Culturally Appropriate Hospice and Palliative Care

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Disclosures

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Objectives for Today

• Demographic trends, disparities and burdens for migrant populations during advanced illness and end of life
• Patient/family-centered care and decision making
• Understand how the tenets of Cultural Humility can be applied to advanced illness and end of life
Major trends for Minnesota

Aging
Diversity & Immigration
Population Shifts

+ 3
For the first time in MN history: More 65+ than school-age by 2020
Silver Tsunami
• Over 50% of U.S. adult deaths occur in hospitals
• Virtually all seriously ill persons spend time in hospitals
• Up to 55% of Medicare decedents had at least one stay in the ICU in the 6 months prior to death
• Death among strangers in a strange place
Note: Because small numbers of individuals are listed as both black and Hispanic, totals are slightly greater than 100 percent.

Sources:

Primary* Refugee Arrivals to MN by Region of World
1979-2016

Number of arrivals

- Southeast Asia
- Sub-Saharan Africa
- Eastern Europe
- FSU
- Middle East/North Africa
- Other

*First resettled in Minnesota
Population by age and race
Minnesota, 2016

Sources:
U.S. Census Bureau, Population Estimates.
Aging of Diverse Communities

- Over 20% of older adults in the US are racial/ethnic minority
  - 8% Black → 114%
  - 7% Latino → 220%
  - 3% Asian / Pac Isl → 145%
  - <1% Native Am → 145%

- The projected growth for this group through 2040 is 160% (c/w’d 50% for white)
EXPERIENCE ANOTHER WORLD WITHOUT LEAVING YOU.
Health equity means that everyone has a fair and just opportunity to be as healthy as possible.

Life Expectancy in Twin Cities – 13 years

Zip code is more important than genetic code
Association Between Immigrant Status and End-of-Life Care in Ontario, Canada

Christopher J. Yarnell, MD; Longdi Fu, MSc; Doug Manuel, MD, MSc; Peter Tanuseputro, MD, MHSc; Therese Stukel, PhD; Ruxandra Pinto, PhD; Damon C. Scales, MD, PhD; Andreas Laupacis, MD, MSc; Robert A. Fowler, MDCM, MS(Epi)

End-of-Life Care Among Immigrants: Disparities or Differences in Preferences?

Michael O. Harhay, PhD; Scott D. Halpern, MD, PhD
Cultural differences: Survey of 800 patients

Should a patient:

Be told of a cancer dx? Decide about withdrawing LST?

Blackhall, JAMA, 1995; 274:820
EoL Disparities

- AA less satisfied w QoC and communication with providers
- Outcome care conferences more likely discordant
- Worse pain and sx management
- Minorities more likely to die in hospitals
- Less likely to be aware of and to complete AD
- Lower rates of hospice use and higher disenrollment

J Palliative Medicine 2013, 16(11)
“To be rooted is perhaps the most important and least recognized need of the human soul. [...] Uprootedness is by far the most dangerous malady to which human societies are exposed.”

Simone Weil
From patient-centered approaches only, to **patient/family-centered** care and decision making

(Castañares, Davis, McLaurin, 2012)
Family and Kinship

“Whoever the person says his or her family is. It may include relatives, partners and friends.”

Canadian Hospice and Palliative Care Association, 2013

Are there any family members or other persons who should be present and involved in your care?
Family Systems Lens

Immigrant Experience and the EoL

Clinically, making assumptions about individuals based on ethnic and cultural identity risks stereotyping. However, ignoring the profound influence of culture and social situation on patients’ experiences of illness, expectations of medical interventions, communication styles, and ways of coping can lead to misunderstanding, conflict, anger, resentment, and lower quality of care.

JAMA, March 11, 2009—Vol 301, No. 10
Patient-Reported Barriers to High-Quality, End-of-Life Care: A Multiethnic, Multilingual, Mixed-Methods Study

- Finances/health insurance barriers
- Doctor behaviors
- Communication chasm between doctors and patients
- Family beliefs and behaviors
- Health care system barriers
- Cultural and religious/spiritual barriers

A framework for why health disparities occur

THE PATIENT

THE HEALTH CARE SYSTEM

THE PROVIDER(S)

Quality of Healthcare

Difference

Non-Minority

Minority

Adapted from
Source: Gomes and McGuire, 2001
Cultural Competence

Ability to understand, appreciate, and interact with persons from cultures and/or belief systems other than one’s own.

Knowledge and understanding of another person’s culture: adapting interventions and approaches to health care to the specific culture of the patient, family, and social group.

