INTEGRATING PALLIATIVE CARE INTO THE PCMH-N MODEL

Cultural Aspects of Care

1

Welcome

- Thank you for attending this event.
- For the in-person presentation, I will be using Active Learning Strategies, such as break out sessions, open discussion, and question and answer opportunities. Your active participation will enrich and enhance this presentation.
- Please ask questions and seek clarification whenever you have a concern.
- Please complete the evaluation. Your feedback is important.

2

2

Disclosures

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Continuing Education

Social Work

This course is approved by the NASW-Michigan Social Work Continuing Education Collaborative Approval # 121621-01, # CE Hours approved: 2

Presenter

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Professor Emerita

Learning Objectives

- Define culture and cultural groups
- Describe how culture influences palliative care
- Explain how sexual orientation impacts palliative and serious illness care
- Discuss the importance of cultural competence in pain and palliative care

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- It is important to note that permission was obtained from either the authors or the journal to give you this handout or the questionnaires/surveys.
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This Presentation

- During this presentation I am going to share stories from my clinical, professional, and personal experiences that enhance the content, and which will also, hopefully, open the door for more discussion.
- All of these stories really happened and are not made up.
- Since I'm Black and have predominately worked clinically in a city that is 85% Black, most of my stories will involve African Americans and the AA experience and issues of culture.
- It is my hope that those of you who have had experiences with other cultural groups will share your stories.
- If you do, this will help to provide some balance and a broader view of how culture and health intersect.

Group Discussion

What is Culture?

What are examples of cultural groups?

What is cultural competence?

Why Cultural Competence Is Important

- The cultural competence of healthcare providers is important and integral to the ability of the healthcare system to provide access and delivery of high-quality health care, particularly one that reduces health disparities for marginalized groups and people of color

  Doorenbos, et al., 2005

- One of the reasons this is important, is the browning of America.
- It is projected that by 2050, non-whites as a whole, will outnumber whites in this country.

Why Cultural Competence Is Important

- Health and health care are not evenly distributed.
- Almost 20 years ago, the Institute of Medicine (IOM) published their report on unequal treatment to focus on health disparities among ethnic and cultural groups.
- Many of the disparities that exist are subtle, as they are not readily apparent as being racially motivated.

Why Cultural Competence Is Important

- The ultimate goal is for Health Care Professionals (HCP) to provide relevant, effective, and culturally responsive care reducing racial and ethnic disparities in health and healthcare, and improving healthcare quality, patient satisfaction, and health outcomes

Shen, 2015

- Thus, the research has focused on cultural competence as the vehicle to meet the challenges identified by the IOM.

Culture Defined

- The classic, anthropological definition of culture:

  Culture is a complex whole which includes knowledge, beliefs, arts, morals, law, customs, and many other capabilities and habits acquired by man as a member of society.

- Culture is dynamic and every changing.

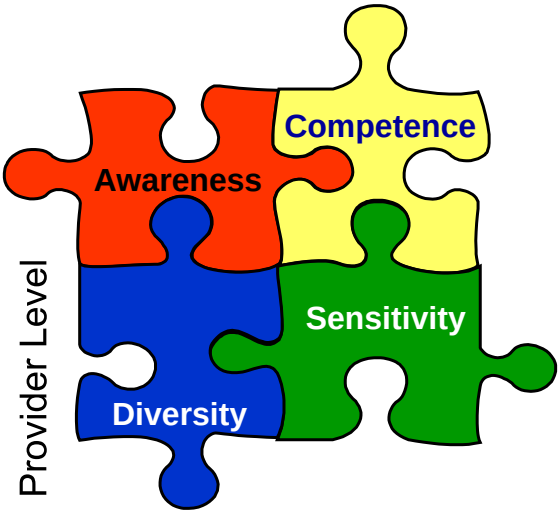
Cultural Competence Defined

Definition	Goal
▪ Cultural competence is defined as the "demonstration of knowledge, attitudes, and behaviors based on diverse and relevant cultural experiences"	▪ Achieving complete cultural competence is not the goal. ▪ The goal is that HCP will continue to strive to match their competencies to the *specific populations and subgroups with whom they work*.

Doorenbos, & Schim, p.326

Cultural Aspects of Care

Cultural Competence Model



Schim, Doorenbos, Benkert, & Miller, 2007

15

Cultural Diversity

- Cultural diversity is recognized as a complex and dynamic reality of the health care system.
- HCP will have varying experiences with different populations of patients.
- Most healthcare agencies have some variation in the diversity of the patients they serve.

