the process of advance care planning often results in the completion of a written health care directive, the main focus of advance care planning is on the discussion between the patient and health care agent regarding the patient's wishes. Written advance directives are legal in every state; however, laws and forms vary state to state. See the Resources Table in the original guideline document for additional information regarding advance directives. It is important to remember that travelers should be aware of differing laws in whichever state they plan to travel, and bring a copy of their document with them so that they may present their health care directive to a facility where they intend to receive medical care.

Legal advance directive consists of:

- Designation of a **health care agent** (a.k.a., durable power of attorney for health care, health care agent, 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.

- Writing a formal **health care directive**—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 sufficient health care directive. A health care directive goes into effect only when the patient becomes unable to communicate his/her preferences.

There are programs designed to support and spread the use of advanced care planning. See Resources Table in the original guideline document for more information.

The POLST (Physician/Provider Order for Life-Sustaining Treatment) is designed as a communication tool to translate the patient's advance care plan into clinician orders that clinicians (including emergency medical technicians [EMTs], emergency room [ER] staff and hospitalists) can follow in emergencies and review with patients and families at transitions of care. It is becoming more widespread in its acceptance in many parts of the country. POLST was developed as advance care planning document, to be completed by health care professionals, together with a patient or surrogate decision-maker. The actual form should consist of these sections:

- Resuscitation decision
- Medical intervention decisions
- Antibiotics
- Medically administered nutrition
- Signatures from the clinician, and if possible, the patient/surrogate

The major advantages of the POLST form over standard advance directives is that, when adopted as the community standard, the information is clear, unambiguous, flexible, portable, available across all sites of care, and more likely to be honored by all clinicians when needed (http://www.ohsu.edu/polst/).

A similar form is called Medical Orders for Life Sustaining Treatment (MOLST). Like POLST, it is an order sheet based on the patient's current medical condition and wishes. It is intended to summarize any advance directive. Both forms are based on communication between the patient and surrogate (the health care agent or other legally designated decision-maker) and health care clinicians. It facilitates informed medical decision-making by communicating an individual's wishes regarding care across health care settings.

Barriers to Completing Advance Directives

- Many clinicians believe it is not appropriate to begin advance directive planning on an outpatient basis. In reality, multiple studies have shown that **patients want their clinicians to discuss advance care planning** with them **before** they become ill. Many others have shown a positive response from patients when advance directive discussions are held during outpatient visits.

  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?" If you are afraid the patient may respond negatively, perhaps saying to you, "Is there something wrong with me? Am I sicker than you are letting on?" respond by saying, "I ask all of my patients this question, sick or well." The Patient Self-Determination Act of 1991 mandates that every person be asked about advance directives when first seen (inpatient and outpatient).

- 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 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 patient 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 a person names a proxy in an advance directive he/she loses control of his/her own care.

  Overcoming this barrier: When explaining advance directives to your patients, make sure he/she understands that as long as he/she retains decision-making capacity, he/she retains control of his/her medical destiny. Advance directives become active only when a person cannot speak for himself or herself.

- 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 Terry Schiavo case (a young person who had a tragic accident and left in a vegetative state with no directives) as a trigger to enlighten the discussion. Ask "What would you want if you were in a similar situation?"

10. **Develop or Revise Palliative Care Plan Including Care of the Actively Dying Patient and Establish Goals of Care Through the Process of Shared Decision-Making**

(See Appendix B in the original guideline document for the ICSI Shared Decision-Making Model.)

Recommendations:

- Clinicians should discuss the likelihood of disease progression to death with patients and/or their families (*low quality evidence, strong recommendation*).
- Ongoing communication with the patient and/or family regarding the dying process and the treatment plan is recommended (*low quality evidence, strong recommendation*).

Use "shared decision-making" when developing or revising the plan or care. This promotes collaboration between the clinician and patient in making treatment decisions, where the clinician shares information and knowledge about the treatment options and the patient uses his/her values to weigh the risks and benefits of the different care options. Note that this does not preclude the clinician making a strong treatment recommendation based on clinical knowledge and experience. However, level of interest in medical information tends to be stronger with younger age and increased educational attainment; older patients may prefer less information and want to rely

more on the clinician's expertise alone. More acutely ill patients may have limited ability to successfully weigh risks and benefits of the different options and thus may rely more on family members or on the clinician's recommendation. This underscores the need to individualize care option discussions to patient preferences and illness status. Discussions on treatment preferences should be periodically revisited to account for changes in patient preferences and course of illness, especially given that treatment strategies at one stage of the illness may be inappropriate for another stage. Also see Annotation #3, "Assess Patient's Palliative Care Needs Based on the Following Domains of Palliative Care."

