

Cultural Considerations



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Acknowledgement



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Objectives



- Describe a definition of culture.
- Identify how the FIFE interview can help when talking to patients about their illnesses in relation to their culture.
- Describe methods for managing a request for non-disclosure from a patient's family.

Disclaimer



While this program provides educational information, this information is not medical advice. Health care providers should exercise their own independent clinical judgment. Some of the information cites the use of a product in a dosage, for an indication, or in a manner other than that recommended in the product labeling.

Accordingly, the official prescribing information should be consulted before any such product is used.

Case Question



- You are taking care of a 79 year old female who has newly diagnosed colorectal cancer. The patient was born in Afghanistan and was brought to this country 15 years ago by her family. She does not speak English and looks away every time you try to speak to her. Her English speaking son tells you that all decisions about his mother's care will be made by himself. He wants the cancer treated but does not want his mother to be told the diagnosis.
- How do you proceed?

What is Culture?



“A set of guidelines (both explicit and implicit) which individuals inherit as members of a particular society, and which tells them how to view the world, how to experience it emotionally, and how to *behave* in it in relation to other people, to supernatural forces or gods, and to the natural environment.”

Helman, CG, *Culture, Health and Illness*, 5th Ed. 2007.

What is Culture?



- Culture is more than ethnicity or religion. Other attributes contribute to our cultural make-up including:
 - national and geographic origin and language
 - gender, sexual orientation
 - age/generation
 - social class and marital status
 - family, professional and community roles

What is Culture?



- It is important for clinicians to remember that we, too, have our own cultures.

Our cultural make-up significantly influences our interactions with patients and families and the care we deliver. We can better serve those we work with by gaining insight into our own cultural make-up.

Stop and Reflect



- Think about your own culture...write down three elements of your culture that impact how you practice as a health professional?

Culture and palliative care practice



- ✓ Requests for non-disclosure
- ✓ Mistrust due to past cross-cultural abuses, prejudice
- ✓ Different values regarding life, treatment withdrawal, place of death, manner of death
- ✓ Misunderstanding regarding rituals
- ✓ Misunderstanding based on language differences
- ✓ Misunderstanding of “Western” values by both doctors and patients

Cultural Assessment



- The FIFE Interview for understanding the illness experience
 - F = Feelings
 - I = Ideas
 - F = Functioning
 - E = Expectations

F = FEELINGS



- Some potential questions/phrases:
 - *What are you most concerned about?*
 - *Do you have any specific concerns or worries right now?*
 - *I imagine you have had many different feelings as you have coped with this illness. Are you willing to share some with me?*
 - *Sometimes people have fears that they keep to themselves and don't tell their doctor. Is this true for you?*

I = IDEAS and explanations of the cause



- Potential questions to ask:
 - *What do you think might be going on?*
 - *What do you think this pain means?*
 - *Do you have ideas about what might have caused this illness?*

F = FUNCTIONING



- Potential questions to ask:
 - *How has your illness affected you day to day?*
 - *What have you had to give up because of your illness?*
 - *What goals do you have now in your life? How has your illness affected your goals?*
 - *How does this illness affect important people in your life?*

E = EXPECTATIONS



- Potential questions to ask?
 - *What do you expect or hope I can do for you today?*
 - *Do you have expectations about how doctors can help?*
 - *What do you hope this treatment will do for you?*
 - *What are your expectations about what might happen with this illness?*

Asking about cultural practices



- Ask open ended questions about the person's culture, rather than about the specific patient.
 - *How are people informed about a serious illness?*
 - *How do people cope, what sources of strength do they turn to?*
 - *Where do people prefer to die?*
 - *Are there special issues concerning control of physical symptoms?*
 - *What are the rituals prior to, during and after death?*
How do you care for the body after death?
 - *What are your attitudes toward organ donation, autopsy?*
 - *What are your funeral practices?*

Asking about cultural practices



- Start with a *Statement of Respect*

I know very little about how your culture deals with things at such a time. I understand and respect the fact that different people handle things in very different ways.

I would very much appreciate it if you would teach me what I need to know to be of help.

