# Embracing Cultural Humility in Palliative Care: A Journey from the Professional to the Personal

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# Disclosure & requests

- Presenter has no relevant financial or non-financial relationship(s) in the products or services described, reviewed, evaluated or compared in this lecture

- Details of any case study examined, except for the presenter's own, are a composition of cases with similar cultural variables and medical details in order to protect the privacy of patients and families involved

- Due to *personal* details included in lecture, presenter ask that no pictures or recordings be taken

- This talk is meant to be interactive, there are opportunities throughout to participate

## Objectives

- Examine how our own personal cultural identities can (and do) intersect with those of the patients and families we serve
- Understand how the medical model "culture" can impact how a patient and family may make medical decisions at the end-of-life
- Describe how cultural identity impacts decision making at the end-of-life
- Explore the importance of understanding and respecting culture at the end-of-life

## Definitions:

- Cultural Humility:  the ability to maintain an interpersonal stance that is open to the "other" in relation to aspects of cultural identity that are most important to the person, family, group etc.

- Implicit bias:  *unconscious, automatic*
  *Example:* being surprised that your Black colleague has an advanced degree.

- Explicit bias:  *conscious, deliberate*
  *Example:*  All people who have neck tattoos are gang members

# Cultural Variables

# What is a journey?

*Miriam Webster Dictionary* definition:

- **1 :** something suggesting travel or passage from one place to another
  - the *journey* from youth to maturity
  - a *journey* through time
- **2 :** an act or instance of traveling from one place to another
  - A trip
  - three-day *journey*
  - going on a long *journey*
- **3** *chiefly dialectal*
  - a day's travel
  - to travel over or through

# Forrest

- Son & daughter arrive
- Daughter immediately begins telling Forrest's story to all providers who enter the room
  - Humanizing him
  - Consciously attempting to counteract any biases that may be present in any provider, nurse, tech etc.
  - Not "just" another patient in Trauma ICU
  - Brings pictures & Forrest's Bible from home
  - Plays Forrest's favorite music non-stop
- Requests Palliative Care Team

## US Population

White ……………………………………76.6%

Black/African American…………..13.4%

American Indian/Alaska Native….. 1.3%

Asian……………………………… 5.8%;

Native Hawaiian/Pacific Islander…..0.2 %;
Two or more races………………… 2.7%
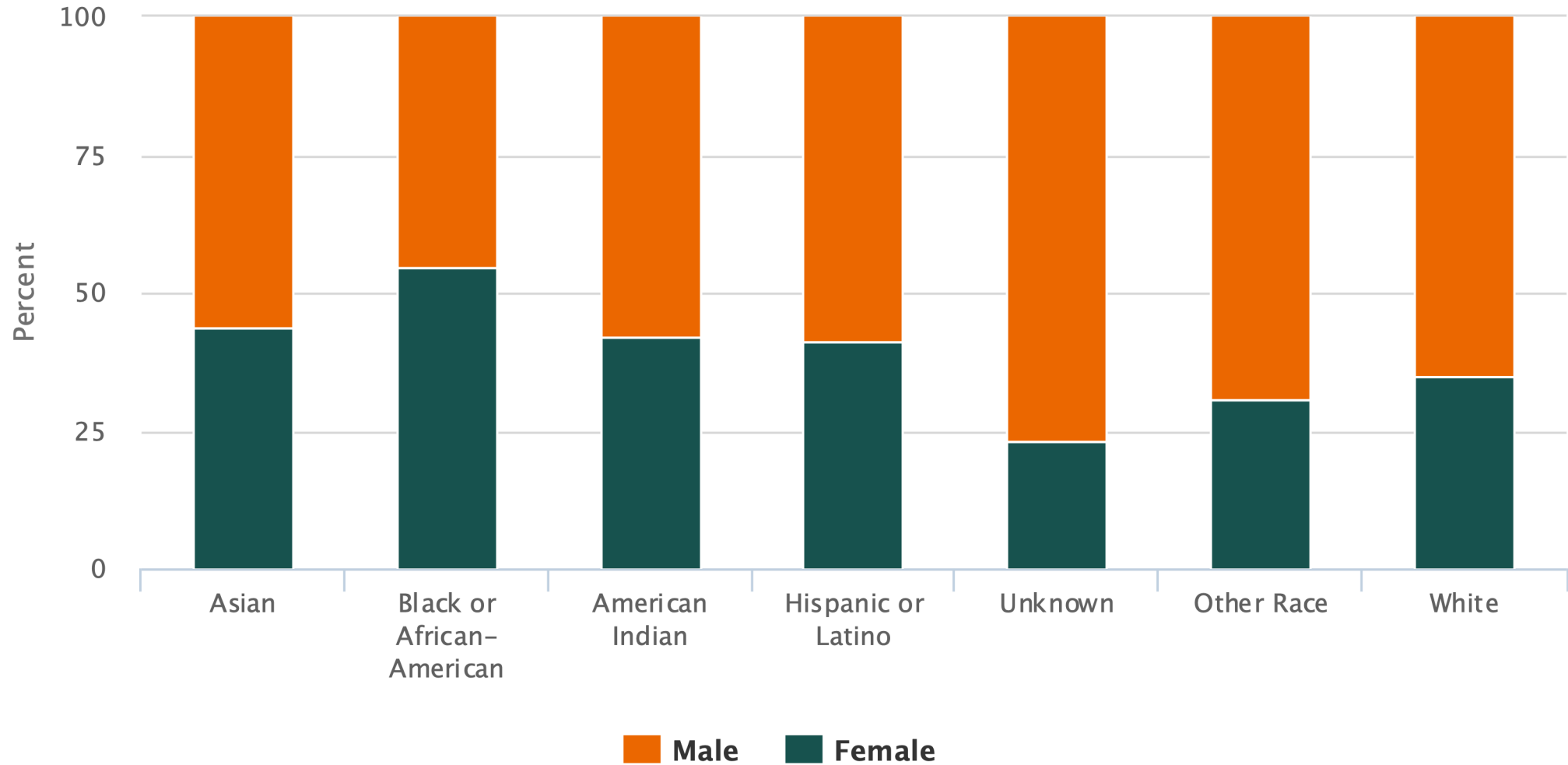
Hispanic/LatinX……………………18.1%

