Domain 7: Care of the Patient Nearing the End of Life

This domain highlights the care provided to patients and their families near the end of life, with a particular emphasis on the days leading up to and just after the death of the patient. The meticulous and comprehensive assessment and management of pain and other physical symptoms, as well as social, spiritual, psychological, and cultural aspects of care, are critically important as the patient nears death. It is essential that the interdisciplinary team (IDT) ensures reliable access and attention in the days before death, and provides developmentally appropriate education to the patient, family and/or other caregivers about what to expect near death, as well as immediately following the patient’s death.

The interdisciplinary model of hospice care is recognized conceptually and philosophically as the best care for patients nearing the end of life. Discussion regarding hospice as an option for support should be introduced early so that patients and families can understand eligibility, and the benefits and limitations of accessing this care model. Early access to hospice support should be facilitated whenever possible to optimize care outcomes for the patient and the family. Palliative care teams, hospice providers and other healthcare organizations must work together to find innovative, sustainable supportive care solutions for all patients and families in their final months of life.

Guideline 7.1 Interdisciplinary Team

The IDT includes professionals with training in end-of-life care, including assessment and management of symptoms, communicating with patients and families about signs and symptoms of approaching death, transitions of care, and grief and bereavement. The IDT has established structures and processes to ensure appropriate care for patients and families when the end of life is imminent.

Criteria:

7.1.1 IDT members have training and expertise regarding care of patients nearing the end of life. Staff training includes:

   a. Ensuring frequent telephone and in-person contact with patient and family caregivers in the days before death

   b. Supporting notification of distant family and friends, as desired by the patient and family caregivers

   c. Assessing and managing physical symptoms that are common among patients nearing the end of life, including, but not limited to, pain, dyspnea, nausea, agitation, delirium, and terminal secretions (see Domain 2: Physical Aspects of Care)

   d. Identifying signs and symptoms of approaching death, and what can be expected before and after the patient dies

   e. Talking about approaching death with patients and families

   f. Identifying spiritual concerns related to dying, death, and beliefs about the afterlife (see Domain 5: Spiritual, Religious, and Existential Aspects of Care)

Note: Words bolded in red are defined in the Glossary.
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g. Facilitating cultural assessments and attending to the cultural aspects of care at the end of life, including cultural rituals and beliefs related to dying, death, or the afterlife (see Domain 6: Cultural Aspects of Care)

h. Supporting legacy building activities, including life review, notes to family and friends, or a video diary

i. Supporting resolution of legal issues (see Domain 8: Ethical and Legal Aspects of Care)

j. Coordinating care for patients and the importance of seamless care transitions

k. Discussing hospice eligibility and services

l. Planning for post-death care, including funeral planning

m. Assessing and addressing the needs of children or adolescents facing the loss of a family member, including custody arrangements as needed, and coordinating with perinatal and pediatric grief specialists as needed

n. Providing grief and bereavement support

Guideline 7.2 Screening and Assessment

The IDT assesses physical, psychological, social, and spiritual needs, as well as patient- and family preferences for setting of care, treatment decisions, and wishes during and immediately following death. Discussions with the family focus on honoring patient wishes and attending to family fears and concerns about the end of life. The IDT prepares and supports family caregivers throughout the dying process, taking into account the spiritual and cultural background and preferences of the patient and family.

Criteria:

7.2.1 The IDT:

a. Assesses for signs and symptoms that the patient is nearing death

b. Prepares family and other caregivers regarding how to recognize and manage common symptoms

c. Reviews and confirms treatment decisions, including potential transitions in care settings, and documents patient wishes and preferences

d. Reviews advance directives (as applicable) and honors the patient’s wishes

e. Provides information and support to the family and others who are providing care to the patient

7.2.2 For patients who have not accessed hospice, the IDT discusses the benefits of hospice with the patient and family.

7.2.3 Before the patient’s death, the IDT discusses autopsy, organ and tissue donation, and anatomical gifts in a culturally sensitive and age-appropriate manner, adhering to applicable organizational policies and laws.
Guideline 7.3  Treatment Prior to Death

In collaboration with the patient and family and other clinicians, the IDT develops, implements, and updates (as needed) a care plan to anticipate, prevent, and treat physical, psychological, social, and spiritual symptoms. The care plan addresses the focus on end-of-life care and treatments to meet the physical, emotional, social, and spiritual needs of patients and families. All treatment is provided in a culturally and developmentally appropriate manner.

Criteria:

7.3.1 With the involvement of the patient and family, a plan is developed to meet patient needs during the dying process, as well as the needs of family members before, during, and immediately following the patient’s death. Cultural and spiritual preferences of the patient and family are particularly relevant when developing this plan. Reassessment and revision of the plan occurs regularly, with the frequency identified in agency or program policies.

7.3.2 Care of the patient at the end of life is time- and detail intensive, requiring expert clinical, psychological, social, and spiritual attention to the process as it evolves.

