Cultural Competency and Humility: A Prep Course for Hospice and Palliative Professionals

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DISCLAIMER #1

• This hour is not designed to create a culturally competent and humble human being in all aspects of life in our society. Our goal is much more reasonable and modest, and our focus is more particularly placed on our day-to-day work in hospice/palliative care.

DISCLAIMER #2

• This hour is not to give you bullet-points of information of a single racial/ethnic and religious group’s beliefs and practices.
“Cultural humility is a lifelong process of self-reflection and self-critique. The most serious barrier to culturally appropriate care is not a lack of knowledge of the details of any given cultural orientation, but the providers’ failure to develop self-awareness and a respectful attitude toward diverse points of view.”


Culture: The learned, shared, and transmitted values, beliefs, norms, and life practices of a particular group that guides thinking, decisions, and actions in patterned ways.


➢ Why are we talking about cultural competency and humility today?
➢ Why are they important in healthcare/palliative and hospice care?
Shifting Perspective – Culture Matters (in Health Care)

- Culture provides context in which the patient experiences diseases.

  Disease in the Western medical paradigm is malfunctioning or maladaptation of biologic and psychophysiological processes in the individual, whereas illness is shaped by cultural factors. Disease is a state of normative deviance, whereas illness is understood in terms of perceptions, labeling, explanation, valuation of the discomforting experience, and process embedded in a complex family, social, cultural nexus. Because these experiences are an intimate part of social systems of meanings and rules for behaviors, they are strongly influenced by culture as we shall see, and so illness experiences are similarly embedded in cultural factors.


DISCLAIMER #3

- Yes, we are going to talk about race/ethnicity and diversity today. (But, the presenter does not come from the Human Resources department.)
- This is not annually mandated education (i.e., your participation is voluntary).
- There will be no “forced” small group sharing of thoughts and feelings.

WARNING

Handle any portion of your learning experience today with care; use it as a tool in your mental toolbox that helps you to understand your patient better, not a “colored lens” through which you see him/her (this could lead to STEREOTYPING).
STEREOTYPING ALERT:

1. **Unity vs. Diversity** – Any cultural group is not homogeneous (though a cultural unity may be detected).
2. **Subcultures** within each racial/ethnic group (intracultural differences) exist.
3. **Culture is fluid and dynamic.**


"Is it because he is black (Hmong, Latino, etc.)?"

“Efforts to use racial or ethnic background as simplistic, straightforward predictors of beliefs or behaviors will lead to harmful stereotyping of patients and culturally insensitive care of the dying….Culture is only meaningful when interpreted in the context of a patient’s unique history, family constellation, and socioeconomic status.”


The intersectionality of our differences

*(from a relational perspective)*

“We, as humans, are a complex intersection of the many dimensions of diversity that make us unique and yet like other people. Such thinking supports an understanding of the complex interactions of social relations and fosters the skills necessary to navigate our increasingly multicultural world. I cannot separate my gender from my race or my ethnicity, or my mental from my physical abilities, or my age from my sexual orientation. I am a wonderfully made complex set of variables that makes me uniquely me.”

Race and Ethnicity – Why They Matter (in Health Care)

- Race/ethnicity is a greater personal attribute than other socioeconomic factors (e.g., gender, income, educational achievement, etc.) relevant to a predisposition to use hospice care and other health-care decision-making.


- “Even patients who generally display low adherence to ethnic culture may report to ethnically-derived, nonmainstream modes of health behavior in certain situations, especially those involving great emotional stress, such as terminal illness.”


Different Attitudes among Racial/Ethnic Minorities in Health Care Decision-Making

- More racial/ethnic minorities prefer the use of life support and other aggressive life-sustaining measures at the end of life than whites and want to live as long as possible under any circumstances.

Different Attitudes among Racial and Ethnic Minorities in Health Care Decision-Making

Racial and ethnic minorities patients hold less knowledge of advanced care directive and more resistant to it than whites.*


Different Attitudes among Racial and Ethnic Minorities in Health Care Decision-Making

African Americans are the most religious group as a whole in the United States (and more likely to identity religion as having had more influence upon their attitudes toward death).*

CI, Neubauer, et al., “Racial Differences in Attitudes Toward Hospice Care,” The Hospice Journal (1990); Reese, D. J. et al., “Hospice Access and Use by African Americans: Addressing Cultural and Institutional Barriers through Participatory Action Research,” Social Work (1999). According to the 1997 Gallup Poll, 71% of African Americans were Protestant (44% Baptist), 9% Catholic; only 6% had no religious affiliation.