Asking about cultural practices



- Ask, *“What is important?”*
 - For the dying person to do
 - For the caregivers to do
 - At the time of death
 - Following death

- Ask, *“Are there important things that we should NOT do now?”*
 - At the time of death
 - Following death

Asking about cultural practices



- Ask, *“Are there special concerns or fears that we should know about?”*
- Ask, *“How can we be most helpful to the patient/family?”*
 - In the dying process
 - At the moment and after death

Language Barriers



- Discussions involving breaking bad news or important decisions should occur with a trained medical interpreter (preferred) or language-line translator.
- Having family members interpret
 - Puts them in an uncomfortable/unfair position
 - Allows the possibility of deliberate mistranslation to protect the patient or for other motivations

Delivering Bad News



- A clash of cultures typically occurs at the time of bad news, when a serious or terminal illness is diagnosed.
- *What* and *how* to tell the patient, as well as *who* should do the telling, can contribute to conflict.

Delivering Bad News



- **Western Culture: *Patient Centered***
 - Patient is the autonomous decision-maker
 - Patient has a “right to know”
 - Full disclosure is the cultural norm
 - Family has secondary/supportive role
 - Doctor feels a “duty” to tell the patient

Delivering Bad News



- **Non-Western Culture:** *Family-Centered*
 - Family is primary decision-maker
 - Patient is shielded from direct information as a cultural norm
 - Family requests non-disclosure
 - Patient him/herself may or may not want to cede decision making to the family

Non-Disclosure



- Requests for non-disclosure are common and usually relate to one of three causes:
 - The family believes the patient will not be able to cope with the bad news based on the family's fears, which are typically not proportional to reality.
 - The family believes the patient will not be able to cope with the bad news (lose hope, commit suicide) based on real past experience (e.g. past major depression or suicide attempt).
 - Major difference in value of personal vs. family role at the time of a major illness. (see prior slides)

Management of Non-Disclosure



- **Family Fears > Reality**

Explore with the family their concerns, provide reassurance; talk to the patient—ask how much they wish to know.

- **Family fears may match reality based on past experience**

Work to corroborate fears; ask for psychiatric assistance to determine how and how much information to provide.

- **Difference in values**

Negotiation with families



1. Provide a statement of respect
2. Ask why the request for non-disclosure has been made.
3. Ask the family if they have discussed with the patient; what do they think the patient's opinion would be?
4. Statement of your (the doctor) values—but be very careful to avoid the appearance of coercion!

Negotiation with families



5. Talk to the patient

- Suggest to the family that you confirm directly with the patient how they wish information be presented.
 - If the patient asks to have full information, tell the family you will comply.
 - If the patient asks that you present information only to the family, then respect the patient's wishes and talk to the family as requested.

Case Question



- You are taking care of a 79 year old female who has newly diagnosed colorectal cancer. The patient was born in Afghanistan and was brought to this country 15 years ago by her family. She does not speak English and looks away every time you try to speak to her. Her English speaking son tells you that all decisions about his mother's care will be made by himself. He wants the cancer treated but does not want his mother to be told the diagnosis.
- How do you proceed? Answer provided on next slide.

Answer



- Provide a statement of respect, do not make assumptions
- Explore why the son is making this request
- Explain your viewpoint to the son
- With the help of an interpreter, ask the patient if she would like to make her own decisions or if she would prefer that her family make the decisions.

Learning Points



List 3 new things you learned from this presentation.

- 1.
- 2.
- 3.

References



- American Medical Association. *Cultural Competence Compendium*. American Medical Association; 1999. Braun KL. *Cultural Issues in End-of-Life Care*. Sage Pub. 2000.
- Hallenbeck JL, Goldstein, MK, Decisions at the end of life: cultural considerations beyond medical ethics. *Generations*, 1999; 23(1):24-29.
- Orona CJ, Koenig BA, Davis AJ. Cultural aspects of non-disclosure. *Cambridge Quarterly of Healthcare Ethics*. 1994; 3:338-346.
- Seelman, C et al. Cultural competence: a conceptual framework for teaching and learning. *Medical Education* 2009: 43(3);229-37.
- <http://www.xculture.org> *Focus on cross-cultural healthcare. Vast resources and links available. Excellent start-site for web searches on the topic.*
- <http://www.omhrc.gov/CLAS> National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health Care Office of Minority Health Resource Center
- Stewart, M, JB Brown, WW Weston, IR McWhinney, CL McWilliam, TR Freeman. *Patient Centered Medicine: Transforming the Clinical Method*. Sage Publications, Thousand Oaks, California, 1995.
- Fast Fact and Concept #17 Understanding the illness experience. EPERC
www.eperc.mcw.edu.