Women……………………………...50.8%

# Physician Demographics

- "…..approximately 8.9 percent of physicians identify as Black/African-American, American Indian /Alaska Native, and Hispanic/LatinX."

- Example:

"Black/African-Americans comprise 13.4% percent of the general population, yet account for only 4 percent of the physician workforce."

# U.S. Physicians by Race, Ethnicity, and Sex, 2013



Percent

100
75
50
25
0

Asian | Black or African–American | American Indian | Hispanic or Latino | Unknown | Other Race | White

■ **Male** ■ **Female**

## Physicians in Hospice & Palliative Medicine (HPM)

- Although the race and ethnicity composition of practicing HPM physicians is not readily available:

  - Black/African American physicians are only 4.5% of HPM fellows compared with 5.3% of all physicians from 2010 through 2012.

  - Hispanic/LatinX fellows make up 7.7% of HPM fellows compared with 6% of all physicians from 2010 through 2012.
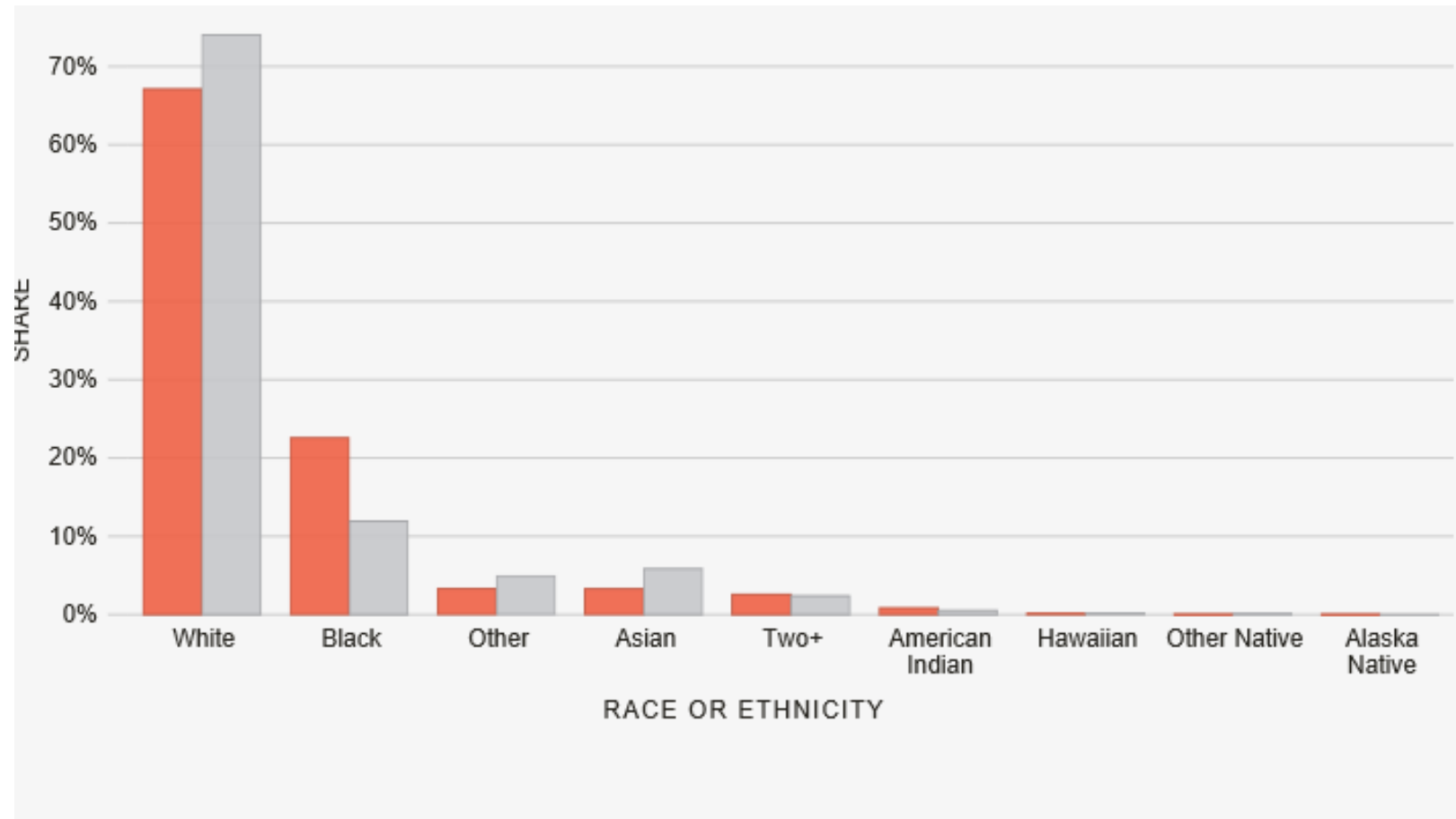
# Social Worker Race/Ethnicity
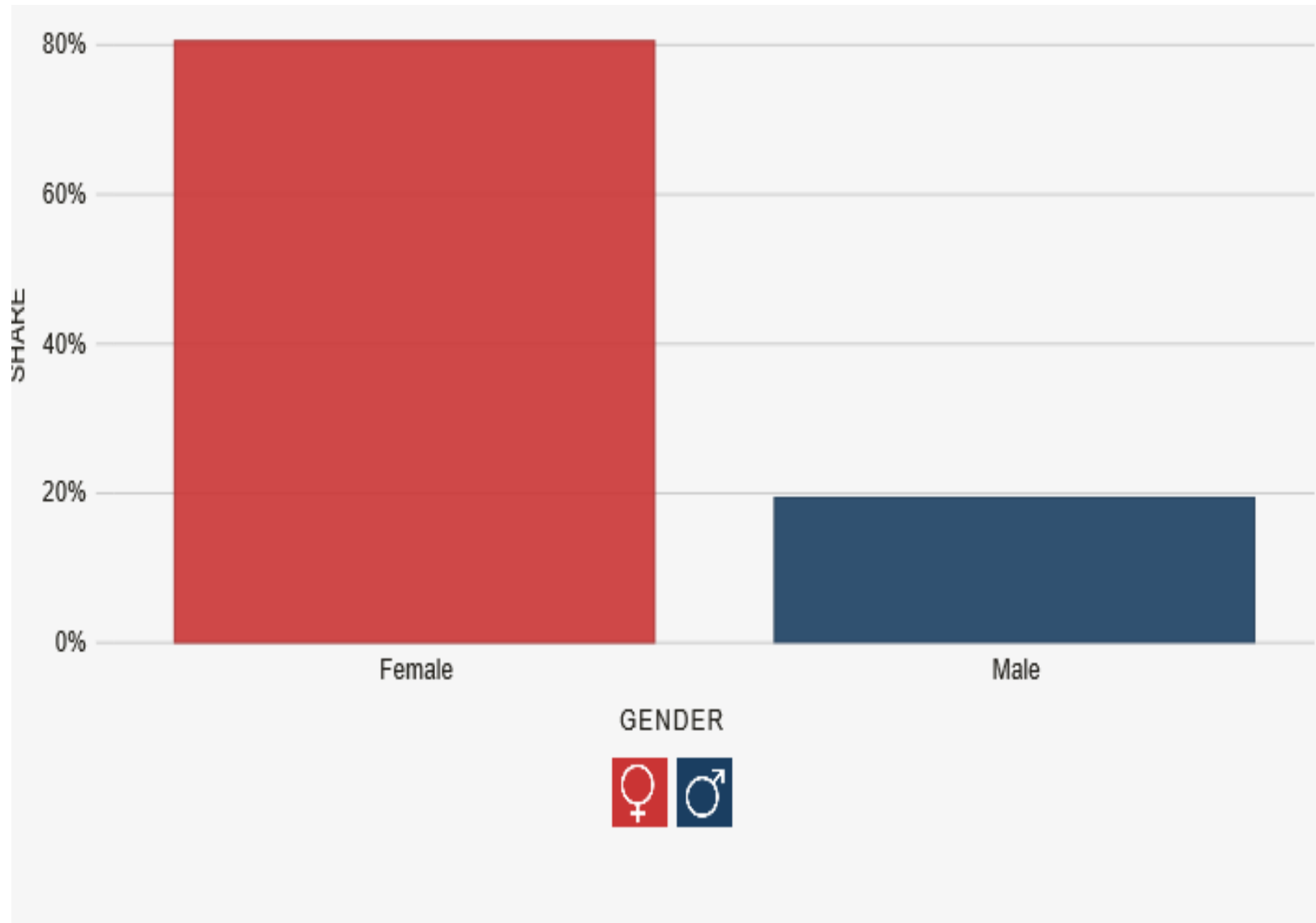
**MOST COMMON RACE OR ETHNICITY OF SOCIAL WORKERS**
**1.** White
**2.** Black or African American
**3.** "Other" & Asian

