Domain 6: Cultural Aspects of Care

Assessing and respecting values, beliefs and traditions related to health, illness, family caregiver roles and decision-making are the first step in providing culturally sensitive palliative care. Palliative care interdisciplinary team (IDT) members continually expand awareness of their own biases and perceptions about race, ethnicity, gender identity and gender expression, sexual orientation, immigration and refugee status, social class, religion, spirituality, physical appearance, and abilities. Information gathered through a comprehensive assessment is used to develop a care plan that incorporates culturally sensitive resources and strategies to meet the needs of patients and family members. Respectful acknowledgment of and culturally sensitive support for patient and family grieving practices is provided.

Guideline 6.1  Global

The IDT delivers care that respects patient and family cultural beliefs, values, traditional practices, language, and communication preferences and builds upon the unique strengths of the patient and family. Members of the IDT works to increase awareness of their own biases and seeks opportunities to learn about the provision of culturally sensitive care. The care team ensures that its environment, policies, procedures, and practices are culturally respectful.

Criteria:

6.1.1 The IDT asks the patient or surrogate to identify and define family, which may include members of the family of origin, as well as the patient’s family of choice.

6.1.2 IDT members recognize that the provision of quality palliative care requires an understanding of the patient’s and family’s culture and how it relates to their decision-making process, and their approach to illness, pain, psychological, social, and spiritual factors, grief, dying, death, and bereavement.

6.1.3 The IDT understands that each person’s self-identified culture includes the intersections of race, ethnicity, gender identity and expression, sexual orientation, immigration and refugee status, social class, religion, spirituality, physical appearance, and abilities.

6.1.4 The IDT recognizes that patients and families may have experienced barriers to receiving culturally respectful health care, and that these prior experiences may result in mistrust of the health care system.

6.1.5 The IDT commits to continuously practice cultural humility and celebrate diversity.

6.1.6 In delivering culturally sensitive care, the IDT regularly participates in trainings to increase cross-cultural knowledge, empathy, and humility. The IDT focuses on building and practicing these skills to avoid imposing personal values, beliefs, and biases on the patient and family. The IDT also recognizes that culture is a strength that patients and family members bring to their plan of care.

Note: Words bolded in red are defined in the Glossary.
Domain 6: Cultural Aspects of Care

6.1.7 Communication occurs using verbal, nonverbal, and/or symbolic means appropriate to the patient, with particular attention to cultural and linguistic considerations, cognitive capacity, the presence of learning or developmental disabilities, and the developmental stage across the lifespan.

6.1.8 The IDT implements policies regarding recruitment, hiring, retention, and promotion practices to reflect the cultural and linguistic diversity of the community it serves, to the extent possible.

6.1.9 The care team regularly evaluates and, if needed, modifies services, policies, and procedures to maximize cultural sensitivity and reduce disparities in care. Input from patients, families, and community stakeholders is elicited and integrated into this process.

6.1.10 The IDT is aware of cultural factors that may necessitate changes in staffing assignments (e.g., a patient who can only receive hands-on care from someone of the same gender). Policies and procedures are in place to identify these issues and substitute staff, when possible, so that patient preferences are respected.

6.1.11 The IDT performs a community assessment to identify underserved populations in need of palliative care.

Guideline 6.2 Communication and Language

The IDT ensures that patient and family preferred language and style of communication are supported and facilitated in all interactions.

Criteria:

6.2.1 Palliative care staff tailor their communication to the patient and family’s level of health literacy.

6.2.2 When patients and families do not speak or understand English, or prefer communicating in a language other than English, the IDT uses qualified medical interpreter services, either in person or via telephone or video.

   a. When possible, the need for medical interpreter services is assessed and addressed before the patient and family encounter to reduce the likelihood of communication issues and misunderstandings.

   b. Prior to the patient and family encounter, the medical interpreter is provided a summary of the anticipated focus of the conversation.

   c. If medical interpreter services are unavailable, bilingual clinicians provide information in the patient and family’s preferred language. Family members are not placed in the role of interpreter.

6.2.3 The IDT asks about preferred ways of receiving materials and information and uses culturally representative images and language in printed and online materials.

6.2.4 Written materials in each patient- and family’s preferred language is provided by the IDT. When accurately translated written materials are unavailable, the program utilizes medical interpreter services to facilitate patient and family understanding of program information.
Domain 6: Cultural Aspects of Care

6.2.5 The IDT uses the patient’s preferred pronouns (e.g., he, she, they) in all communication, including documentation.

6.2.6 As needed or upon request, the IDT incorporates cultural representatives/cultural brokers in the plan of care.

Guideline 6.3 Screening and Assessment

The IDT uses evidence-based practices when screening and assessing patient and family cultural preferences regarding health care practices, customs, beliefs and values, level of health literacy, and preferred language.

