Disclosure Information

Cultural Considerations in Decision-Making and Goals of Care Discussions
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Cultural Considerations in Decision-Making and Goals of Care Discussions

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This Can Be Intimidating

- What concerns do you have when thinking about cultural differences and medical decision-making?

"I might offend patients and families….."

"The medical care I provide may influenced by my own cultural biases….."

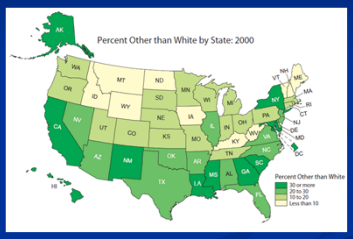
"It's so frustrating when families want to keep information from the patient…."

"My lack of knowledge about certain cultural issues may lead to suboptimal care…"

"I don't know how to make that patient/family understand….."

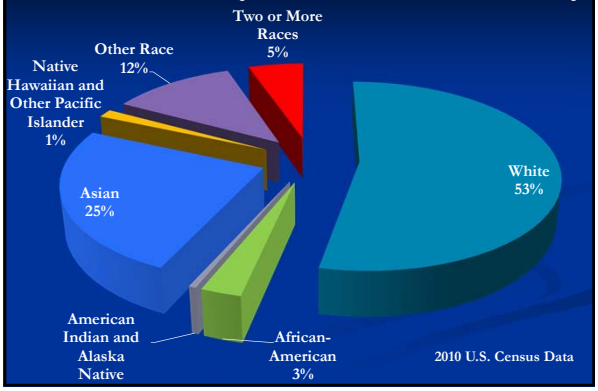
Increasing Cultural Diversity

- Ethnic minorities currently compose 1/3 of US population
- In 2010, 1 out of 5 adults over 65 was of an ethnic minority
- By 2050 ethnic minorities are expected to be the majority



US Census Bureau, 2010; **US Health and Human Services 2011**

Racial Diversity in San Mateo County

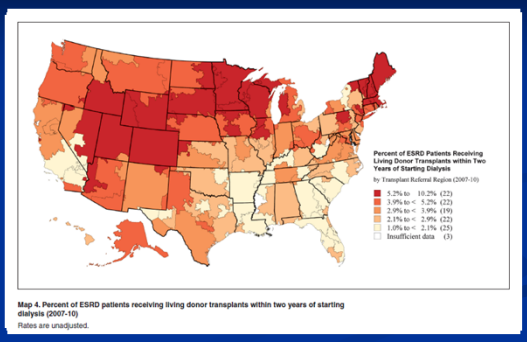


Disparities in Care and Outcomes for Chronic Kidney Disease

- Ethnic minorities suffer disproportionately from CKD and ESRD
  - ESRD 3 times the incidence than for whites
  - Geographic disparities in CKD prevalence exist and vary by race
  - CKD progression more rapid for ethnic minority groups than for whites
    - Largely but not completely explained by genetic factors
  - Stark socioeconomic disparities in outcomes for dialysis patients exist and vary by race, place of residence, and treatment facility

Crews, 2014

Renal Disease in the US



Map 4. Percent of ESRD patients receiving living donor transplants within two years of starting dialysis (2007-10)
Rates are unadjusted.

Dartmouth Atlas, 2014

Our Hopes for the Next Hour

- Recognize racial, ethnic, and socioeconomic differences contribute to disparities in treatment for patients with renal disease
- Define the concepts of cultural competency and cultural humility and learn to apply these concepts in conversations with patients and families
- Describe eight common cultural factors that influence decision-making and employ strategies to more effectively address these issues

Let's Define Some Concepts

- What is Culture?
  - Integrated patterns of human behavior that include language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, social or work groups.

Adapted from Cross, T., et al. (1989) and Yuen, E., et. al. 2010

Many Factors at Play

- Race/Ethnicity
- Acculturation
- Sex/Gender/Gender Identity
- Socioeconomic Status
- Religion/Spirituality
- Education
- And many more…..




Culture and Relation to Health Care

- "culture defines how health care information is received, how rights and protections are exercised, what is considered to be a health problem, how symptoms and concerns about the problem are expressed, who should provide treatment for the problem, and what type of treatment should be given."
- " In sum, because health care is a cultural construct, arising from beliefs about the nature of disease and the human body, cultural issues are actually central in the delivery of health services treatment and preventative interventions"

US Department of Health and Human Services. Office of Minority Health

Cultural Competence

- "Cultural competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency or among professionals and enable that system, agency or those professions to work effectively in cross-cultural situations."
  -Cross et al, 1989
- "Cultural competence is defined simply as the level of knowledge-based skills required to provide effective clinical care to patients from a particular ethnic or racial group."
  - U.S. Department of Health and Human Services, Health Resources and Services Administration, Bureau of Health Professions

Referenced from Georgetown University, National Center for Cultural Competence

Cultural Competence

- Knowledge and skills
  - Knowledge base of factors that can influence cultural beliefs, values, and health behaviors
    - Reasonable to learn about populations frequently seen in your practice
  - Skill in communication
    - Verbal
    - Non-verbal communication
  - Use of professional interpreters

