ADDRESSING CULTURAL DIVERSITY IN HOSPICE

Presented by the Hospice Foundation of America, with support from the Centers for Medicare & Medicaid Services

Experiences Common to Everyone

- Illness
- Death
- Grief

Addressing Cultural Diversity in Hospice

- Backgrounds and cultures can influence end-of-life experiences
- Learn more about how our differences, and our similarities, affect end-of-life decisions
- How hospice care can support culturally diverse patients and families

Many Elements of Culture

- Language
- Social circumstance
- Religion and spirituality
- Sexual orientation and gender
**Culture**

- Human instinct to hope for comfort, peace and dignity at the end of life
- Differences reflect deeper values and priorities
- Disparities do exist

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**Program Defines:**

- Aspects of cultural diversity
- Knowledge, skills and resources that can promote cultural awareness and respect
- Why different cultures may, or may not, utilize hospice
- How hospices can respond and reach out

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**Culture**

- Beliefs, customs, practices, and social behavior
- Defined by family of origin and by groups and communities of choice
- Never static

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Tawara Goode, Director, National Center for Cultural Competence at Georgetown University
Major Areas of Diversity

Race  Ethnicity  Spirituality

Identities may or may not have the same level of personal importance

Concerns at the End of Life

Finding peace
Presence of family and loved ones
Minimizing pain
Being able to say goodbye

Hospice Care

Goal
- To help the process of living and dying be as natural as possible
- Addresses physical and emotional discomfort
- Keeps patient’s needs at center
- Supports both the patient and family

LaFrance Williams, whose husband Robert was cared for by hospice
In 2009, over 1 million people received hospice care

- 80% White or Caucasian
- Less than 10% African American
- Less than 5% Latino or Hispanic
- Less than 1% Asian Americans

Complex reasons for disparities

“People of color in the US are more likely than whites to lack health insurance, to receive lower-quality care and to suffer from worse health outcomes. The causes of these disparities are broad and complex.”

--Families USA, 2009

Complex reasons for disparities

- Diagnosis and start of treatment often delayed
- End-of-life decisions made sooner
- Emotional Reasons

Michon Lartigue, family caregiver
Complex reasons for disparities

- Distrust of the medical community
- Disparities in education and work opportunities

How can hospices do a better job at communicating the facts?
How can hospices educate staff and volunteers?
How can hospice professionals help overcome barriers?

Dorotea Gonzalez, Hospice Nurse, Capital Caring

Communicate clearly and honestly
Be sensitive to cultural beliefs and experiences
Develop strong relationships in communities
How Hospice is Paid For

Medicare Hospice Benefit

Centers for Medicare and Medicaid Services (CMS)
www.medicare.gov

1-800-633-4227
1-800-MEDICARE

What is Cultural Competency?

“Cultural competency is one of the main ingredients in closing the disparities gap in health care. It’s the way patients and health professionals can come together and talk about health concerns without cultural differences hindering the conversation, but enhancing it” –Office of Minority Health

Cultural differences in experiences with end-of-life care

Concerns about pain management
--Need to preserve dignity
--Concept of stoicism

Tawara Goode, National Center for Cultural Competence, Georgetown University
Cultural differences in experiences with end-of-life care

- Concerns about prolonging life
- Differences in use of CPR
- Differences in development of living wills

Doka’s “Culturally Effective Hospice Practitioner”

- Uses diverse strategies
- Operates with deep sensitivity
- Listens and asks, rather than makes assumptions
- Employs neutral language
- Aware of personal bias

General realities about cultural beliefs must always be balanced with the recognition of the individual.
Self-reflection as a way to strengthen cultural awareness

- What is positive or negative?
- What is your bias?
- How do you see yourself?
- How do others see you?
- What is the difference?