■ Percent of social workers in workforce

□ Percent of individuals by race in workforce

# Social Workers by Gender

# Nursing Demographics

- National Survey of Registered Nurses:
  - Approx. 3.0 million registered nurses (RNs) residing in the U.S.
    - non-Hispanic white nurses……………75.4%

  - minority nurses underrepresented:
    - Black/AA (non-Hispanic)…………………………………9.9%
    - Asian……………………...………………8.3%
    - Hispanic/LatinX……….…..……............4.8%
    - Multiracial (2+ races)…….…..………1.3%
    - American Indian/Alaska Native……...0.4%

# Nurses by Gender



GENDER:

About 9% of RNs are men

## Case Study:

## Malika
(case composition)

- 3-years old
- Refugee family from East Africa
- Limited English proficiency (LEP)
- Muslim
- Cannulated onto ECMO for severe respiratory failure
  - ECMO described as "life support" by the medical team
- ECMO therapy not working; patient worsening
- Family refused to "allow" team to remove "life support"
- On day 3 of ECMO, Malika died when the circuit failed

## How do we approach patients of a different worldview/culture than our own?

- Be aware of our own implicit & explicit biases
- Withhold judgement, practice openness to the differences, especially differences that make us uncomfortable
- Consideration of language that we use
  - layperson versus technical medical language
- Be present, remain present even when a patient or family is "difficult" or challenges us either directly or by their cultural "difference" from our own
- Take time to listen
  - Acknowledgement that this is difficult in a fast paced environment such as an ICU
- Allow our patient, patient's family to lead us
- Maintain flexibility as safely able
- Develop culturally tailored tools such as the *Conversation Guide* and ABCDE to determine level of cultural influence in the patient and family's decision making process

# ABCDE Cultural Assessment Model

- Attitudes of patient & families
  - What attitudes does this ethnic /cultural group in general – and the patient and family in particular – have about truth telling with regard to diagnosis and prognosis?   • What is their general attitude towards discussion of death and dying? • Do they have positive or negative attitudes about particular aspects of care?

- Beliefs
  - What are the patient's and family's religious and spiritual beliefs, especially relating to the meaning of death and dying, the afterlife, and miracles?

- Context
  - Determine the historical and political context of the patient's and family's lives, including place of birth, refugee or immigrant status, poverty, experience with discrimination, health disparities, language spoken, and degree of integration within their ethnic community and the degree of assimilation into Western culture

- Decision making style
  - What is the general decision-making style of the cultural group and specifically of the patient and family? • Is the emphasis on the individual decision making process or the family decision making process?

- Environment
  - • What resources and support are available to the patient and family?   • What resources are available to assist the health care provider to interpret the significance of the patient's culture?