Although patients and family members should have a say in treatment options, the clinician should make a clear recommendation based on his/her expertise and experience. It is important that the patient does not feel rushed into deciding between treatment options, as he/she may need to digest the initial bad news first.

Care of the Actively Dying Patient

Care of the actively dying patient is an intense interval for the patient, family and the health care team. Initiating discussion with the patient and family is the first step in establishing the individual plan of care for the actively dying patient. This allows for clarification of prognosis, identification of end-of-life goals and identification of care preferences.

The patient's transition to the dying phase should be consistently communicated by all members of the health care team. Mixed messages should be avoided as they can lead to loss of trust, miscommunication and poor care management. The National Consensus Project Clinical Practice Guidelines and the National Comprehensive Cancer Network Advance Care and Palliative Care Treatment Guidelines for Patients endorse open communication with the patient, family and care team regarding the dying phase and plan of care.

Care of the actively dying patient requires an intensive plan of care. Essential to this plan is recognition of the dying patient. Recognizing the dying patient requires a set of clinical skills. There are key signs and symptoms that indicate that death will occur in hours to days. Patients and family members need clear information about the physical and psychological aspects of the dying process. Diagnosing dying is complex and at times uncertain. Agreement between care team members that the patient is dying, and communicating this to the patient and family, improve satisfaction and fosters trust.

Establishing a treatment plan takes into account individual and family goals and preferences. Despite barriers, it is important to have this treatment plan available at the point of care, regardless of the site of care (inpatient, long-term care, home care, assisted living, emergency department [ED], etc.).

The treatment plan should include education for the patient and family. This education should include the signs and symptoms of imminent death. Attention to developmental, cultural and religious needs is critical. 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?")

The comprehensive treatment plan must be medically sound and concordant with the patient's wishes and values. Attention to adequate symptom management allays fears and allows comfort during the dying process. The treatment plan includes physical, psychological, social and spiritual care. Ongoing communication remains key. There are several example order sets and nursing care plans on the Center to Advance Palliative Care (CAPC) Web site:

http://www.capc.org/tools-for-palliative-care-programs/clinical-tools/

Also see Annotation #4, "Physical Aspects of Care."

11. **Does Patient Meet Hospice Criteria?**

Hospice care, now available in most communities in the United States, offers palliative medical care from a multidisciplinary team and serves patients and families as a unit with emotional, social and spiritual support.

Medicare patients certified by their physician as terminally ill with a life expectancy of six months or less may elect to receive hospice care. Most private insurances now have hospice benefits, although coverage may vary.

Discharge from hospice occurs if prognosis improves or if the patient wishes to seek curative treatment.

A patient may be readmitted at any time, as long as the criteria for hospice are met.

See Appendix D, "Comparison Between Palliative Care and Hospice," in the original guideline document for a table outlying symptoms and conditions relative to palliative and hospice care settings. See Appendix E, "Medicare Hospice Benefit: Eligibility and Treatment Plan," in the original guideline document.

13. **Hospice Care Team Coordinates Palliative Care Plan with Primary Provider**

Although the palliative care model encompasses hospice care (see diagram in the Introduction section of the original guideline document), it is beyond the scope of this guideline to include all aspects of care once the patient is admitted to hospice. See Appendix D, "Comparison Between Palliative Care and Hospice," in the original guideline for a table outlying symptoms and conditions relative to palliative and hospice care settings. See also Appendix E, "Medicare Hospice Benefit: Eligibility and Treatment Plan," in the original guideline document.

17. **Remission or Resolution of Disease?**

While palliative care is delivered across care settings and throughout the full course of illness, a patient may no longer require focused palliative care when:

- There is a remission of symptoms and the illness is no longer progressing
- The disease process is resolved (cured)
- Death occurs

If symptoms recur or the patient's condition deteriorates, a new evaluation of the patient's palliative care needs should be done.

19. **Death and Bereavement**

Grief is the normal, expected emotional suffering caused by a significant loss, such as the death of a loved one, that includes both physiologic and psychological reactions. Grief can be anticipatory, such as that experienced by the patient or a loved one prior to the expected death of the patient. Grief can also be complicated, leading to maladaptive behaviors associated with a distorted or prolonged grief period. Grief following a death is called bereavement. However, bereavement interventions can begin prior to and in anticipation of the actual loss.

Clinicians play an important role in facilitating healthy grief and bereavement processes. Honesty at the end of life is essential. By avoiding mixed messages, patients may review their lives and assist loved ones in future plans. At this time it may be possible to identify bereavement needs of patients and their loved ones. By assessing the grief response prior to death, it is possible to identify risk of complicated grieving and provide early intervention.