7.3.3 The IDT continues to evaluate the best setting of care for the patient, including consideration of patient- and family wishes and caregiver capacity, as well as the evaluation of symptom management issues that may need an inpatient stay or a higher level of staff support. The IDT is in regular communication with the patient and family to evaluate options and prepare for transitions in care if needed.

7.3.4 The IDT ensures access to medications, supplies, and equipment that may be needed.

7.3.5 In all care settings, the IDT provides education and instructions to family members and/or caregivers in preparation for the patient’s death, with emphasis on whom to notify, and what to expect when symptoms change and after the patient dies.

   a. Education and instructions are provided in accordance with the patient- and family’s health literacy levels and cultural preferences.

7.3.6 Family expectations regarding IDT availability during the dying process are identified in advance so that staff can alleviate concerns and communicate realistic expectations.

7.3.7 The IDT elicits and honestly addresses hopes, fears, and expectations about the dying processes in ongoing communications with the patient and their family in a developmentally appropriate and culturally sensitive manner.

7.3.8 The IDT provides anticipatory grief support to the family and caregivers.

Guideline 7.4  Treatment During the Dying Process and Immediately After Death

During the dying process, patient and family needs are respected and supported. Post-death care is delivered in a manner that honors patient and family cultural and spiritual beliefs, values, and practices.
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**Criteria:**

7.4.1 The IDT communicates signs and symptoms of imminent death in culturally and developmentally appropriate language, taking into account the cognitive abilities of the patient and family.

7.4.2 Consistent with commitments to the patient and family, the IDT is available to provide support during the dying process.

7.4.3 Immediately following death, the IDT either directly or in collaboration with others, provides respectful care of the body and support for the family based upon the cultural and spiritual practices identified by the patient and family. Post-death care is in accordance with agency practice, local laws, and state regulations.

7.4.4 An IDT member supports the family before and immediately following the patient’s death, assisting with cultural or spiritual practices, funeral arrangements, and cremation or burial planning.

7.4.5 Medications are disposed of in accordance with Drug Enforcement Administration (DEA) disposal guidelines, local, state or federal laws, and agency policies in all care settings. If the medications are in the home, providers must adhere to the drug disposal policy of the DEA, paying particular attention to the role of the health care professional in the home setting.

**Guideline 7.5 Bereavement**

Bereavement support is available to the family and care team, either directly or through referral. The IDT identifies or provides resources, including grief counseling, spiritual support, or peer support, specific to the assessed needs. Prepared in advance of the patient’s death, the bereavement care plan is activated after the death of the patient and addresses immediate and longer-term needs.

**Criteria:**

7.5.1 The IDT directly, or through referral, provides bereavement services and support to the family for a minimum of 13 months after the death of the patient. Bereavement services include:

   a. Support, including individual counseling or group support as desired

   b. Information and educational resources regarding grief, including the potential physical manifestations of grief

   c. Rituals that acknowledge loss and transition, provide opportunity for remembrance, and establish a sense of community

7.5.2 The IDT has processes in place outlining specific roles and responsibilities of IDT members in the provision of bereavement services, and identifies one IDT member with bereavement care expertise to help other staff and volunteers offering bereavement support utilize evidence-based practices.

7.5.3 The IDT refers to the care plan to review issues identified during the assessment of anticipatory grief (see Domain 3: Psychological and Psychiatric Aspects of Care), and formulates and activates a post-death bereavement plan based on a social, cultural, and spiritual grief assessment.
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7.5.4 Either directly or through referral, patients and families at risk for prolonged grief disorder are identified and provided with services and support consistent with the assessed need.

7.5.5 Prior to and after death, the IDT works with the family to identify cultural beliefs and traditions, as well as emotional, spiritual, and social resources that can provide them with comfort and support in their grieving process.

7.5.6 Grief and bereavement support and interventions are in accordance with developmental, cultural, and spiritual needs and the expectations and preferences of the family.

7.5.7 Grieving children are referred to pediatric grief specialists, programs, and camps based on their age and needs.

7.5.8 The IDT assesses resiliency, cumulative loss, and grief, and offers supports and services to IDT members. Emotional support services are also made available to ancillary team members involved in supporting palliative care patients.

Clinical and Operational Implications

Clinical Implications

While the IDT may follow patients receiving palliative care from early in their disease process, additional clinical skills help to identify signs and symptoms of approaching death. Discussions about, and referral to, hospice are offered as early as possible. The IDT must assess for fears, address concerns, provide caregiver training, and support the family through the dying process and post-death. It is essential that the IDT attends to patient and family cultural and spiritual beliefs, values, and practices to promote a peaceful, dignified and respectful death, in all settings of care.

Operational Implications

Caring for patients nearing the end of life may take place in any setting (eg, hospital, nursing home, assisted living facility, hospice inpatient facility, or at home). Decisions regarding preference and need for transitions in care settings may be required. Attention to patient comfort and wishes, as well as support to family members during the dying process are paramount operational concerns. Care near the end of life is often more intense than care earlier in the disease process, requiring increased visit length and frequency, as well as timely telephone response, to adequately care for patients and their families. In addition, staffing is needed to support families during the grief process. Specialist-level pediatric palliative care may be required when the patient is a minor or when the patient’s immediate family includes children.