Different Attitudes among Racial and Ethnic Minorities in Health Care Decision-Making

Different care-giving patterns*:

- African American patients are more likely to have a caregiver outside the immediate family (while European American patients cared by a spouse);
- Substantial intergenerational support between elders and their children exist;
- Hispanic elderly tend to live in the community and are less likely to utilize long-term care institutions;
- Hispanic elderly are almost twice as likely as the general elder population to have more than one limitation in activities of daily living. CI, Colon, et al., “Prevalence of Impairment and Functional Limitation Among Older U.S. Hispanic and Non-Hispanic Adults,” The J. of Pain and Symptom Management (2003); Colon, et al., “Prevalence of Impairment and Functional Limitation Among Older U.S. Hispanic and Non-Hispanic Adults,” The J. of Pain and Symptom Management (2003).
Changing Demographics (Race and Ethnicity – Why They Matter)

- By 2042, minorities are expected to become the majority in the United States. In 2050, the United States is projected to be 54% minority.

- According to the U.S. Census Bureau estimate, in 2015 Minnesota is 19% “people of color” and 81% Whites. (In 1980, “people of color” were 3.8%, in 1990 6.3%, and in 2000 11.8%. From 2000 to 2015 Minnesota added 4 times as many “people of color” as Whites.)

Racial/Ethnic Disparities in Hospice Care – Snap Shots

- Between 2000 and 2011, the proportion of Medicare beneficiaries who enrolled in hospice nearly doubled from 23% to 45%. However, despite its growth, African Americans continue to use hospice at lower rates (35%) than whites (47%) – Johnson, Payne, Kuchibhatla, Tulsky, “Are Hospice Admission Practices Associated with Hospice Enrollment for Older African Americans and Whites?” J. of Pain and Symptom Management (2016).

- 83% of hospice patients nation-wide are whites – National Hospice and Palliative Care Organization (2000).

"Access to hospice services, i.e., admission to hospice care, among minority groups has been consistently low."

Racial/Ethnic Disparities in Hospice Care – Snap Shots

- Persistent health care disparities throughout the course of life (shown in, e.g., higher infant and maternal mortality rate, shorter life expectancy, inadequate pain relief, greater instability at hospital discharge, fewer mammograms, etc.)

  "Large disparities exists between use of the most varied medical services by minorities and use of the same services by European Americans…Evidence of disparities is most plentiful for African Americans." - Krakauer, E. L., Crenner, C., Fox, K., "Barriers to Optimum End-of-Life Care for Minority Patients," JAGS (2000).

- Lack of racial/ethnic diversity among hospice workers (including hospice volunteers) and lack of primary physicians of color as referral sources for hospice (and lower rate of African Americans access to primary physicians and lower rate of African American with health insurance than whites)


Race and Ethnicity – Why They Matter

"Same treatment does not mean equal treatment."

"Whites tend to take an assimilation approach and ignore power and privilege by downplaying differences. This approach results in people of color feeling disrespected. 'We are all alike… We all bleed the same way… I don’t see race. You are just like me!' This kind of thinking makes people of color smile politely and then run to the nearest exit." - Plummer, D., Some of My Friends Are… The Daunting Challenges and Untapped Benefits of Cross-Racial Friendships (2019).
REMINDER: Lack of sensitivity to, and respect for, cultural differences may compromise end-of-life care for minority patients.

“Every person is like all others, like some others, and like no others.”
(Quoted in Payne, R., “Culturally relevant palliative care,” Clinics in Geriatric Medicine [2015])

INTERMISSION & SHORT Q&As

Brief Case Study
A chaplain speaks at an Advance Care Directive training session —
"The patient filled out the form and looked at her daughter at bedside and said, "This is also what you want, right?"
When I noticed that, a red flag went up in my head!"
Questions:

- What do you think raised a “red flag” in this chaplain’s mind?
- What was his main concern?
- What bioethical principle is at stake in this case?

Four Bioethics Principles

- **Autonomy**: The concept that characterizes the person (patient) as a solitary competent individual who possesses a sphere of protected activity or privacy free from unwanted interference. Cf. Kuczynski, M., “Recovering the family: the process of consent in medical decision-making,” The Hastings Center Report (1988).

**Q. Is the principle of autonomy universally accepted?**
Western Civilization “at a Glance”

Phase 1: “…how to order society…how to balance the needs of individuals and groups... Most societies have chosen the sociocentric answer…”

Phase 2: “The sociocentric answer dominated the most of the ancient world, but the individualistic answer became a powerful rival during the Enlightenment.”

