



TALKING ABOUT END OF LIFE CARE AND ADVANCE DIRECTIVES ACROSS CULTURES

Your ability to discuss advance directives and end-of-life care with patients from diverse backgrounds can be improved with a better understanding of the differences in beliefs, practices and attitudes toward death and dying. The following provides some important information about the cultural variations you may encounter during your discussions.

Knowledge about particular cultural groups should serve only as a guideline to begin asking questions regarding individual beliefs and behaviors. Patients and their families may or may not subscribe to cultural norms.

AREAS OF CULTURAL VARIATION	POINTS TO CONSIDER	SUGGESTIONS
<p>Talking about end of life care</p>	<ul style="list-style-type: none"> • Not all cultures prefer direct disclosure of a serious illness. Disclosure may be viewed as disrespectful, impolite, harmful and/or burdensome. In many cultures, the elderly are considered more vulnerable to ‘bad news’ and it may provoke depression or eliminate hope. • Historical and contemporary racism may lead some patients to see the healthcare system as untrustworthy. Those communities with a history of suffering from discrimination may fear neglect if they do not insist on maximal care. • For some cultures, discussing cancer is taboo and shameful, as it is believed to be caused by a wrongdoing in a past life. It may have a negative impact on the family’s social status in the community. 	<p>General Guidelines:</p> <ul style="list-style-type: none"> • Establish trust by eliciting information through active, non-judgmental listening to the patient and family. Demonstrate curiosity. Assess each individual in the context of his/her family and culture. Be respectful of the patient’s understanding of the cause of the illness and preferences for end of life care. • Seek information about cultural norms of your patient base. Consider sociopolitical and historical facts that may influence beliefs about illness, healthcare and death such as poverty, discrimination, refugee status, and healthcare access issues. • Work from a place of shared values, Find a common ground and introduce information gradually. Beware of jargon. Assess the language the patient and family use in discussing the illness, including the extent of openness with regard to diagnosis, prognosis and death. Let the patient and family guide you regarding preference for disclosure. • If the word “cancer” is considered taboo, consider alternative descriptors such as ‘growth’ or ‘mass’. • Use trained healthcare interpreters when language barriers are identified.

	<ul style="list-style-type: none"> • Some patients believe that negative words spoken aloud and direct questions of mortality or thoughts about illness and death may become self-fulfilling. 	<p>Possible Cross Cultural Interview Questions:</p> <ul style="list-style-type: none"> • “Is there anything that would be helpful for me to know about how your family, community, and/or religious faith views this illness and treatment?” • “What questions do you have? How much do you want to know?” • “Sometimes people are uncomfortable discussing these issues with a doctor who is of a different race or cultural background. Are you comfortable with me treating you? Will you please let me know if there is anything about your background that would be helpful for me to know in working with you or your family?”
<p>Spiritual and religious beliefs about end of life</p>	<ul style="list-style-type: none"> • While many people have a spiritual or transcendent dimension to his or her life, not all believe in an afterlife. • For some, death may be an extremely fearful process. • Religious perspectives, beliefs and practices may override one’s cultural background. • For some, death is merely a path to get to where we are going. For others it is a struggle to be overcome. • Some patients feel that death is an “act of God” or a “Supreme Being”. It is inappropriate to question God’s decisions. • Many patients seek aggressive treatment because they value the sanctity of life, not because they misunderstand the limits of technology. Some 	<ul style="list-style-type: none"> • Seek information about the spiritual beliefs and practices common to your patient base. Solicit information from all possible sources within the community, including religious leaders. • Assess religious beliefs of the patient and family. Focus on the meaning of death, the existence of an afterlife, and belief in miracles. Establish beliefs about the body after death (i.e., who owns the body and how is it to be treated.) • Ask your patient: “What role does religion play in your decisions related to this illness and treatment.” • Consultation with the family and Spiritual Counselor will help you assess what is appropriate and acceptable. Variation from standard treatment regimens may be necessary to accommodate religious practices.

