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Cultural Competence Module 16
Family Involvement vs. Patient Autonomy

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Module 16: Family Involvement vs. Patient Autonomy

Module Estimated Time: 30-35 minutes

Statement of Purpose:

The purpose of this module is to address different values that exist around family structures and roles, and how these may create an ethical dilemma in a medical context that emphasizes the patient's competence to make medical decision for himself. The module presents how family care-giving, diversity and the rules that govern the U.S. healthcare system may present a challenge in establishing trust between patient, patient's family members and medical providers.

Objectives:

Upon the completion of this module, the learner will:

1. Be able to identify variations of family structures that may impact decision-making
2. Be able to identify gender roles and their impact as the authority figure
3. Be aware of the degree of family presence in health care situations in some cultures
4. Learn the ethical dilemmas that may occur during the interface between the predominant cultural healthcare value of patient autonomy with the different family structures of culturally diverse patients

Terminology

Health Beliefs
Folk Medicine
Family Structure
Gender Role
Family Care-giving
Patient Autonomy
Consent
Extended Family
Diagnosis
Disease
Autonomous decision-making
Family decision-making
Social norms
Primary decision making responsibility
Treatment decisions
Family's Perspective
Nondisclosure
Locus of decision-making
Patient competency
Informed choice

1. **Family Structure Diversity (Introductory Lecture)**
   Discuss the difference of Family Structure across cultures

Time: 2 minutes

Materials: None

Every culture has unique beliefs, myths, power rules and variations of what constitutes family. The variations in family structure and the degree of cohesion of family members - how gender roles mesh with power and authority, who should be a part of the decision-making or even be present during a medical assessment, interview or follow up appointment – can change quite greatly from culture to culture.

Family roles and expectations are shaped by cultural values that emerge out of the social, political, legal and religious context of particular nations.

When it comes to making a healthcare decision, the Northern American society established that competent patients have the right to self-rule, that is, each person makes decision about certain medical treatments he/she wants and refuses those that he/she does not want. This right is also known by term "Patient Autonomy." To be completely autonomous, the notion assumes that a patient has to be told about the nature of the illness, the prognosis, the treatment and any risks associated with treatment.

2. It's All About Family! (Lecture)

Time: 15 minutes

Materials: Laptop/Computer
LCD Projector/Screen
PowerPoint of Module 16
Internet access
Speakers
Video Link 1: http://www.youtube.com/watch?v=3vxZHU0oijE
Video Link 2: http://www.youtube.com/watch?v=mWispEM3900

Preparation: Before class, prepare laptop, screen and LCD projector. Check for internet connection and have remote control at hand to advance PowerPoint Slides.

Step 1: Choose either Video Link 1 or Video Link 2, or both to show a video about family values.

Video 1 shows the contrast between the Anglo nuclear family (husband, wife and son) versus the extended family.

Video 2 shows the values of acceptance of non-blood related family and the level of information that can be shared with individuals once accepted as family.

Step 2: Start PowerPoint Slide to present lecture points.

Slide 1

According to many dictionaries, "Family" is defined as a group of people affiliated by consanguinity, affinity, or co-residence.

Anthropologists have generally distinguished family as *matrilocal* (mother and children); *conjugal,* also referred to as the nuclear family (husband, wife and children); and *consanguinal* (also known as extended family).

Slide 2

Several anthropologists have conducted surveys on the concept of kinship, with relationships defined based on sexes, generational differences, blood or conjugal relation.

The Western concept of Kinship, for example, is based on the conjugal family where nuclear families have a certain level of mobility.

- **Mother**: a female parent
- **Father**: a male parent
- **Son**: a male child of the parent(s)
- **Daughter**: a female child of the parent(s)
- **Brother**: a male child of the same parent(s)
- **Sister**: a female child of the same parent(s)
- **Grandfather**: father of a father or mother
- **Grandmother**: mother of a mother or father
- **Cousins**: two people that share the same grandparent(s)

See Wikipedia

Collateral Family includes terms that are not built on nuclear family, e.g., Uncle, Aunt, Nephew and Niece.

In many cultures, Collateral Family members have equal importance of value of participation as nuclear family members.

Slide 3

Whatever the national origin and cultural groups an individual may identify with across all cultures, a family is a group of individuals who takes responsibility for one another and provides emotional, physical and financial support. This may include 1 person or 50, depending on the cultural framework and values around the meaning of family of a particular group. It can include people of all ages and sexes who may be united by blood or friendship or adoption. The role and responsibility of each person may have a degree of variation, but they all come together in a moment of crisis or conflict. They share how they see wellness and illness and how to cope with it, including who should be present and involved during the decision-making process.