Phase 3: “The individualistic answer largely vanquished the sociocentric approaches in the twentieth century (in the Western world).”

- Excerpted from Haidt, J., The Righteous Mind (2012), reorganized by the presenter.

“I think; therefore I am.” – Rene Descartes (1596-1650)

(“I am because we are.” - A Ubuntu [South African] proverb)

Biomedical Ethical Principles of, by, and for the “Weird” People?

“It is a truly unusual group: people from Western, Educated, Industrialized, Rich, and Democratic (WEIRD) society.”

A distinctive trait of the WEIRD people –

"...Westerners tend to have more independent, and less interdependent, self-concepts than those of other populations."

- Henrich, J. et al., “The weirdest people in the world?”

Much research has underscored how Westerners have more independent views of self than non-Westerners...people from Western populations are far more likely to understand their selves in terms of internal psychological characteristics, such as personality traits and attitudes, and less likely to understand them in terms of roles and relationships, than are people from non-Western populations...

Q. So, westerners, in general, are equally individualistic (in healthcare decision-making)…?

"American medical ethics places a premium on patients serving as their own decision makers."

The Weirdest People in the World…?

"Americans stand out relative to other Westerners on phenomena that are associated with independent self-concepts and individualism. Americans are, on average, the most individualistic people in the world."

"The unusually individualistic nature of Americans may be caused by, or reflect, an ideology that particularly stresses the importance of freedom and self-sufficiency, as well as various practices in education and childbearing that may help to inculcate this sense of autonomy."

- Henrich, J., et al., "The weirdest people in the world?"

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<th>Autonomy - Italian Examples</th>
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<tr>
<td>✓ Autonomy is often synonymous for isolation.</td>
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<td>✓ The possibility of truth-telling (to the patient) withholding still exists (but not to the family).</td>
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<td>✓ The general public holds the attitudes that the patients will never acquire enough knowledge to enable them to fully and appropriately participate in their care.</td>
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<td>✓ The patients typically know or at least strongly suspect the truth, but they are part of a generally accepted farce of deception that prevents open discussion about the truth and how to act on it.</td>
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<th>Autonomy - Greek Examples</th>
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<td>✓ “Doctors should not lie, but should disclose to their patients the part of the truth they are ready to accept.”</td>
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<td>✓ Diverse opinions exist regarding the Greeks’ wish to be informed of the nature of their illnesses (per age, marital status, occupation, education, etc.) but the words “rights to know” are rarely invoked.</td>
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<td>✓ The extent of medical litigation is still limited and Greek doctors do not feel obligated to disclose the truth in the same way American or British doctors would.</td>
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Autonomy - Russian Examples

- The doctor, not the nurse, is expected to transmit the medical news to the family or to the patient.
- Patient problems are family problems and are discussed by the entire family; the entire family makes decisions.
- It is important to include family members in the decision about the time and the way that “telling of the truth” about the illness will take place.


Truth-Telling (Cancer Diagnosis)

- A low percentage (< 40%) of oncologists revealed the word cancer (and substituted with a “swelling,” “tumor,” “lump”) in Africa, France, Hungary, Italy, Japan, Panama, Portugal, and Spain; a high percentage (> 80%) revealed it in Austria, Denmark, Finland, The Netherlands, New Zealand, Norway, Sweden, and Switzerland;
- The majority of the physicians tell the family diagnosis;
- The languages between doctor and patient is constrained by cultural norms.


“While in North America, the move from paternalism to autonomy has been substantial, in Europe and other parts of the world, these ideas coexist.” - Oppenheimer, A. et al., “Cross-cultural ethical decision-making in critical care,” Critical Care Medicine (1988)
“...autonomy remains a vital moral bulwark against oppression, but [that] it is not an all-encompassing guide to living good lives or building good communities.”

“Any conception of autonomy that fails to incorporate socially situated interpersonal relations rests on illusion.”

Question: In increasingly multi-racial/multi-ethnic, diverse America...

- Are ALL Americans equally individualistic or are some groups more collectivistic?
- Do some racial/ethnic minorities possess different social values and attitudes toward healthcare decision-making from whites?

Answer: (Your Answer Here)

“...the individualism associated with American culture is a minority paradigm in relation to the world’s population and cultural frameworks. The impact of the cultural imposition of Western principles is evident not only in global relationships but also within the common diverse cultural context of American society.”
Multi-Racial/Multi-Ethnic America – Snap Shots

"In the ethnic groups (e.g., East Asian, Bosnian Americans, Japanese, Korean Americans, Middle Eastern Lebanese, etc.), group consensus and decision making by family are more valued than individual decision making."


