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## KNOW THE FACTS

# Culturally Diverse Communities and Palliative and End-of-Life Care

### WHAT IS PALLIATIVE AND END-OF-LIFE CARE?

**Palliative care** is a team-based approach to care for people with serious illness that is appropriate at any age/stage of illness. It can be provided along with curative treatment. Palliative care:

- Is focused on improving the quality of life for individuals facing serious and limiting illness, and their care partners
- Provides symptom management and relief from pain
- Includes assessment and treatment of physical, psychological, and spiritual issues
- Can also include respite care for family caregivers and bereavement care after the person dies

**End-of-life** care focuses on palliative care for terminally ill individuals who may have only very limited time to live and have elected to no longer pursue curative treatment. It is often tied to hospice care, which is defined in the United States as encompassing the final six months of life.

### WHY IS CULTURE IMPORTANT?

As the U.S. population becomes more diverse, the need to offer culturally competent palliative and end-of-life care increases.

- The population is aging. The number of Americans aged 65 and older (the group in which most deaths occur) is projected to double to more than 98 million by 2060.
- Our country is becoming more racially and ethnically diverse. The non-Hispanic White population is shrinking across age groups.

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- The number of people who identify as lesbian, gay, bisexual, transgender, queer, or questioning (LGBTQ) has increased in recent years. Approximately 2.4 million older adults identify as LGBTQ.
- Individuals with disabilities are living longer due to advances in medicine and increases in the availability of services, resulting in a population with more diverse ways of functioning.

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This individual diversity, combined with differences in human values, status, power, and resources, leads to a range of views and needs regarding palliative and end-of-life care.

## **HOW DOES CULTURE INFLUENCE PALLIATIVE AND END-OF-LIFE CARE?**

Research indicates that culture contributes to differences in attitudes, preferences, behaviors, perceptions, and experiences related to palliative and end-of-life care. One's age, race, sex assigned at birth, ethnicity, disability status, sexual orientation, gender identity, socioeconomic status, education, health status, geographic location, immigration status, and religion can influence how people approach serious or life-limiting illness and end-of-life. For example:

- **Treatment and care preferences:** Some racial and ethnic groups, such as African Americans, Latinxs, or Asians, may want more and aggressive treatment. They may also have unique perspectives on treatments that may impact their quality of or length of life. Judgments about what constitutes quality of life or even what suffering means are very personal and often influenced by one's culture. Individuals from different cultural and religious backgrounds may also have different preferences about how pain should be managed (e.g., with or without pain medication). Furthermore, individuals may have
- different beliefs about issues such as wanting to know that a diagnosis is terminal, involving family as primary decision makers, using life support measures (e.g., resuscitation, feeding tube, intubation), and location of death (e.g., in the home, at a hospital, in a hospice facility). If providers do not understand cultural differences in care preferences or do not ask questions about one's cultural identity (including sexual orientation and gender diversity) in a culturally sensitive way, it may result in negative outcomes for individuals and families, including their preferences not being honored.
- **Views toward health care, death, and dying:** Some racial and ethnic minority groups and people with disabilities have mistrust in the health care system and providers. There are valid reasons for this mistrust including longstanding healthcare disparities and unequal access to curative or life extending treatments for some marginalized groups. Mistrust can influence one's views of health care options at end of life. For example, African Americans may believe that enrollment in hospice and palliative care services will prevent them from receiving the care they desire. These beliefs may be a reason that non-White individuals are less likely to use or remain in hospice. Religious or sexual minority individuals may also hold different views of health care, death, and dying.
- **Advance care planning:** Individuals of certain cultural groups (Whites and Asian Americans) are more likely to engage in the process of advance care planning and record the type of health care they would prefer, if they are no longer able to express their preferences. Other cultural groups are less likely to participate in advance planning. Some cultural groups prefer not to be directly informed of life-limiting diagnoses, or do not believe in talking openly about diagnoses of life-limiting illnesses with family members. As a result, they may not engage in advance care planning. Although attitudes towards advance directives are often positive, many believe they are not needed because family or physicians know their wishes. However, physicians' and families' decisions may not be in agreement with an individual's wishes.