Slide 4

In Asian cultures, family includes extended family. Grandparents, uncles, aunts and cousins are given an important psycho-social support and decision-making role.

Because family is defined to include a whole community, solidarity and community support is very important to many Asian-American patients.

Slide 5

Family in Latino culture is the center of existence and the basis of Latino culture. Many Latino cultures do not distinguish immediate from extended family – everyone who is present and responds during the good and bad moments of life is considered family. There is a wealth of traditions around family and many festivities are celebrated with the entire family.

The cultural norm of *familismo* refers to the notion of interdependency, which includes the obligation of providing support to family members, as well as the expectation to rely on the kin for encouragement and support. The concern for the welfare of the family is a constant presence, and it justifies the notion of "we celebrate together and suffer together as a family."

Slide 6

In Black communities, anyone that shares a common lifestyle, or the same eating, cooking and housekeeping habits is considered family. This may include people who may not share blood or ancestry, but who have shared similar experiences they have endured together.

In some Black communities, the residual of slavery still influences the level of trust and values that establish who they may consider as family. Black immigrants who left African or Caribbean regions due to political reasons or natural disaster may be influenced by factors of poverty and physical suffering.

Slide 7

Because much medical and clinical training puts emphasis on the professional as the expert and the patient as an autonomous individual who is capable to make decisions without external influences, the idea of including family in the medical decision-making process is the cause of anxiety among some medical providers.

However, since the internal dynamics of many families are altered by the illness of one family member and by the obligatory norms that exist in providing all levels of support during a time of conflict, if family members are excluded from the interaction between patient and providers, the healing process may get impacted negatively.

Where medical decisions are made together as a whole family, excluding family members from conversations that deal with informed consent and treatment decisions may not be conducive to improve the patient's health as it will create a stressful situation.

In many cultures, the idea to be open about a cancer diagnosis with the patient may be completely inappropriate and should be discussed with family members to decide how and what level of information should be delivered to the patient.

3. Would you tell? (Whole Class Activity)

Students are given an opportunity to share their own values about family involvement versus autonomy

Time: 10 minutes

Materials: None

Instructor tells class: "*Imagine you have learned that your mother (you can use spouse or father or child) has just been diagnosed with a terminal condition."*

Please raise your hand if you would want your mother (spouse, or father or child) to know the news.

Wait for people to raise hands.

Please raise your hand if you would NOT want your mother (spouse, father or child) to know the news.

Instructor elicits information from students who have responded differently. You may want to question why each group would or would NOT want to give the news to their mother.

Remind students that we are not here to judge opinions, or to force people to agree or disagree. The purpose is to simply illustrate the cultural differences that may be present with the student group as an example of what is reflected by diverse patients.

4. **Final Thoughts on Family Involvement and Patient Autonomy (Closing Lecture)**

Time: 2 minutes

Materials: None

Close this lesson with these points:

- Cultural Humility assumes that a health care system has incorporated the importance of culture in patient care and integrates the ability to see and respond to the unique needs of individual patients through a complex set of knowledge, skills and attitudes that will allow providers to engage in cross-cultural negotiation.
- With this in mind, Cultural Competence is a series of layers of complex accomplishments and it requires health care providers to have knowledge of the concept of culture and its key elements, as well as to appreciate the differences in health values and foster an attitude of empathy, curiosity, sensitivity, and respect.
- The role of family in many cultures is different and often family is the locus of decision-making. Understanding and negotiating the concerns and values of family members while focusing on the importance of keeping the patient informed can be very challenging. Family may require guidance when faced with a "should we tell or not" situation. Although the concept of patient autonomy is in the best interest of the patient to allow an unbiased and free-of-pressure opportunity to make choices that will impact medical outcome, it is very important that we don't lose sight of the importance of maintaining family solidarity during a stressful time for the patient. What may be considered undue pressure is indeed cultural and relative based on values. Keeping family out of the decision-making process may indeed not be a good compromise between autonomy and well-being for patients who do not feel comfortable making decisions without their family as a whole.
- Providers should not feel skeptical, anxious nor threatened when presented with a family that wants to be at the driver seat with the medical team and the patient during the decision-making process; rather they should try to embrace a new level of partnership by understanding the full intention behind the family and the benefits that family-driven care may lead to, such as a greater level of satisfaction and better outcomes for the patient, and their family as a whole unit.