Hispanic older adults are less likely than Whites to believe that a formally designated health care proxy was needed when the family was involved in the medical setting, because of the risk that family members other than the designated surrogate could be removed from the decision-making.


Among Korean, Japanese and Chinese Americans are found to believe that end-of-life decision making is the family's responsibility and that filial piety* and family-centered decision making patterns are commonly observed.

Filial piety: One of the key Confucian moral values; the concept widely accepted and culturally rooted in East Asia that a family member, particularly in a child-parent relationship, has a particular obligation that he/she must undertake, and to do other than what is culturally expected would be a failure or disgrace (or “to lose face”).


An intracultural conflict - Frequent conflict between the dominant (White) culture and the subgroup culture, between the group and the individual in American

"This idea that the younger generation is culturally mandated to take care of their parents is deeply ingrained in the Chinese culture," Mr. Feng said. "Children are supposed to take care of older parents in need." But that tradition is being eroded, he said, by the increasing number of families that are geographically dispersed or in which both spouses have to work.


Informed Consent/Truth-telling

"In the case of bad news" being given in a mainstream health care context, there are high expectations among some cultural groups (e.g., Greek, Italian, Chinese, Indian Hindus, Middle Eastern Lebanese, Bosnian migrants/refugees, Indigenous peoples) that the family will assume a protector-advocate and gatekeeping role to ensure that if and when disclosures are made they are made in a manner that does not deny hope and/or plunge their ill loved one into a state of soul destroying and hopeless despair.”

"For Asian and Hispanic Americans, the family’s role is mean to remove the burden of making treatment decisions from the patient."


For the Chinese and other communities, it is considered callous and inconsiderate to give all the information regarding grave decisions directly and openly to the patient. Usually, the situation is discussed with the family, and only the information the family deems necessary is disclosed to the patient."

– Oppenheim, A. et al., “Cross-cultural ethical decision making in critical case.”

Japanese (American) Examples

✔ Talking about death and dying is not taboo in their daily conversations but do not occur with the patients who are close to death.
✔ The family should be informed of the patient information first and then family members would share the appropriate information with the patient.
✔ The preferred decision-making model is by a consensus among the physician and the family, and at times, the patient.
✔ The patients and families use Advance Care Directive to be rather intrusive; they use it in order to reduce burden on the family, not to expressive individual wishes.

Ethiopian (American) Communities

✓ The extended family is the most important institution.
✓ Families are responsible for managing the information, including diagnostic facts, and the illness experience of a family member during a period of illness. (A family will judge how and when they want to let a patient know and the disclosure of bad news is “staged.”)
✓ Deception has its more subtle passive forms – deceiving by omitting the truth rather than committing a falsehood.
✓ Denying the knowledge of an imminent death is mutually understood by the patient and the family.


“...the high value placed on open expression of emotion and on the rights of individuals to control their destiny are not necessarily shared by all segments of American society.”


Cultural Competency and Humility – Review

➢ “…the basic values, principles, and assumptions of western medicine and bioethics are themselves historically situated and culturally determined. They are the values and assumptions of a dominant, but no less particular, culture: the culture constituted by European and American philosophical and legal traditions.” - Krakauer, E. et al., “Barriers to Optimum End-of-Life Care for Minority Patients,” JAGS (2002); also cf. Koong, B. A. et al., “Understanding Cultural Difference in Caring for Dying Patients,” WJM (1995).
Cultural Competency and Humility – Review

"The use of autonomy as a panacea for ethical problems in medicine is a very recent, and peculiarly American solution to the problems of modern, technological biomedicine."


Cultural Competency and Humility – Review

Shifting Perspectives – Culture Matters (in Health Care)

"...our ethical framework must be recast and refined to remove the presumption that all health care encounters are unicultural."


A Scene at One Interdisciplinary Group Meeting...

A hospice nursing supervisor points out that a patient, Russian-speaking, has not completed the DNR/DNI portion of his POLST form. A social worker, looking resigned and sighing, "They are going back and forth... the patient doesn’t know that he is dying and the family doesn’t want to tell him... it’s a cultural thing..."
“It’s a cultural thing…”

Is there anything we can do about it?

OR

There is nothing we can do about it?

CHOICE A:

Paternalism: "Your doctor knows the best; don’t question and do as he/she says."

Principalism: The view that ethical decision making and problem solving are best undertaken by appealing to "universal" moral principles.