Following the death of the patient, it is essential to allow the patient's loved ones to perform any customs or rituals that are important to them, within the policy guidelines of the facility. Failure to do so may lead to complicated grieving. 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. Clinicians may wish to offer emotional support by sending a card expressing their condolences. Providers 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.

Several models defining grief are available, yet it is important to note that progress through grief is not predictable. Movement through grief varies from person to person, and the bereaved may vacillate between stages, or elements of stages may appear concurrently. **Grief is not on a linear continuum and does not follow a specific time frame**. In complicated grieving, the person may fail to progress through grief or may be "stuck" in one stage of the grief process.

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
- Culpable deaths
- Inability to carry out valued religious rituals
- 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)

Others who are vulnerable to complicated grief include children, confused elders and those with learning disabilities. Many resources are available for children, including storybooks, workbooks and a regional camp for grieving children. For confused elders or survivors with learning disabilities, repeated explanations and participation in important events, such as the funeral, may decrease the repetitious questions about the deceased.

In order to provide support through the first anniversary of the death, it is suggested that the length of follow-up with the bereaved is a minimum of thirteen months. Although it is not realistic for clinicians to personally provide bereavement services for the grieving loved ones of a patient, it is imperative that each clinician be aware of the needs of the bereaved, potential risk factors for complicated grieving and the services available within their area so that appropriate referrals can be made to promote healthy grieving. Possible community services include pastoral care, support groups, counseling services, grief groups, bereavement follow-up programs and communities of faith. A referral to social services or contacting a local hospice program may be appropriate for assistance in bereavement interventions.

Definitions:

Quality of Evidence and Strength of Recommendations

Category	Quality Definitions	Strong Recommendation	Weak Recommendation
High Quality Evidence	Further research is very unlikely to change the work group's confidence in the estimate of effect.	The work group is confident that the desirable effects of adhering to this recommendation outweigh the undesirable effects. This is a strong recommendation for or against. This applies to most patients.	The work group recognizes that the evidence, though of high quality, shows a balance between estimates of harms and benefits. The best action will depend on local circumstances, patient values or preferences.
Moderate Quality Evidence	Further research is likely to have an important impact on the work group's confidence in the estimate of effect and may change the estimate.	The work group is confident that the benefits outweigh the risks, but recognizes that the evidence has limitations. Further evidence may impact this recommendation. This is a recommendation that likely applies to most patients.	The work group recognizes that there is a balance between harms and benefit, based on moderate quality evidence, or that there is uncertainty about the estimates of the harms and benefits of the proposed intervention that may be affected by new evidence. Alternative approaches will likely be better for some patients under some circumstances.
Low Quality Evidence	Further research is very likely to have an important impact on the work group's confidence in the estimate of effect and is likely to change. The estimate or any estimate of effect is very	The work group feels that the evidence consistently indicates the benefit of this action outweighs the harms. This recommendation might change when higher quality evidence becomes available.	The work group recognizes that there is significant uncertainty about the best estimates of benefits and harms.

	uncertain.		

Supporting Literature

In addition to evidence that is graded and used to formulate recommendations, additional pieces of literature will be used to direct the reader to other topics of interest. This literature is not given an evidence grade and is instead used as a reference for the associated topic and is found in the references section of the original guideline document.

Clinical Algorithm(s)

A detailed and annotated clinical algorithm for palliative care in adults is provided in the original guideline document.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of supporting evidence is identified and graded for selected recommendations (see the "Major Recommendations" field).

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

Improved palliative care resulting in facilitating appropriate discussions with patients and family; improved symptom control and quality of life; improved utilization of resources; and improved satisfaction of patients, families, and clinicians

Potential Harms

- Advance directives can be a trigger for disengagement by the medical staff.
- Opioid rotation, especially for patients with cancer, should be considered when opioid side effects are difficult to manage or if inadequate analgesia is present. If symptoms of delirium and confusion are present and are attributable to opioids, a switch to a different opioid may be advisable.

Qualifying Statements

Qualifying Statements

- This clinical 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. A guideline will rarely establish the only approach to a problem.
- This clinical guideline should not be construed as medical advice or medical opinion related to any specific facts or circumstances. Patients are urged to consult a health care professional regarding their own situation and any specific medical questions they may have.

Implementation of the Guideline

Description of Implementation Strategy

Once a guideline is approved for general implementation, a medical group can choose to concentrate on the implementation of that guideline. When four or more groups choose the same guideline to implement and they wish to collaborate with others, they may form a guideline action group.