16

16

Cultural Awareness

- Cultural awareness reflects the knowledge of the HCP regarding variations in cultural expression between and among groups of patients

Many of the articles published on culture describe cultural differences in such areas as

Language	Kinship Patterns
Religion	Food Preferences
EOL Preferences	Rituals

17

17

Cultural Sensitivity

- Describes provider attitudes, values, beliefs, and personal insight.
- HCP need to acknowledge their own cultural heritage, beliefs, openness to others, and respect for the complex ways cultural issues influence every aspect of healthcare.
- In any interaction between a client/patient and HCP, there are three cultures present:
  - The culture of the HCP
  - The culture of the client/patient
  - The culture of the institution

18

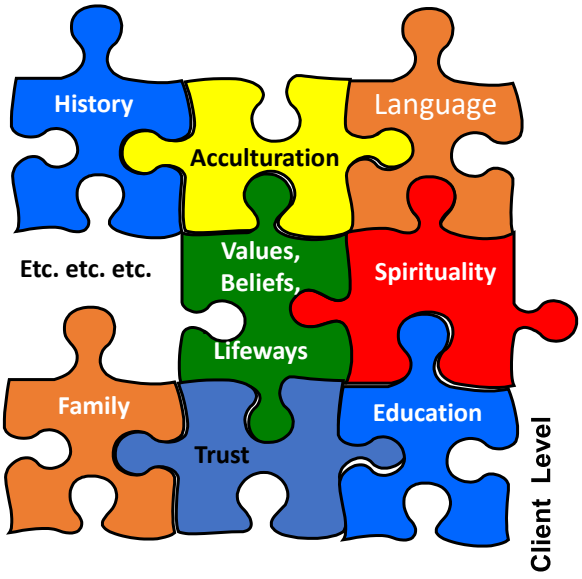
18

Cultural Competence

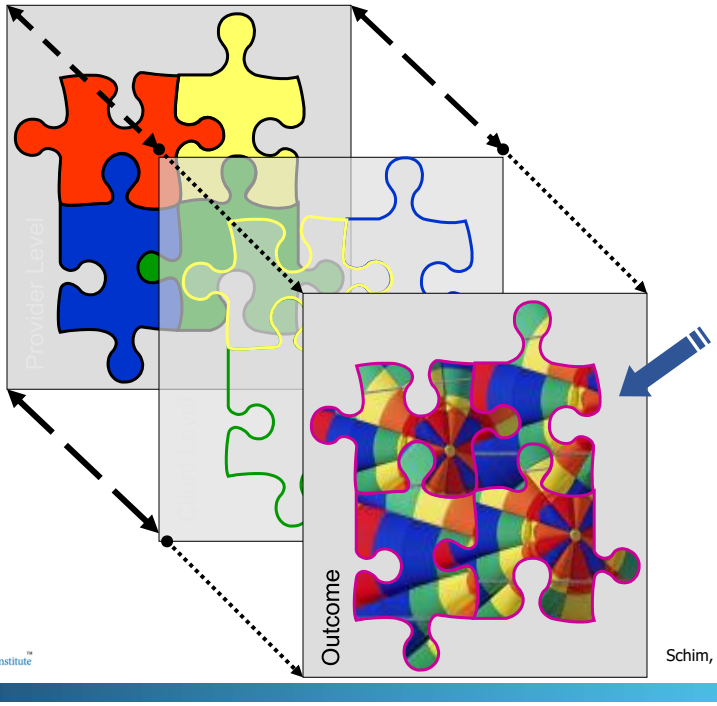
- Cultural Competence is a *behavior* that includes:
  - Assessing culture
  - Adopting interventions that respect the cultural needs and restrictions of patients
  - Seeking new information and resources about the patients served

Cultural Aspects of Care

Cultural Competence



Cultural Model



Culturally Congruent Care

Schim, Doorenbos, Benkert, & Miller, 2007

21

Cultural Competence

- Any interaction between a HCP and a dying person has the potential to reveal cultural differences that can lead to misunderstandings and subsequent problems.
- What is acceptable and appropriate for one group is seen as problematic or even dangerous for another (Werth, et al., 2002).
- Racial/ethnic biases do not need to result in discrimination for problems to develop.
- HCP can commit cultural faux pas, cultural insensitivity, cross-cultural misunderstanding and have cultural blind spots that can lead the HCP to do or say something that may negatively affect the patient's (and family's) trust.