Criteria:

6.3.1 Before the screening and assessment, the IDT recognizes the need to be:
   a. Non-judgmental of the patient and family
   b. Mindful of potential biases
   c. Conscious of historical trauma and how it can impact patient and family care
   d. Aware of power dynamics inherent in patient and family care

6.3.2 During the assessment process, the IDT elicits and documents:
   a. Cultural practices, customs, beliefs, and values relevant during serious illness, the dying process, at the time of death, and post-death
   b. Patient’s preferred name, pronouns, and gender identity
   c. Preference for IDT interaction, including whether decision-making will be communal, collective, or individualistic, with attention to patient and/or family preferences for participation in the decision-making process
   d. Truth-telling and whether the preferred cultural practice is to share or not share diagnosis and/or prognosis with the patient
   e. Preferred and taboo practices (e.g., using the words “dying” and “death” or the place of death)
   f. Community resources and supports, including community leaders, faith community, or cultural groups
   g. Preferences related to physical contact
   h. Level of health literacy
   i. Prior health care experiences with attention to historical trauma and impact on care
   j. Perception of illness and disability, including patient understanding of, and what caused, their illness
k. Beliefs about pain and suffering

l. Perceptions of and approaches to help-seeking (eg, reluctance to accept “charity” or from anyone other than the family and/or faith community)

m. Differing levels of acculturation within the family that can impact decision-making

n. Use of traditional healing practices and involvement of traditional medicine practitioners or healers

6.3.3 When the patient is a child or adolescent the IDT assessment also identifies:

a. The role of the child or adolescent in the family and how culture defines a minor’s status in the family

b. Whether parents share information about important matters with their child(ren), including siblings and foster children, and whether these decisions reflect the family’s cultural preferences

c. How the parents define being a good parent, and how that impacts medical decision-making

d. Whether the family’s culture permits parents to make decisions for their minor or if medical decision-making authority is deferred to religious or cultural leaders

e. The meanings attributed by the minor and family regarding how and why the illness occurred, childhood suffering and death, and how that impacts decision-making

f. When serious illness is diagnosed in utero (perinatal), the meaning of the pregnancy and childbirth practices are valued in the parent’s culture(s)

6.3.4 The IDT reaches out to cultural representatives if lacking information and/or experience with regard to the patient’s culture.

Guideline 6.4 Treatment

A culturally sensitive plan of care is developed and discussed with the patient and/or family. This plan reflects the degree to which patients and families wish to be included as partners in decision-making regarding their care. When hosting meetings to discuss and develop the plan, the IDT ensures that patient and family linguistic needs are met.

Criteria:

6.4.1 The plan of care incorporates and the IDT verbally and non-verbally communicates respect for:

a. Who the patient defines as their family

b. Beliefs, values, and traditional practices

c. Language and communication preferences

d. Level of health literacy
Domain 6: Cultural Aspects of Care

6.4.2 If historical trauma was assessed the treatment plan adopts a trauma-informed approach to develop trust over time.

6.4.3 When a traditional healer is involved, the care team ensures that the healer participates in care planning discussions.

6.4.4 With patient and/or family permission, IDT members involve cultural representatives to develop a care plan that honors cultural practices.

6.4.5 When discussing diagnosis and/or prognosis, preferences regarding taboo language, as well as truth telling are respected, prioritizing fidelity to the patient (see Domain 8: Ethical and Legal Aspects of Care, including 8.4.6 for truth-telling with children and adolescents living with serious illness).

6.4.6 The IDT ensures that culturally respectful grief support is available.

Clinical and Operational Implications

Clinical Implications

In order for patients and family members to receive culturally sensitive care, it is incumbent on professionals to continually explore their own biases, work to suspend judgment, and seek frequent training to further enhance and strengthen their cultural assessment, treatment, and communication skills.

Operational Implications

Palliative care teams perform a cultural assessment of all policies, processes, and practices, build strong relationships with communities and their cultural representatives, maximize service delivery to vulnerable populations, and address disparities in care. All employees receive training in cultural humility, the provision of patient-centered culturally sensitive care, and appropriate use of interpreter services and translated materials.