“This is our way (i.e., American medicine, health system, organizational policy, etc.)

or

no way (otherwise there would be anarchy)!"
CHOICE B

Powerlessness and Frustration: “We cannot do anything about it (because they are not going to change)”

Moral Relativism and Nihilism: “We cannot even question it or talk about it and we must give them whatever they want.”

Between the two choices…are there any other?

Changing Models/Expectations
  ➢ Old Model/Expectation
Changing Models/Expectations

- New Model/Expectation (?)

(Clarification: Ethical principles, organizational guidelines, philosophical frameworks, etc. are not bad things; they are useful on many occasions.)

REMINDER #1

“Cultural thing” is integral to the patient’s illness experience and to our understanding of it;

it is neither “deviation” from the norm nor “obstacle” placed in our normal care delivery.

REMINDER #2

Challenges Ahead

- Our Segregated Lives
  - 75% of white Americans do not have significant relationships or daily interactions with the people of color.
  - The typical social network of a white American is 1% black. Among whites, 91% of the people in their social networks are white; among black Americans, 3% of the people in their social networks are white; and among Hispanic Americans, about 64% were Hispanics, and among Asian Americans, about 54% were Asians.


A 2015 study of the American Sociological Foundation found that the highest level of segregation is between blacks and whites, the lowest is between Asians and whites, and the level between Latinos and whites occupies an intermediate position. A majority of whites, in both the expression of their beliefs and the practices of their lives, do not want to integrate with blacks.


Challenges Ahead – Social Context of Hospice Care

- The “Lock-in” Racial Inequality
  “A perpetual economic structure in America where, during the Jim Crow era and in its wake, racial discrimination leads to financial profits. This unfair advantage that happened early in America's history is present in the racial gap of family wealth distribution, homeowners associations, labor unions, political parties, school districts, and other groups that have created monopolies by excluding racial groups.”

Challenges Ahead

- How can we spread accurate information about hospice and dispel the misperceptions about the motives of providers and medical institutions advocating for advance care planning and greater hospice/palliative care use (through community partnership, through religious institutions and faith leaders, etc.)?

Hospice and palliative care programs are living up to their goals: There is currently no evidence of racial disparity in the pain treatment of dying patients. Cf. Wilkie, D. et al., “Pain and Symptom Management in Palliative Care and at End of Life,” Nura Outlook (2012).

- Public Health Advocacy


- How can we help strongly religious patients reframe the meaning of their spiritual beliefs (“Only God decides when life ends…” “It is in God’s hands…” in the context of their particular medical circumstances in such ways that do not exclude care in hospice and palliative care settings? (Does God/gods/Divine work through the hands and minds of hospice and palliative care workers…?)
Conclusion – Challenges and Hopes Ahead

The next time you encounter a situation where...

...an African American patient declines the Palliative team's repeated advice for hospice consult...

...the family of a hospice patient (immigrant from Ukraine) does not want the hospice team to use the word “hospice” in front of their mother...

...a Hmong patient enrolls in hospice care and the son does not want to discuss funeral arrangements...

...a Latino family wants to continue to care for their dying father despite your professional judgment that they are stretched thin and need a nursing home placement...

...a Somali patient is cared at home and always so many people are coming in and out of her apartment and you don’t know who is a family member, friend, or neighbor...

Can we stop and think...

“Maybe their responses are more normal and common and my reactions and perspectives represent the minority view, an outlier position, according to the rest of the world…”?

So, instead of asking...

“why can’t they as we do?”
How can we skillfully accommodate culturally different views and lead to less aggressive care at the end of life?
How can we help minority patients reframe the meaning of their particular beliefs in the context of their particular medical circumstances in ways that do not exclude care in hospice and palliative care settings?

(Paraphrased from Payne, R., "Racially associated disparities in Hospice and Palliative Care Access," J. of Palliative Medicine [2016] and changes added by the presenter.)

Steps Forward

✓ Take time to build trust.
✓ Involve local community leaders and agencies for education and promotion.
✓ Understand historical and social backgrounds and their psychological impact.
✓ Recognize "social justice" aspect of health care/hospice/palliative care.

Build racially/ethnically diverse workforce.

✓ Tailor services to meet unique needs of racial/ethnic minority communities.
Hospice workers of the 21st century will need to increase cultural competency and humility as a critical edge to their conventional clinical skills.

So, today, we have just begun

“(Cultural humility is) a lifelong process of self-reflection and self-critique… the most serious barrier to culturally appropriate care is not a lack of knowledge of the details of any given cultural orientation, but the providers’ failure to develop self-awareness and a respectful attitude toward diverse points of view.”

Any other challenges and signs of hope you see?
Thank You
and
I hope to see you all again soon!