Cultural Issues For Palliative Care

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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, 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, 3rd Ed. 1994:2

Cultural Attributes

- National and geographic origin/ethnicity
- Sexual Orientation
- Gender Identity
- Gender roles
- Age/Generation
- Marital Status
- Religious or spiritual orientation
- Family, professional and community roles
- Education
- Socioeconomic status
- Ability

Culture may influence:

- Belief systems related to health, healing and end of life
- How illness, disease and their causes are perceived
- The behaviors of patients and their attitudes toward healthcare providers
- The delivery of services by the provider
It is important to remember

We too have our own cultures.

Sexual Orientation

- LGBT patients may have fear associated with being “out” in medical situations
- Different concept of extended family
- 4.9% of N.M. population is LGBT (U.S.-3.5%)
- N.M. Healthcare Decisions Act

Discussion:
Your cultural influences on health and end of life

1. How do your beliefs affect your healthcare decisions?
2. Who do you talk to about healthcare decisions? Who would you want to make decisions for you? Who provides comfort to you?
3. Where will you prefer to be at your time of an advanced illness or death? Why?
4. Do you—or anyone close to you—have any discomfort with any types of medicine or end of life?

Case Study Mrs S.

- Middle-aged White Hispanic Woman
- Stage IV Breast Cancer
- Husband and two adolescent-aged kids
- Sister, mom, mom’s boyfriend
- Strong underlying family tension
- Mystery man
- The hug
- The full story…
Gender Identity

- Wide spectrum of gender identity
  - Transgender
    - MTF, FTM, Intersex, transvestism
  - Gender-non conforming
  - Gender queer
  - Two Spirit
  - Androgyny
- Distrust of medical community
- Body betrayal

Religious or Spiritual Orientation

- >90% people believe in “God” or a higher power
- 77% of patients want physicians to consider their spiritual needs (including many non-religious patients)
- 40% report “faith is the most important that helps them cope”

Religious Affiliations in New Mexico

- Roman Catholic: 27%
- Protestant: 22%
- LDS: 3%
- Buddhist: 2%
- Other: 3%
- Unaffiliated: 43%

Ethnicity in New Mexico

- White: 41.4%
- Hispanic/Latino: 46.4%
- Native: 8.8%
- Black: 2%
- Asian: 1.5
Another statistic to consider...

- 18.4% of N.M. population is living below the poverty level (U.S.-13.8%)

Case Study Mrs. M.

- 59 year old African American female with h/o DM, COPD, OSA and lung cancer s/p right pneumonectomy. Patient repeatedly asking for something to kill her. As she recovered she continued to have issues with various members of medical team.

Understanding the Patient and Learning as a Provider

- Reassess what is being heard, understood and agreed upon frequently, from both the patient’s and clinician’s standpoint.
- Specifically confirm the patient’s understanding or agreement (beyond nodding or yes responses)
Origin of Distrust
- Broken Treaties
- Lost of land
- Reservations
- Boarding Schools
- Urban relocation programs
- Poor health care
- Deliberate infection

Levels of Acculturation
- Traditional – Follow their traditional ways and customs
- Transitional – Are in the process of accepting the ways of mainstream culture in which they have relocated
- Assimilated – Have become alike or similar to the environment and culture which they have adopted
- Dualistic – Live in and adapt to both cultures and consciously adjust to each with flexibility

Communication style
- Pace
- Volume
- Eye contact
- Interjection
- Passive or Active
- Indirect or Direct
- Same language or Interpreter

Beliefs & practices to consider with Native patients
- Beliefs about death
- Taboos about death: language, contact
- Burial or cremation, traditions around burial
- Location of death: in the home, outside, on homeland
- Community versus individual decision making
- Who has speaking or decision-making power

Sue D. Counseling the culturally different: Theory and Practice, 1990.
Case Study Ms. S.
- Native American pueblo woman with Cystic Fibrosis
- In need of lung transplant
- Native taboos about transplant, burial with whole body
- Family blessing of transplant
- Unique spiritual process communicating with the donor, asking permission to receive the lungs

When language is a barrier . . .
- Use a skilled interpreter
- Avoid family as primary interpreters
- Speak directly to the patient (not to interpreter)
- Use of a “Cultural Broker”

Principles of Culturally Sensitive Communication about End of Life Issues:
- Patient and family's perspectives
- Role of the family, who is part of the family?
- Patient and family communication
- The patient's role in decision making

Case Study Mr. Y.
- 54 year old Chinese man with relapsed Natural killer T-cell lymphoma. Patient is in the ICU, intubated, with sepsis and multi-organ system failure. Patient is married with two adult sons. Patient's older son, an orthopedic resident, lives out of town and is his decision maker.
Giving Bad News

- **Western Cultural Values**
  - Patient is autonomous decision-maker
  - Family has secondary/supportive role
  - Doctor feels a “duty” to tell the patient

- **Other Cultures**
  - Family is primary decision-maker

Cultural Humility

A process that involves self-reflection and self-critiques, acknowledges power imbalances, involves patient-centered interviewing, and focuses on the development and maintenance of mutually beneficial partnerships


Cultural Humility in Palliative Care

- Come from a place of not knowing
- Every person experiences their wellness and illness differently
- No agenda
- Avoid assumptions
- What can I learn? How can I help?

Conclusions

- Using/understanding the cultural humility framework, it is possible:
  - To engage patients from diverse backgrounds in discussions about end of life
  - Helps us understand their process for medical decision making
- People from different cultures approach end of life care in unique ways
  - Each family has its own unique culture (make no assumptions)
  - Use a communication style that is appropriate for the culture and the family
Remember...

- When in doubt, ask patients about cultural issues. Never assume to know what is important to a patient.
- Use your team to bounce things off of. They may have an experience that can help you better understand.
- To be more effective, End-of-Life discussions and care must be individually tailored.

“In end of life care, the patient is the primary teacher of all of us caregivers. Each person with a serious illness holds the key to the secret of why s/he gets up to face the day. Once they know we care, they may chose to let us know what helps them to do it.”
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References

- Sue D, Counseling the culturally different: Theory and Practice, 1990