Impact of language
Issues of trust and discrimination in healthcare
Customs and rituals
Attitudes toward death and advance directives

Strengthening communication skills

- Assurance that life has had meaning
- Listen with dignity and respect
- Acknowledge and learn more about unique cultural identity
- Builds trust and helps meaning-making process

Frank Sesno and Dr. Paul Rosenblatt on HFA's "Diversity and End-of-Life Care" panel
Fife’s ten steps to develop a culturally competent program

- Make a long-term commitment
- Hold focus groups and community meetings
- Hire a community liaison
- Recruit staff and volunteers from the community
- Secure training materials, and develop focused programs and marketing materials
- Train for cultural awareness
- Train in communication skills
- Train in flexibility
- Take advantage of outside resources and workshops
- Train to monitor and assess

Work with leaders in the community

- Hire a community liaison
- Work with families served by hospice to help advocate and share stories

LaFrance Williams, whose husband Robert was cared for by hospice
Recruit staff, volunteers, and board members

If possible, find staff and volunteers who can speak in the primary language

Important that materials are not just directly translated but are interpreted appropriately

In print materials, website, intake procedures, staff composition--

If people from other cultures or groups don’t see themselves reflected, they may wonder...will we be welcome here?

Additional Resources

Resources in Chinese and Spanish

Tutorial addressing Aging and End-of-Life challenges in the LGBT community

www.hospicefoundation.org/infocenter
Advance care planning can be impacted by cultural beliefs

Decisions that a person makes about medical treatment
• Often leads to completion of legal documents
• Recognize various factors and be responsive to needs

Advance care planning can be impacted by cultural beliefs

Research shows varying beliefs about advance directives
• Can be very helpful tool in expressing wishes
• Need to educate physicians about advance care planning

Hospice Assessment, Intervention and Measurement Toolkit (AIM)

Developed by Centers for Medicare & Medicaid Services
Offers several approaches for community outreach

www.ipro.org

Research Demographics

Assess knowledge and misperceptions about hospice
Look carefully at the meaning of commonly used words or phrases
Cultural and religious beliefs can be barriers to:

- Good pain management
- Participating in hospice care

Education is key, often in partnership with trusted local organizations

Key Questions

- Are there other faith or healthcare organizations to partner with?
- What are the needs of community during serious illnesses or crises?

Key Questions

- How can your hospice become more involved in local activities and events?
- How can your hospice work to educate physicians and other healthcare professionals?
“Quite simply, health care services that are respectful of and responsive to the health beliefs, practices and cultural and linguistic needs of diverse patients can help bring about positive health outcomes.”

---Office of Minority Health

The Hospice Foundation of America thanks the following people for contributing their stories and expertise:

- Tawara Goodie, National Center for Cultural Competence at Georgetown University
- LaFrance Williams
- Dorotea Gonzales, RN, Capital Caring
- Nellie Kwan, Self-Help Hospice
- Frank Sesno, George Washington University
- Dr. Paul Rosenblatt, University of Minnesota
- Michon Lartigue
- Guadalupe Pacheco, US Dept. of Health and Human Services
- Nillie Ye Yip
- Dr. Richard Payne, Duke Institute on Care at the End of Life at Duke University
Resources

Hospice Foundation of America
- www.hospicefoundation.org
- www.hospicefoundation.org/infocenter
- www.hospicedirectory.org

AARP
- www.aarp.org/relations/healthy-care-caregiver-end-of-life-care.html

Agency for Healthcare Research and Quality
- www.ahrq.gov/research/endlife/ptend/life.html

Aging with Dignity
- www.agingwithdignity.org/five-wishes.php

American Bar Association’s Commission on Law & Aging
- www.abanet.org/aging/toolkit

For More Information
For more information on hospice care, grief and bereavement, caregiving and end-of-life issues, please visit our website at www.hospicefoundation.org
Or call us toll-free at: 1-800-854-3402

Other resources:
Centers for Medicare & Medicaid Services
www.cms.gov

National Hospice and Palliative Care Organization
www.nhpco.org

National Long Term Care Ombudsman Resource Center
www.ombudsman.org

Office of Minority Health
http://minorityhealth.hhs.gov

U.S. Uninsured Help Line
1-800-234-1317

National Center for Cultural Competence
www.nccc.georgetown.edu

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National Resource Center for LGBT Aging
www.lgbtagingcenter.org

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- www.cms.gov

CMS toolkit on written translation

Foundation for Health Coverage Education
- www.coverageforall.org

Institute for Care at the End of Life
- http://divinity.duke.edu/initiatives-center/icatel

National Association of Social Workers
- www.socialworkers.org/practice

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Office of Minority Health
www.omh.gov
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