## WHAT ARE THE BARRIERS TO EFFECTIVE COMMUNICATION?

Individuals from diverse backgrounds may find it challenging to talk to health care providers about treatment options. For example, limited English proficiency may complicate interactions. Deaf or disabled individuals may communicate through interpreters, alternative modalities (e.g., tactile rather than visual), or assistive technology. Differences in language may also prevent individuals from asking for what they want and getting the information they need. Translations, accessible communication formats, and culturally sensitive written information in native languages are often lacking.

Limited health literacy and lack of knowledge of care options and medical terms can also interfere with advance care planning. Individuals may not understand the descriptions of treatments used by the care team, which can impair their ability to make informed decisions. Furthermore, providers often have difficulty talking about death, or talk too briefly or too late in the illness trajectory about palliative and end-of-life care options. This is especially true when communicating with individuals from diverse cultures. All of these factors can result in increased confusion when individuals do not understand their providers, and when providers have difficulty explaining care options.

Culturally diverse individuals may also have concerns that members of the care team are treating them differently, are not culturally aware, or have negative attitudes toward them. As a result, they may not feel confident about speaking openly with their providers about their needs and care preferences.

## WHAT IS THE ROLE OF THE FAMILY?

Families may want to be involved in their loved one's care and pain management. In fact, some cultures believe caring is the family's duty and obligation, so they are active participants in the individual's care. For example, in some cultural groups (e.g., African Americans), extended family members may be very involved in all health care decisions and providing care at end-of-life. Gender roles often affect the way that care is managed, with women frequently the primary caregiver. For some socially marginalized groups (e.g., LGBTQ, people with disabilities), individuals may feel devalued within their families of origin and, therefore, prefer to rely on chosen friends for support in end-of-life decision making.

Culture can influence the role of family in palliative and end-of-life care in other ways. For example, in some cultures, individuals do not want to know what their diagnosis is, due to a concern that it may result in hopelessness for themselves or their families. In sexual minority groups, health care providers may not acknowledge gay/lesbian partners in health care decision making, which can put a strain on the family.

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## WHAT IS WORKING?

Psychologists and other mental health providers with palliative care expertise can improve communication between individuals, their family members, and the health care team. They can conduct assessments of cognitive and overall psychological functioning that can inform the best types of treatment and support to provide to those with advanced serious or life-limiting illness. They can help individuals and their families access resources and connect other providers to resources that help to enhance the care they offer.

Psychologists and other mental health experts help health care and aging services providers understand the individual's concerns and culture, and they can help the person feel heard. They can encourage collaboration among those involved in patients' care. Mental health providers also help relieve the common emotional distress and grief resulting from a terminal illness or caregiving. They also work with families to address conflicting views about end-of-life to diminish tension.

## WHAT CAN YOU DO?

- Treat all people with dignity, and respect each individual's rich cultural traditions, rather than viewing those traditions as barriers to overcome.
- Consider cultural values when providing care for all individuals, and understand how those values may influence decision making about palliative and end-of-life care.
- Be aware of your own attitudes about palliative and end-of-life issues.

- Increase your awareness of biases that you and others might hold.
- Communicate with the individual and their family in advance about how the treatment and care plans are aligned with their beliefs about death and dying, their concerns, and their values and preferences.
- Consider differences in expectations about how pain and symptoms will be managed (e.g., what how much medication will be used).
- Communicate with the individual and their family about how goals for care management align with their values and preferences.
- Use clear explanations that can be understood by individuals of varying education levels—avoid jargon and technical terms.

## SAYS WHO?

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## WHAT RESOURCES CAN HELP?

National Hospice and Palliative Care  
Organization Diversity  
[www.nhpco.org/Diversity](http://www.nhpco.org/Diversity)

Culture Clues and EOL Care Sheets  
[depts.washington.edu/pfes/CultureClues.htm](http://depts.washington.edu/pfes/CultureClues.htm)

Older Adults and Palliative and End-of-Life Care  
[on.apa.org/end-of-life-care](http://on.apa.org/end-of-life-care)

End-of-Life and Socioeconomic Status Fact Sheet  
[on.apa.org/ses-end-life](http://on.apa.org/ses-end-life)

Palliative Care: Conversations Matter® for pediatric  
palliative care  
[bit.ly/2ITn4F9](http://bit.ly/2ITn4F9)

"End of Life Decisions" site of the National Resource  
Center on LGBT Aging  
[bit.ly/2ISJ4Qt](http://bit.ly/2ISJ4Qt)

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