22

22

Cultural Competence

- HCP need to avoid gross generalizations by:
  - confirming the patient's wishes, attitudes and decisions
- This is just as true for Caucasian Americans as it is for people of color.
- All of us have culture that influences many of the decisions we make, particularly when it involves serious illness or end of life care.

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Cultural Competence

Self-Assessment

Take out the following two handouts

1. Table 2 – Guiding Questions for Critical Reflection
2. Cultural Self-assessment Questionnaire
   - Since this one is the shortest of the 3, I would like everyone to answer the questions on this one, then add up your score.
   - *What did you learn from doing this exercise?*

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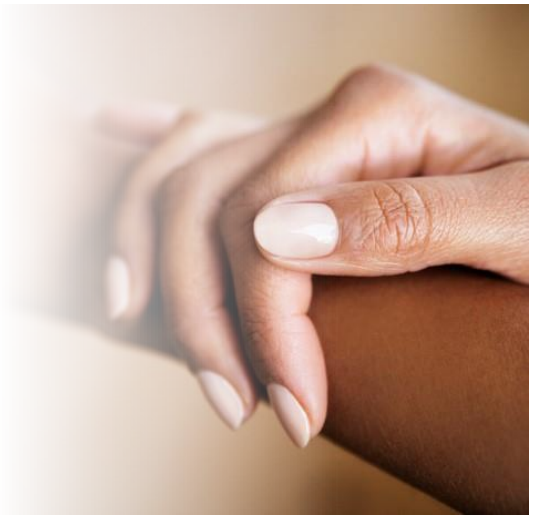
Cultural Competence

- Cultural competence demands a commitment to patients, ourselves, and lifelong learning. It's a commitment to understanding patients' health in context through knowing, being, and doing Botelho & Lima, 2020
- In understanding culture and its role in making serious illness care decisions, patients are the authors of their life stories.
- HCP need to let go of their professional role and embrace learning about the patient.

Cultural Competence

- It is important to note, that being a member of a specific ethnic group does not make us or anyone else more sensitive to the issues faced by other groups.
- We need the same education, exposure, experiences as everybody else regardless of our race and ethnicity.

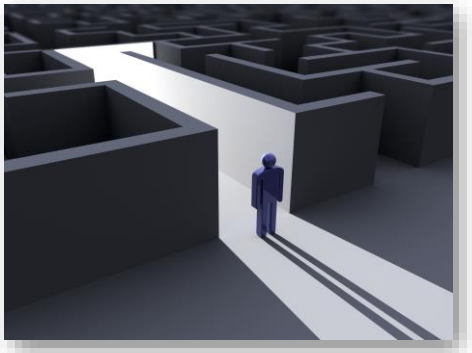


Cultural Aspects of Care

Ethical Metaprinciples, Serious Illness and EOL Decisions

Culture and Serious Illness Care Decisions

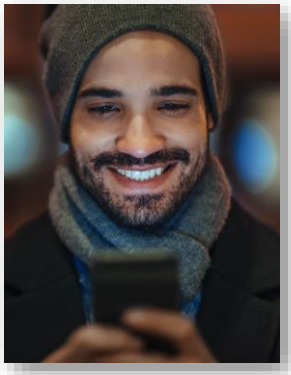
- One of the primary ways that cultures may clash in EOL decisions relates to differences in the ethical metaprinciples of the dominant US society and other cultures (Werth, et al., 2002).
- These standard principles include autonomy, beneficence, nonmaleficence, fidelity, respect, and justice.



Autonomy

- Autonomy is the ability for an individual to act on their own values and interests.
- In the United States, there is a general importance placed on self-determination and individualism.
- The issue of autonomy is reflected in the general idea of such documents as informed consent for medical care and in EOL specifically, the concept of advance directives (Werth, et al., 2002).
- However, not all cultures place the same primary importance on autonomy as the dominant majority in this country.

Autonomy



- In some cultures (Asian, Arab, Latino), medical decision making is a family decision.
- One can take it a step further. In some cultures, choosing not to participate at all in certain decisions is how they exercise their autonomous decision making.
- There are also cultures (Latino) that view the physician as the person who has the knowledge and power to make the best decisions.

Autonomy

- In general, Mexican Americans and Korean Americans were less likely to think a patient should be told a diagnosis of metastatic cancer or a terminal prognosis.

  They were also less likely to believe that the patient alone should make decisions about life-sustaining treatments and more likely to believe the patient's family should make these decisions.

- Filial responsibility is more likely to be held by people of Asian descent. It means that a family member has a particular obligation to adhere to the cultural norms of their group even if the patient's wishes are contrary to these norms.