Essential Palliative Care Skills Needed by All Clinicians

Clinicians can acquire knowledge and skills to recognize how culture influences patient and family decision-making, their approach to illness, pain, psychological, social and spiritual factors, and grief, dying, death and bereavement. Clinicians incorporate palliative care specialists and cultural representatives into the care plan to navigate cultural nuances, as needed.

Key Research Evidence

The systematic review addressed the following key question: KQ6) What is the impact of culturally- and linguistically-sensitive care on physical, social, emotional, and spiritual wellbeing of the patient and family/caregiver? Three systematic reviews were identified pertaining to KQ6. The evidence table in the systematic review describes 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 D6-A**

A long-term care community incorporates palliative care screening and assessments into the care plan for all its residents with serious illness, and includes an interdisciplinary team in the regular family case review. This community has experienced a significant demographic shift over time with more aging residents who have recently immigrated to the area to be near family, as well as an aging lesbian, gay, bisexual, transgender, queer, intersex, asexual (LGBTQIA) community. To promote culturally respectful palliative care, this long-term care community expands its comprehensive assessment to better assess values, beliefs, and traditions related to health, illness, chosen family, caregiver roles, and decision-making. All patients are asked to identify their gender identity and preferred pronouns. A more comprehensive cultural assessment is completed on admission and reviewed with status changes of the resident’s condition. The community provides an ongoing educational series for all staff related to culturally respectful care.

**Practice Example D6-B**

A palliative care program on a Native American reservation provides palliative care to adults in the hospital and clinic settings. The program has three palliative care specialist physicians within its family medicine practice. The interdisciplinary team is created to reflect the needs of the people it serves and includes team members with shared roles:

- Registered nurses who provide hands on care and care coordination
- Social workers who also serve as translators for native-speaking patients and families
- Patient advocates from the community who help patients complete advance directives
- Dieticians who provide supplements to eligible patients and help with diabetes teaching and counseling
- A medicine man who offers spiritual support performing rituals for patients, family members, as well as the staff

**Practice Example D6-C**

A hospice provides a rural telehealth palliative care program to support underserved populations. The program consists of a comprehensive in-person assessment conducted by a palliative care specialist followed by weekly nurse coaching sessions by telephone. The registered nurse coaches receive intensive training in symptom management, as well as problem solving and supporting patient-family decision-making skills. They help coordinate and connect the patients and families to other resources and prompt clinical visits when necessary.

**Practice Example D6-D**

A public hospital struggles to provide palliative care services with limited resources and the complex needs of its socioeconomically disadvantaged and culturally diverse patient population. Some patients do not live in areas where there are hospice programs, so the hospital has made referrals to the public health department for follow-up nursing care for the seriously ill patients. A hospital discharge to the home of a dying Hmong child demonstrated the need for better communication and training of the expanded team. The public health nurse making the home visit had not been briefed on the imminent
Domain 6: Cultural Aspects of Care

death of the child or the cultural observances of the family and unfortunately misinterpreted them – prompting a 911 transport despite the family’s objections. The child died in the ambulance. The palliative care service is working with others to better highlight and explicitly communicate the cultural context of care within the written and verbally transmitted medical discharge plans, and to collaborate more actively with community partners through education and training.

Practice Example D6-E

A large community hospice would like to better serve the Hispanic and Latino population in its urban community. There are many misconceptions regarding hospice care and advance care planning. The hospice and the local community center work together to create a program for local public radio. The program is set up as a multi-episode radio novella story of a family with an aging grandmother who is reaching the end of life, and the challenges the family faces with her care and with the hospital. The radio novella is an entertaining and engrossing way to present information around advance care planning, correct misunderstandings about hospice, and educate people about end-of-life care. Families in the community identify the radio program as helping pave the way for them to understand and utilize hospice care when it is indicated. The process also creates a powerful collaboration between the hospice and local community center that better supports families with grief and bereavement needs and creates a more culturally sensitive bereavement program.

Practice Example D6-F

A large pediatric tertiary care hospital provides palliative care to a diverse patient population. To better serve patients and families whose primary language is not English, the team partners with the medical interpreter services department to provide education on palliative care topics. The team meets with the interpreter prior to patient and family encounters to prepare the interpreter for the topics that will be discussed. In addition, an interpreter is assigned primary responsibility for palliative care patients and is a member of the weekly palliative care interdisciplinary rounds. Palliative care team members have found incorporating medical interpreter services into the IDT to be extremely helpful, and it has resulted in improvements in patient- and family communication and increased cultural sensitivity. Incorporating the interpreter into the palliative care team offers opportunities for additional support for the interpreter staff, for debriefing for both the team and the interpreter staff, and enhanced cultural competency for IDT members.