Crawley, 2002

Cultural Humility

- Coined by Melanie Tervalon and Jann Murray-Garcia in 1998
  - Lifelong commitment to self-evaluation and self-critique
  - Recognize and work to fix power imbalances that exist between providers and patients
  - Develop mutually beneficial clinical and advocacy partnerships on behalf of individuals and populations

Tervalon & Murray-Garcia, 1998

Cultural Humility

- Attitudinal
  - Awareness that culture shapes values
  - Acknowledge differences exist
  - Respect the differences
  - Accept the patients' world view and values as a starting point for the physician-patient relationship

Crawley, 2002

Comparison

	Cultural Competence	Cultural Humility
Goals	Build understanding of minority cultures to better and more appropriately provide services	Encourage personal reflection and growth around culture in order to increase awareness of providers
Values	Knowledge Training	Introspection Co-learning
Strengths	Allows for people to strive to obtain a goal Promotes skill building	Encourages lifelong learning with no end goal but rather an appreciation of the journey of growth and understanding Puts clinicians and patients in a mutually beneficial relationship and attempts to diminish power dynamics

Comparison

	Cultural Competence	Cultural Humility
Shortcomings	Enforces the idea that there can be 'competence' in a culture other than one's own	Challenging for providers to grasp the idea of learning with and from patients
	Supports myth that cultures are monolithic	No end result, which providers can struggle with
	Based upon academic knowledge rather than lived experience	

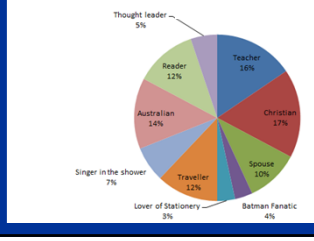
Competency and Humility

- Components that may contribute to building the road

- Unique path
- Desire and process of going on the journey
- Never reach the end

Practicing Humility: Clinician Know Thyself

- What cultural pieces do you as an individual bring to the table?



Practicing Humility: Western Medical Culture

- Our own culture
  - Language
  - Values
  - Customs
  - Norms
  - Hierarchy
  - Subspecialties – Sub cultures

The Culture of Western Medicine

Full disclosure	Withholding bad news
Patient as sole decision-maker	Family plays key role in decision-making
Key value of making choices and exercising control	Unfamiliarity with or reluctance to make "choices"
Avoiding unnecessary care indication of caring	Advocacy for greater intervention indication of caring
Science/technology approach to EOL	Spiritual/ faith-based approach to EOL
Avoidance of pain	Cultural meaning attributed to pain

Adapted, Clark 2012

Theories of Disease Causation

- Natural Etiologies
  - Germs, environmental factors, humors, heavenly bodies
  - Factors beyond human control, little personal
- Behavioral risk factors
  - Ex. Diet, habits, sexual behavior
  - Individual responsible for the disease
- Supernatural
  - God punishing, kharma, lack of respect for ancestral spirit
- Social etiologies
  - Disease arises due to conflict, social interaction
  - Jealousy, envy, "evil eye"

Borkan, 2008

Different Explanatory Models

- Mr. S. 65 y/o third generation German American recently diagnosed with lung cancer and wonders why this happened to him
  - Physician – developed since he smoked for 50 years
  - Wife – God is punishing him for turning away from the Catholic church early in their marriage
  - Daughter – admonishes him for not taking vitamin supplements she had asked him to take for years
  - Son – sue the Navy for the work at the shipyard that he did during WWII

Borkan, 2008

Techniques to Elicit Explanatory Models

- *What health problems or illnesses do you have and what do you think is causing them?*
- *What kinds of care have you sought to treat your illness?*
- *Tell me about you and how your illness fits into or changes your life?*

Borkan, 2008

Interpretation of Bodily Signs and Symptoms

- Individuals – "sick" – abnormal signs or symptoms
- Social mileu - family members/health care providers – must concur before patient can assume "sick role"
  - Withdraw from work, family responsibilities, receive assistance from others

Borkan, 2008

Techniques to Elicit Interpretation of Symptoms

- *How is this illness affecting your daily functioning and the things that are most important to you?*
- *What do you think will happen, or are concerned about, for the future?*
- *What changes have occurred for your family since your illness began?*
- *How well do you feel your family is coping?*

Borkan, 2008

Types of Treatments

- Differing beliefs in types of treatments to relieve symptoms, cure illness, or prevent future harm
  - Protective clothing, practices
  - Rituals (prayer, offerings)
  - Hygiene
  - Non-Western medicine techniques (acupuncture, cupping, herbal remedies)

Borkan, 2008

Techniques to Elicit Perspective on Treatments

- *What treatments have you sought to treat your illness and which have been the most effective?*
- *What things help you the most in coping with your illness?*

Borkan, 2008

Truth Telling

- Western biomedical framework (recent)
  - Value patient autonomy, informed consent, and discussion of prognosis
- Not the norm in much of the world
  - Many countries southeastern Europe, much of Asia, Central and South America, Middle East physicians, patients, families feel withholding medical information is more ethical and humane