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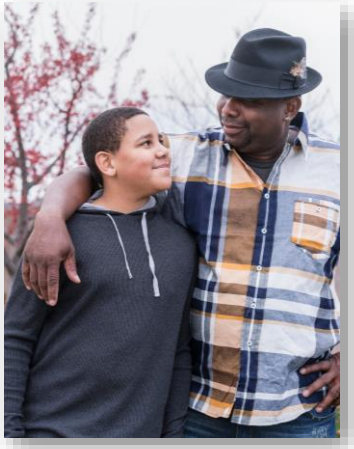
31

31

Autonomy



- African Americans were more of a mixed bag on EOL issues:
  - There are certainly some who wanted the autonomy of making their own decisions and what their family wanted while important was not the deciding factor
  - Then there were Black families that clearly had a family-centered, decision-making approach and the patient was not going to decide anything until he or she discussed it with their family.

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32

32

Beneficence and Nonmaleficence

- Beneficence is doing good and nonmaleficence is do no harm

Berger, 1998, p. 2085

- In one study involving Navajo Indians, they found that in this culture, language does not merely describe reality, language shapes reality.
- Thus, in discussing advance directives, which includes discussing decisions about serious illness, serious treatments, loss of ability to make decisions, the discussion itself was deemed harmful and a violation of traditional Navajo values.

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33

33

Fidelity

- Fidelity is truth telling.
- There are many non-European cultures that have cultural prohibitions against full disclosure.
- In these cultures, family members screen the information given to the patient to prevent them from being told bad news because it is believed to do so, will take away all hope.
- In fact, being brutally honest may be perceived as disrespectful or even harmful.

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34

34

Respect

- Respect is a basic professional value for each individual patient.
- Treating a patient with respect means treating them in ways that acknowledges their value system.
- This might be contrary to the HCP's own values.

Religion

- Religion is a particular system of faith and worship.
- In some cultures, physical pain and suffering are a test of faith.
- There are also cultures who believe that God/a higher power is the ultimate decision maker in their treatment and no matter what the doctor says about stopping treatment because it is futile, it is God/a higher power who ultimately decides if they are going to live or die.
- To be disrespectful of these beliefs, to show or express skepticism, could hijack your relationship with your patient.

- Justice is a concept on ethics and law that people are treated in a way that is fair, equal and balanced for everyone.
- There are a myriad of circumstances where actions and decisions by HCPs may be viewed as preferential or discriminatory.
- Other cultural issues involve the care and treatment of older members of ethnic minority groups.

Cultural Aspects of Care

EOL Decisions: The Influence of Race/Ethnicity, Gender, LGBTQ, and Linguistics

End of Life (EOL) Decisions

Studies investigating the role of ethnicity on EOL decisions have been fairly uniform in their conclusions Werth, et al., 2002

Compared to European Americans, members of other ethnic groups:

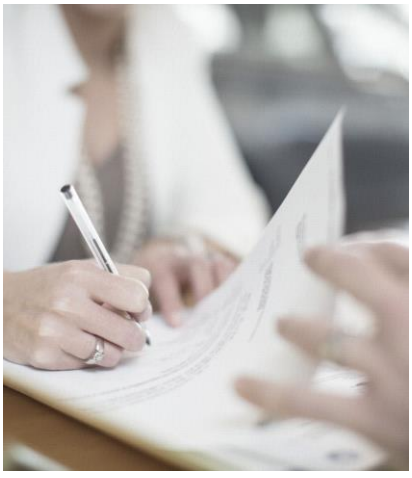
1. Have been significantly less accepting of any action that might hasten death.
2. Are against suicide, assisted suicide and euthanasia, and the withholding or withdrawing treatment.
3. Are less likely to have an advance directive.

EOL and Gender

- African American men were less likely to want extraordinary measures used to keep them alive, but African American women did want such measures.
- We found, in general, that men from minority ethnic groups were more likely to be concerned about the effect prolonging life would have on the family financially.
- One Latino man stated that the doctors just want to take all your money and use it up.

EOL and Advance Directives

- Studies have shown that the lack of executing an advance directive among ethnic minority groups is tied to mistrust and racism in the health care system.
- For those groups that are reluctant to have an advance directive, the fear is that the advance directive will be used as an excuse to withhold or withdraw treatment.