In the action group, each medical group sets specific goals they plan to achieve in improving patient care based on the particular guideline(s). Each medical group shares its experiences and supporting measurement results within the action group. This sharing facilitates a collaborative learning environment. Action group learnings are also documented and shared with interested medical groups within the collaborative.

Currently, action groups may focus on one guideline or a set of guidelines such as hypertension, lipid treatment, and tobacco cessation.

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.

1. 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.
2. Develop a process that will allow providers to identify and assess patients who would benefit from palliative care services. This process should include the use of a screening tool that utilizes the domains of palliative care.

3. Develop scripts for clinicians that will assist them in initiating and discussing palliative care services.
4. Develop a process for timely referral to palliative care consultation for patients with a serious illness.

Implementation Tools

Clinical Algorithm

Quick Reference Guides/Physician Guides

Resources

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

End of Life Care

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

Institute for Clinical Systems Improvement (ICSI). Palliative care. Bloomington (MN): Institute for Clinical Systems Improvement (ICSI); 2011 Nov. 62 p. [85 references]

Adaptation

Not applicable: The guideline was not adapted from another source.

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Guideline Developer(s)

Institute for Clinical Systems Improvement - Nonprofit Organization

Guideline Developer Comment

Organizations participating in the Institute for Clinical Systems Improvement (ICSI): Organizations participating in the Institute for Clinical Systems Improvement (ICSI): Affiliated Community Medical Centers; Allina Medical Clinic; Aspen Medical Group; Baldwin Area Medical Center; Brown Clinic; Center for Diagnostic Imaging/Medical Scanning Consultants; CentraCare; Central Lakes Medical Clinic; Chippewa County – Montevideo Hospital & Clinic; Cuyuna Regional Medical Center; Essentia Health; Fairview Health Services; Family HealthServices Minnesota; Family Practice Medical Center; Fergus Falls Medical Clinic; Gillette Children's Specialty Healthcare; Grand Itasca Clinic and Hospital; Hamm Clinic; HealthEast Care System; HealthPartners Central Minnesota Clinics; HealthPartners Medical Group & Regions Hospital; Hennepin County Medical Center; Hennepin Faculty Associates; Howard Young Medical Center; Hudson Physicians; Hutchinson Area Health Care; Hutchinson Medical Center; Integrity Health Network; Lake Region Healthcare Corporation; Lakeview Clinic; Mankato Clinic; MAPS Medical Pain Clinics; Marshfield Clinic; Mayo Clinic; Mercy Hospital and Health Care Center; Midwest Spine Institute; Minnesota Association of Community Health Centers; Minnesota Gastroenterology; Multicare Associates; New Richmond Clinic; North Central Heart Institute; North Clinic; North Memorial Health Care; Northwest Family Physicians; Obstetrics and Gynecology Specialists; Olmsted Medical Center; Park Nicollet Health Services; Planned Parenthood Minnesota, North Dakota, South Dakota; Quello Clinic; Raiter Clinic; Rice Memorial Hospital; Ridgeview Medical Center; River Falls Medical Clinic; Riverwood Healthcare Center; South Lake Pediatrics; Southside Community Health Services; Stillwater Medical Group; University of Minnesota Physicians; Winona Health

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Guideline Committee

Committee on Evidence-Based Practice

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Financial Disclosures/Conflicts of Interest

In the interest of full disclosure, Institute for Clinical Systems Improvement (ICSI) has adopted a policy of revealing relationships work group members have with companies that sell products or services that are relevant to this guideline topic. It is not assumed that these financial interests will have an adverse impact on content. They are simply noted here to fully inform users of the guideline.

Ken Kephart is on the Advisory Committee for TC Medical Society Honoring Choices Minnesota ACP project (unpaid).

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Kristina Schlecht is a board member for Hospice of the Red River Valley (unpaid).

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Guideline Availability

Electronic copies: Available from the Institute for Clinical Systems Improvement (ICSI) Web site.

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Availability of Companion Documents

The following is available:

- Palliative care. Executive summary. Bloomington (MN): Institute for Clinical Systems Improvement, 2011 Nov. 1 p. Electronic copies: Available from the Institute for Clinical Systems Improvement (ICSI) Web site.

Print copies: Available from ICSI, 8009 34th Avenue South, Suite 1200, Bloomington, MN 55425; telephone, (952) 814-7060; fax, (952) 858-9675; Web site: www.icsi.org; e-mail: icsi.info@icsi.org.

In addition, various resources, including the ICSI shared decision-making model, myths about palliative care, and a comparison of palliative care and hospice, are available in the appendices of the original guideline document.

Patient Resources

None available

NGC Status

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