Essential Palliative Care Skills Needed by All Clinicians

Clinicians in all care settings who learn the hospice eligibility criteria can make timely referrals to hospice. In addition, clinicians can improve patient care by learning how to assess and manage physical symptoms common among patients nearing the end of life. All clinicians must have the knowledge and skills to talk to patients and families about dying.
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Key Research Evidence

The systematic review addressed two key questions: KQ7a) What is the effect of grief and bereavement programs on family/caregiver outcomes; and KQ7b) What is the impact of hospice and palliative care in the final days of life on quality of care and quality of death/dying? Six systematic reviews were identified pertaining to KQ7a and two pertaining to KQ7b. The evidence tables in the systematic review describe the key findings of each included review. The summary of findings table summarizes the research evidence across identified reviews and describes the quality of evidence. The complete findings are published online in the Journal of Pain and Symptom Management (doi: 10.1016/j.jpainsymman.2018.09.008).

Practice Examples

Practice Example D7-A

A large children’s hospital recognized that all units, particularly those caring for children with a higher risk of death, should provide excellent palliative care. The perinatal and neonatology teams provide training for all staff in palliative care, and a team of prenatal/neonatal clinicians, including social work, physicians, nurses, child life, and chaplaincy, have become the leaders for this care. This team has developed protocols for symptom management, and converted a hospital room dedicated to imminently dying infants to provide privacy and support. A comprehensive perinatal and pediatric bereavement program provides support to grieving parents, siblings, and grandparents, including follow-up through the first year after the baby’s death.

Practice Example D7-B

A large renal dialysis group has several dialysis centers located in urban and rural settings. They identify that few of their patients are referred to hospice, and most are dying in acute care settings (often in intensive care). They receive complaints from families who felt ill-prepared for the sudden death of their loved one. The dialysis group commits to improving care at the end of life for their patients and looks to the NCP Guidelines. The dialysis centers begin with palliative care education for all staff, and establish a collaborative relationship with an area hospice to develop educational materials and resources for staff regarding hospice eligibility. The social workers in the dialysis centers take the lead in implementing a systematic approach to advance care planning for all dialysis patients, often facilitating family meetings. This advance care planning initiative identifies the need for more family- and caregiver support, such as educational materials and support groups for family members while patients are receiving dialysis. The dialysis centers in several locations work closely with area hospice programs to ensure that transitions of care are optimized for patients who have decided to stop dialysis. As a result of these efforts, recent audits of patient deaths document better preparation for end of life, increased hospice utilization, and more patients dying in their preferred setting.

Practice Example D7-C

A pediatric neurology practice serves a large population of children with severe neuromuscular diseases and brain tumors. Many of these children utilize the emergency department in the last month of life, and often die in the hospital, emergency department or intensive care unit (ICU). Once hospitalized, the children and families receive support from an inpatient palliative care service, but at discharge there are few resources available to them. In consultation with the palliative care service, the neurological practice recruits an advanced practice registered nurse who is certified in hospice and palliative care. The nurse
works with the inpatient service to create protocols for symptom management, and improve support for parents caring for children at home. This leads to a more active collaboration with home health and home hospice agencies and both agencies commit to rapidly scaling their capacity to care for pediatric patients, particularly those with end-of-life needs.

**Practice Example D7-D**

A well-established hospice program expands into a new region and is quickly challenged by the cultural beliefs of the population it now serves. Increasingly, patients and families ask that only their own spiritual leader provide care, and decline any involvement of the hospice chaplains. Many male patients decline hands-on care from a female nurse (unless she is accompanied by a male physician), and likewise decline care from male physicians and nurses for female patients. Many families request that their family member be hospitalized as death nears, expressing that death in the home is not culturally acceptable and marks them unfavorably. The hospice engages cultural representatives from the community who can help the team better understand the context for these requests in an effort to meet the needs of the patients and families. The hospice chaplains create a monthly interfaith discussion group with community spiritual care leaders, which gives rise to a community advisory council. The hospice explores ways to hire a male staff to increase its capacity. Hospice leaders contract with local nursing homes for beds so that patients do not have to die at home.

**Practice Example D7-E**

A community-based palliative care program finds a small, but substantial, percentage of its patients are not willing to access hospice support when they become eligible. Despite education, support, and frequent conversations, approximately 15% of the patients and families in the palliative care program end up waiting until a few days before death to access hospice. This sets up repeated occurrences of stressful deaths for both patients and family members, as well as hospice staff. The palliative care and hospice teams meet to develop a rapid response program for late admissions in order to work together more seamlessly. They pilot integrating the hospice social worker and/or chaplain into the palliative care team for patients who are eligible but decline to use hospice care. They track outcomes, including time spent on hospice care, and family caregiver distress and satisfaction with this intervention. They also systematically meet to debrief short length of stay hospice patients to gather lessons, identify opportunities for improvement, and support and affirm one another in the work.