Resolving Cultural Differences

Hern, et al. (1998) provided a model for resolving situations where cultural issues may be impeding communication, understanding, and resolution

Werth, et al., 2002

1. **Listening to the Situation:** Being open and non-judgmental will help the team understand the patient's/family's expectations and will help build a relationship.
2. **Explaining Your Side:** The team needs to explain their care plan, their goals for the patient and why they have selected the interventions for the patient.

Resolving Cultural Differences

3. **Negotiation**: Where medically possible, compromise with the patient and family.
   - Focus on where there is agreement and give the patient/family the opportunity to decline any treatment approaches they find troubling
   - If the patient wants certain decisions made by a family member, cooperate with that to the extent legally allowable
4. **Be Truthful:** Even if the patient wants health care decisions made by someone else, make sure the patient knows they can change their minds at any time. This promise should be made if the patient wants it, even if the family disagrees.

Latinos and EOL

1. Latina women were more likely to want to go to the hospital to die.
2. Latina women were more likely to want extraordinary measures used to keep them alive, even when hope of a cure was considered futile by the HCP.
3. Latino men did not want CPR or a respirator.
4. Latino men were concerned about the health care costs associated with prolonging life.
5. Latinos were more likely to refuse dialysis and pain medications.

African Americans and EOL

1. More than any other group, African Americans were least likely to want to die at home.
2. African Americans are not opposed to going to a nursing home or hospital.
3. They are very concerned with being a burden on the family. One participant stated, "I don't want my family to be eager for my death because I've worn everybody out taking care of me."
4. There is a higher level of distrust towards the health care system and doctors than any other group. African American men said, "The doctors only want to take your money."

African Americans and EOL

5. African American women wanted extraordinary measures used to prolong life.
6. They are most likely to state, it's up to God if you live or die, not the doctor.
7. African American men were the opposite of African American women. Pull the plug and let me go.

Muslims and EOL

1. Muslims believe health care decisions are family decisions
2. In the case of bad news, tell the family first.
3. Islam prohibits discontinuing nourishment and hydration.
4. Islam does not encourage prolonging life on machines for a long time.
5. Islam prohibits assisted suicide, mercy killing and euthanasia.
6. Muslims can authorize a Do Not Resuscitate (DNR) order.
7. Muslims openly cry and mourn.
8. Islamic teaching does not include placing flowers or burning candles, playing music or singing.
9. Hugging or physically touching family members is not recommended.

47

47

Activity

- Take out your handout labeled

Table 3 Cross-Cultural Interview Questions Regarding Serious Illness and End of Life Care

This table provides an excellent framework you can use to ask questions that will illicit some of the needed information on how the patient wants to handle issues.

48

48

Death Is Difficult In Any Language

- The article by Green, et al (2017) said something I think is really important, "Death Is Difficult In Any Language."
- Yes, cultural and linguistic considerations are important, and concerns related to approaching the EOL were universal.
- What is that approach? Focus on the needs of the patient.
- Asking questions such as:

  What is important for me to do for you?

  What is important for me to know about you?

  Who do I need to know that is important to you?

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49

49

Linguistic Considerations

- Green (2018) stresses that proficiency in speaking English does not always equate to understanding.
- Full understanding of a patient's condition went beyond a basic understanding of English.
- HCP are largely dependent on family members to translate and interpret what is being said.
- Professional interpreters are mainly used for formal communications (e.g., a consent for procedures).

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50

50

Linguistic Considerations

Guidelines for Medical Interviews With Translators

1. Ideally, the translator should not be a family member.
2. Translators should be trained to respect patient confidentiality.
3. Physicians should orient the translator to the process of the medical encounter.
4. Physicians should request a literal, word-for-word translation.

Searight & Gafford, 2005

Linguistic Considerations

Guidelines for Medical Interviews With Translators

5. Physicians should request the translator to ask the physician to restate or clarify unfamiliar terms.
6. After making a complete statement, the physician should pause for translation.
7. The physician should look directly at the patient, rather than at the translator, when either the physician or patient is speaking.
8. The physician should speak in the second person. For example, he or she might ask, “Where is your pain?” rather than “Can you ask him where he hurts?”

Searight & Gafford, 2005

LGBTQ Considerations

There are three issues that impact this community when it comes to EOL issues:

The first is general **prejudice against LGBTQ** people by some HCP.

The second issue is related to the first, and that is a **general fear of "waiting for the shoe to drop"** (personal communication, Dr. Pat Wren, 11-20-2020). In other words, even if the legalities were handled, i.e., they have a Durable Power of Attorney (DPoA) for Health Care, etc., the fear of some LGBTQ couples is whether the family will try to overturn things.