	<p>strongly believe that each life is unique and must not be destroyed.</p> <ul style="list-style-type: none">• For some, survival alone is an important demonstration of faith.• In some religions, withholding food is strictly forbidden.	
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TALKING ABOUT END OF LIFE CARE AND ADVANCE DIRECTIVES ACROSS CULTURES (continued)

AREAS OF CULTURAL VARIATION	POINTS TO CONSIDER	SUGGESTIONS
<p>Decision making locus of control</p>	<ul style="list-style-type: none"> • Decision models to handle terminal medical decisions and end-of-life care include autonomous, family based, physician based and shared physician-family decision-making. • Patients may exercise autonomy by choosing “not to know”. • Cultural issues around truth telling occur in many cultures and there are variations among members of the same culture and even in the patient’s family. • Working with families can be challenging especially when family members do not share the same cultural assumptions about end of life care. • The definition of family may include extended, immediate and non-blood kinship. • Distrust or unfamiliarity of the US health care system, health care disparities, cultural perspective on death and suffering, and family dynamics all contribute to the type of model used by different ethnic groups. • Those who practice a family based decision making model have relatives or extended family make choices, at times 	<p>General Guidelines:</p> <ul style="list-style-type: none"> • Determine the locus of control over decision-making. Is it the individual patient, the family, or another social unit? • Solicit the patient and family views about the location and timing of death including the preferred role of family members and health care providers. • Consider gender issues and power relationships within the decision-making unit. • Offer the patient the opportunity to learn the truth at the level of detail desired. Allow some decisions about who is responsible for knowing about his/her care. <p>Possible Cross Cultural Interview Questions:</p> <ul style="list-style-type: none"> • “Some people want to know everything about their medical condition, and others do not. What is your preference?” • Do you prefer to make medical decisions about future tests or treatment yourself, or would you prefer that someone else make them for you?” • “Your condition requires several decisions to be made about your treatment. Is there someone, perhaps a family member, who you would like to be with you when we discuss these matters?” • “Some people really do not want to be told what is wrong with them, but would rather their families be told instead. What do you prefer?” • “Would you be more comfortable if I spoke to your (daughter, son, brother...) alone, or

	<p>without the patient’s input.</p> <ul style="list-style-type: none"> • Some cultures practice filial piety, including the responsibility to care and protect the elderly from terminal diagnosis and prognosis. • For some ethnic communities, decisions that are too individualistic – not taking into consideration the affect on the family or consulting the family, is seen as disrespectful to the family and ethnic community. • For some, physicians may share decisions, as they are seen as the ‘expert’. 	<p>would you like to be present?” <i>If the patient chooses not to be present:</i> “If you change your mind at any point and would like more information, please let me know. I will answer any questions you have.” (<i>Document the exchange in medical record.</i>)</p>
<p>Advance directives</p>	<ul style="list-style-type: none"> • There are significantly lower completion rates of Advance Directives among minority groups. Causes may be due to distrust of the healthcare system, historical misuse of signed documents, healthcare disparities, or cultural perspectives on death and suffering. • Direct discussion of advance directives may be undesirable in situations in which they are viewed as potentially harmful to the patient’s well being. • Some do not want to burden children by assigning someone to be the head decision maker. The preference is for the family to make a group decision. 	<ul style="list-style-type: none"> • Inform patients and family members about the availability of written advance directives and durable power of attorney. Provide them in the appropriate language. • Encourage open dialogue about any quality of care concerns.

<p>Special Needs</p>	<ul style="list-style-type: none"> • Some patients will have cognitive dysfunction. • Many patients have sensory (visual or hearing) deficits. • It is not uncommon for depression to occur. 	<ul style="list-style-type: none"> • In the case of cognitive dysfunction, include the patient to the greatest extent possible. Rely on family and advance directives for guidance and on the patient's nonverbal communication for assessing patient comfort. • To maximize the sensory impaired patient's ability to participate, create a quiet, well-lit, comfortable space that enhances communication. Inexpensive headset hearing amplifiers can improve the interaction. • Treating depression will allow the patient to take a more active role. The existence of depression, however, should not limit discussions.
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* **NOTE: Avoid** using family members as interpreters. **Minors** are **prohibited** from being used as interpreters. Find an interpreter with a health care background. When physician-patient communication occurs through an interpreter, trained health care interpreters make fewer errors than untrained interpreters. **Document** in the patient's medical chart the request for or refusal of an interpreter.