Kagawa-Singer, 2001

Truth Telling: Consequences

- Possible Consequences
  - Anger, mistrust, removal of patient from ongoing medical care if clinician proceeds with informing patient against their (or family) wishes
  - Blame for contributing, causing or worsening the situation
  - Introducing hopelessness, misunderstanding as to why the patient is being informed

Kagawa-Singer, 2001

Truth Telling: Strategies

- Informed Refusal
  - *Some patients want to know everything about their condition and others prefer that the doctors talk with their families. How would you like to get this information?*
- Use a hypothetical case
  - *Many patients in a similar condition to yours have found it helpful to consider treatment options such as….*
    - Acknowledges fears
    - Respects need for indirect discussion
    - Implicitly invites additional questions

Kagawa-Singer, 2001; Carrese & Rhodes, 1995

Family Involvement in Decision-Making

- Western biomedical framework
  - Value patient autonomy
  - Right to be informed of condition, treatment options
  - Ability to choose or refuse life-prolonging medical care
  - Advance Directives, POLST – written methods to ensure patients wishes are followed
    - Advance care discussions and written documentation not considered standard of care in many countries

Kagawa-Singer, 2001

Family Involvement in Decision-Making

- For many cultures decision-making is the duty of the family
  - Responsibility to protect a (dying) patient
  - Remove burden of decision-making

Family Involvement in Decision-Making: Consequences

- Possible Consequences
  - Conflict if clinician insists patient must be the one to make decisions
  - Alienate patient and family

Kagawa-Singer, 2001

Family Involvement in Decision-Making: Strategies

- Talk with the patient to determine their desired level of involvement in receiving information and decision-making
- Ascertain key members of the patients family/friends who the patient deems important to include in conversation and ensure they are included
  - *Is there anyone else that I should talk with about your illness?*

Kagawa-Singer, 2001

Response to Inequities in Care

- Recognize several groups have historical past of mistreatment, abuse with medical research, ongoing current inequities other realms of life
  - African-Americans – slavery, Tuskeegee Syphilis Experiment
  - Native American – reservations, 300-mile Long Walk, past mistreatments regarding education and medical treatment
  - Japanese-Americans – Internment camps WWII
- Current studies reveal physicians perception of patients are influenced by patient ethnicity

Van Ryn & Burke, 2000

Inequities in Care: Consequences

- Lack of trust
- Increased desire for futile aggressive interventions
- Lack of ability to collaborate with patient and family
- Dissatisfaction with care for all involved

Inequities in Care: Strategies

- Explicit references to work towards achieving the best care possible
- Address directly
  - *I wonder whether it is hard for you to trust a physician who is not of your same background?*
- Understand and accommodate desires for more aggressive care
  - Respectfully negotiate in instances of medical futility

Communication and Language Barriers

- Medical language is a foreign language
- Impacted by health literacy
- Language other than English as primary language
- Lack of appreciation for non-verbal communication
  - Looking in the eye
  - Nodding

Communication and Language Barriers: Consequences

- Bidirectional misunderstanding
- Unnecessary or undesired treatment
- Unnecessary physical, emotional, spiritual suffering

Communication and Language Barriers: Strategies

- Avoid complex or medical jargon
- Check in frequently to assess understanding
- Use professional interpreters
  - Avoid use of family or "by-stander" medical staff
- Seek advice from cultural insider
  - Interpreter, colleague

Kagawa-Singer, 2001; Crawley 2002

Religion and Spirituality

- Western biomedical framework discounts important religion and spirituality
- Many believe
  - God has ultimate say in issues of life and death, not the physician
  - Suffering may be redemptive and should be endured

Religion and Spirituality: Consequences

- Lack of faith in physician, medical treatment
- Lack of adherence to treatment regimens

Religion and Spirituality: Strategies

- Assess the importance religion/spirituality has in your patients life
  - *Where do you find strength to make sense of this experience?*
  - *Spiritual or religious strength sustains many people in times of distress. What is important for us to know about your faith or spiritual needs?*

Kagawa-Singer, 2001

This Can Be Less Intimidating

- Concepts of cultural competency and cultural humility help in thinking about conversations with patients and families
- Reviewed common cultural factors that influence decision-making and provided strategies to more effectively assess and address these issues

Resources

- EthnoMed - http://ethnomed.org/
  - Provides information on cultural issues which impact health care, patient education and communication tools
- Medical Leadership Council on Cultural Proficiency - http://www.medicalleadership.org/index.shtml
  - Resources for language access, cultural proficiency, and continuing education
- National Standards on Culturally and Linguistically Appropriate Services (CLAS)
  - The14 CLAS standards are primarily directed at health care organizations; however, individual providers are also encouraged to use the standards to make their practices more culturally and linguistically accessible.
- Office of Minority Health Cultural Competency web page –
  - Links to basic information on cultural competence; guides and resources; a list of the national CLAS standards; policies, initiatives and laws; reports; and training tools
- The National Center for Cultural Competence (NCCC)
  - Database of a wide range of resources on cultural and linguistic competence
- The California Endowment has a section of their website dedicated to information on Culturally Competent Health Systems

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