If **two people are NOT married, but live together**, own property together, etc., and one is seriously ill or dying, they need to know what rights they have to make decisions and represent their partner with the health care agency.

These issues become even more tricky if the family refuses to acknowledge the relationship.

Resources for LGBT and EOL

- You might want to try looking at the SAGE Advocacy for LGBT Seniors website for information. https://www.sageusa.org/

Also I found these articles:

- https://contemporaryfamilies.org/same-sex-couples-devote-more-attention-to-end-of-life-plans-than-heterosexual-couples/
- https://www.researchgate.net/publication/320316434_Planning_for_Future_Care_and_the_End_of_Life_A_Qualitative_Analysis_of_Gay_Lesbian_and_Heterosexual_Couples

Cultural Aspects of Care

Pain and Culture

Pain and Culture

Pain is a subjective, physical, and emotional experience shaped by cultural values and beliefs

Martin & Barkley, 2016, p. 32

Pain is perceived by the patient, and can only be reported by the patient

Givier, et al., 2020

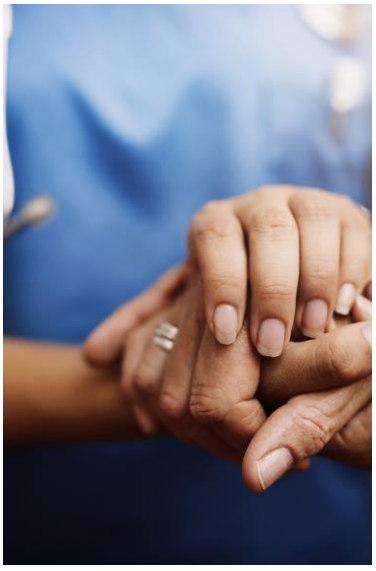
In some religions, pain is seen as being a part of God's plan, or it is a punishment for sins committed, or it is a test of one's faith

Some Chinese patients view pain as an imbalance between yin and yang, a belief that has its roots in Taoism, Buddhism, and Confucianism

Martin & Berkley, 2016

Pain, Culture and EOL

Beliefs	Assessments
• Cultural beliefs can influence how patients express pain. • Stoicism can cause African Americans, Latinos, Asian Americans, and American Indians to be reluctant to complain of pain.	• This can lead to inaccurate pain assessments by HCP who often use facial grimacing and audible sounds to measure the intensity of pain. • Cultural beliefs can also affect the self-report of pain, with Asian Americans reporting significantly lower pain scores than other groups.



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57

57

Pain, Culture and EOL Cont.

- Cultural factors also influence how, when, and even if patients are accepting of taking pain medications

Martin & Berkley, 2016)

- There may be considerable resistance in some groups in using opioid medications for pain.
- A common myth by some groups is that opioids hasten death.
- African Americans and Latinos equate the use of pain medication at the EOL with euthanasia.
- On the other hand, some patients fear the use of opioids because they fear becoming addicted.

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58

58

Pain, Culture and EOL Cont.

- Family members also resist having their loved ones medicated with opioids because they fear the stronger the pain medication, the more severe the illness.
- To some, it meant death was imminent.
- In Asian, Latino, and Muslim cultures where discussing death is taboo, patients may avoid opioids to prevent bad luck or tempting fate.

Natural Remedies/Natural Healers

Many Asian cultures use natural or traditional pain interventions such as acupuncture, herbal remedies and the following to treat pain:

Coining	Rubbing heated oil on the skin, usually the back or shoulders, then strongly rubbing a coin over the area.
Cupping	Heated glass cups are applied to the skin creating a suction that stimulates the flow of energy to relieve pain.
Moxibustion	This is a technique in which herbs are burned near the skin to facilitate healing. Special instruments called moxa sticks are used to hold the burning herbs a few inches above the skin.

Natural Remedies/ Natural Healers Cont.

- Chinese Americans and Mexican Americans may eat certain hot or cold foods to restore balance in the body.
- In Detroit, some of the doctors employed a curandero (folk healer) to manage traditional healing measures with their Latino patients.
- Some Filipinos may seek medicinal healing through the use of halaman (herbs) and an herbolaryo (witch doctor) if they believe that evil spirits entering the body caused the illness

Coolen, 2012

Learning Objectives Recap

- Define culture and cultural groups
- Describe how culture influences palliative care
- Explain how sexual orientation impacts palliative and serious illness care
- Discuss the importance of cultural competence in pain and palliative care

Questions?

Thank you

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