I would like to invite you to attend the breakout session entitled: *Honoring a Family's Goals about a Meaningful Life and Death: A case study* this afternoon lead by my colleague Lauren Schmidt, MSW, LICSW

Lauren will be looking at culture from another vantage point, as we often default to thinking about culture from a race/ethnicity perspective.

Lauren will be focusing on cultural aspects of a white, cis-gender, heterosexual couple whose focus on quality of life from their cultural perspective led them to enact goals of care that were disparate from what others, including what many healthcare providers believed their goals should be.

## Discussion questions:

- What reflections do you have as a palliative care provider about the intersection of your own personal and professional cultural identities?

- How do you observe medical culture impacting how families make decisions at the end of their loved ones lives?

- What observations do you have where an individual or family's cultural identity impacted the providers caring for them?

- Is anyone able to share a time when you observed the care that was provided to a patient and/or family impacted by explicit or implicit biases?

# Immense gratitude to:

- **My dad, *Forrest* for his integrity, love of life, his resilience & immense work ethic that he imparted on me and the rest of our family. Pops, you are forever loved and are missed beyond the bounds of the universe! Thank you for always believing in me.**

- **My *family*, both by blood and chosen**

- ***Katie O'Connell*, MD, MPH, who by ensuring my Dad's comfort at the end-of-his life allowed me to be fully present with him and my family**

- *Caroline Hurd*, MD & the Palliative Care Program at Harborview Medical Center for hearing Dad's story, our family story, supporting our family, and supporting the medical team in being able to care for my dad in part by honoring his and our family's culture

- *Andrew Luks*, MD and the Harborview Trauma ICU physicians and nurses

- Seattle Children's Hospital Division of Bioethics & Palliative Care

- *Tom Brogan*, MD, for his compassion and kindness

- *Nanibaa' Garrison*, PhD (Diné) for mentorship, guidance and encouragement to share Dad's story, to share my story.

- **All of you for your time and for holding space with me today as I share my journey from the professional to the personal**

# Data sources

- Robert Woods Foundation & IOM, 2011

- US Census Bureau Data database

- http://aahpm.org/uploads/AAHPM_Workforce_Study_Executive_Summary_September_2017.pdf

- Office of Financial Management, Population Estimates

- AAMC Data Warehouse: Minority Physician Database, AMA Masterfile, and other AAMC data sources, as of 1/22/2014.

- The US Nursing Workforce: Trends in Supply and Education, Health Resources and Services Administration, Bureau of Health Professions, National Center for Health Workforce Analysis, April 2013

- The Registered Nurse Population: Findings from the 2008 National Sample Survey of Registered Nurses, US Department of Health and Human Services, Health Resources and Services Administration, September 2010

- Phillips, J. M., & Malone, B. (2014). Increasing racial/ethnic diversity in nursing to reduce health disparities and achieve health equity. *Public health reports (Washington, D.C. : 1974)*, *129 Suppl 2*(Suppl 2), 45–50. doi:10.1177/00333549141291S209

- Kagawa-Singer, M., & Backhall, L. (2001). Negotiating cross-cultural issues at end of life. Journal of American Medical Association, 286(3001), 2993-.

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- Sabin, J. A., Rivara, F. P., Greenwald, A. G., 2008. Physician implicit attitudes and stereotypes about race and quality of medical care, Medical Care, 46 (7) July 2008, 678685.

- Hook, J.N. (2013). *Cultural Humility: Measuring openness to culturally diverse clients*. Journal of Counseling Psychology.

- National Association of Social Workers, Center for Workforce Studies & Social Work Practice

- The Ways Inequality Affects Black Americans at the End of Life  https://www.nextavenue.org/end-of-life-inequality-black-americans/

- Tuskegee Experiment: https://en.wikipedia.org/wiki/Tuskegee_syphilis_experiment

- Alaska Native Health Tribal Health Consortium *Conversation Guide* *https://anthc.org/palliative-care/*

- Alicia Adiele, MSW, LICSW & Arika Patneaude, MSW, LICSW, EMMHS, *Bias in the hospital setting,* Lecture, December 2015

- Slide #10 adapted from *Towards a Culturally Competent System of Care,* Terry L. Cross (Seneca Nation)  et al…1989

- Slide #18  graphic from Minority Nurse.Com; https://minoritynurse.com/about-minoritynurse-com/

- https://www.seattlechildrens.org/globalassets/documents/for-patients-and-families/pfe/pe563.pdf

- Georgetown University National Center for Cultural Competence

- **All personal pictures are the presenter's own and cannot be shared or reproduced**