(McGraw-Hill)

(Medical Dictionary for the Health Professions)
Cultural Humility

“Cultural humility incorporates a lifelong commitment to self-evaluation and critique, to redressing the power imbalances in the physician-patient dynamic, and to developing mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals and defined populations”

Tervalon and Murray-García, *Journal of Health Care for the Poor and Underserved*; May 1998; 9, 2; 1998
Cultural Humility

- Life-long attitude and process
- No power imbalance – each person brings something different
- Partnership with people and groups
“ability to maintain an interpersonal stance that is other-oriented (or open to the other) in relation to aspects of cultural identity that are most important to the person”

Lifelong commitment to learning and critical self-reflection
Communication Issues

Don’t attribute to culture what is lack of education

**Background:** Studies of end-of-life care have shown that Latino patients want more aggressive care compared to white patients. While this has been attributed to aspects of ethnicity, national origin, and religion, it is possible that limited education might obscure the true relationship between Latino patients and their end-of-life care preferences.

**Conclusions:** Educational level was an independent predictor of end-of-life preferences after hearing a verbal description of advanced dementia. After viewing a video of a patient with advanced dementia there were no longer any differences in the distribution of preferences according to educational level. These findings suggest that educational level is an important variable to consider in research and in patient care when communicating about end-of-life care preferences. While attention to patients’ culture is important, it is also important to avoid ascribing choices to culture that may actually reflect inadequate comprehension. Attention to communication barriers with techniques like the video used in the current study may help ensure optimal end-of-life care for Latino patients irrespective of educational level.
Communication Issues

• What have you already been told about your illness?
• The cancer has spread
• What questions do you have?
• Can you describe to me what we just talked about in your own words?
Box 2. Questions to Improve Cultural Understanding of Illness

Acculturation is the modification of a group's behaviors, values, and beliefs as a result of contact with a dominant culture. Assessment of acculturation status can help clinicians understand how Latino patients have adapted their perspectives in response to the dominant local culture (Anglo European-American in much of the United States).

In general, be open, curious, and respectful.

Preface with such comments as

“The kinds of care we provide and the way we talk to patients may be different here than in the country you came from. I want to provide you the best possible care, so it would help me if I understood more about your culture.”

Questions to ask about acculturation include

“What language do you speak at home?”

“In what language do you watch television or read the newspaper?”

“Were you born in the United States?” If no, ask,

“At what age did you immigrate?” and

“How long have you lived in the United States?”

Questions to ask about patient's culture of origin (can replace “your culture” with the name of the country the patient came from)

“Tell me what I need to know about your culture.”

“What do you think is the cause of this illness?”

“How would this illness be treated in your culture?”

“How do doctors in your culture talk with people about illness?”

Based on Carrillo et al\(^48\) and Kleinman.\(^49\)
Elicit the Patient’s Explanatory Model of Illness
Address the Patient’s RS Values
Determine the Patient’s Desired Approach to Truth Telling
Understand How the Patient’s Family Is Involved in the Care
Negotiate Cultural Conflicts
LEARN Model

- Listen
- Explain
- Acknowledge
- Recommend
- Negotiate

A teaching framework for cross cultural health care: Application in family practice. West J. Med. 12(139), 93-98.)
Lifelong Commitment to Learning and Critical Self-reflection

- What may be some of the assumptions or biases that you and others may have?
- What feelings do you experience and how are those changing as you get to know patients and their stories better?
- How can we suspend judgment and remain respectfully curious?
Recognizing and Challenging Power Imbalances
85% of immigrants to the U.S.A. have never been to an American’s home.
“An inhospitable space is one in which we feel invisible--or visible but on trial. A hospitable space is alive with trust and good will, rooted in a sense of our common humanity. When we enter such a space, we feel worthy because the host assumes we are.”

Parker J. Palmer
Recognizing and Challenging Power Imbalances

• What power imbalances can you identify?
• How would you best challenge them?
• How can you/we connect more?
• What does “Hospitality” mean to you in the context of your practice?
Developing Partnerships and Institutional Accountability
Developing Partnerships and Institutional Accountability

• What does it mean to you?
• What system changes can you think of?
Along with the capacity for mobility, reinvention and resilience required of migrants, there is another side to our world on the move that deserves greater recognition and understanding. Attending to the situation of the migrant at times of illness and death is to open ourselves to the coming together of two of the most radical thresholds of bodily estrangement and vulnerability: the movement across territories and from life to death.”

Cultural Humility

- Challenging assumptions
- Challenging power imbalances
- Challenging individualism

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