

TOOLS FOR DIAGNOSING AND MEDIATING CULTURAL MISUNDERSTANDINGS

Touch and Gender (Sex and the Palliative Care Worker) Is touching always comforting? Maybe

- Health care givers are instructed that touch conveys concern. This is not so cross-culturally. Even within families, touching may be restricted

For Example... Adult Orthodox Jewish and Muslim men do not touch women of reproductive age, even their daughters, even to shake hands. A female nurse or physician's concerned pat on the shoulder could cause awkward discomfort. Buddhist Southeast Asians for entirely different reasons do not want to be touched, especially on the head, unless it is part of an exam. Navajos for other reasons may be very upset if they or their family member are touched on the head. Nurses and physicians are taught to examine patients from the head down. In the Navajo creation myth, people were created from the feet up. If you examine from the head down, you are, in effect, taking them apart. This is the opposite of healing. This belief is not held among other Native American groups. Muslim women prefer not to be examined by male physicians.

- ASK if your patient requires a physician or nurse of the same sex. If you cannot accommodate this, explain why and ASK if a chaperone is required during the exam and who this should be
- Explain necessary physical contact through the interpreter
- Be especially careful of draping. The interpreter may remain behind the curtain or discreetly turn her back during an exam. "May I see the sore in your groin that you told me about Mr. Ismaili? It will help me decide how to treat it." OR "I will see if Dr. B can come in. HE has a great deal of experience in this too."
- If the patient, or family member, remains uncomfortable, this is not a challenge to your competence and authority. It is a deeply ingrained value about propriety and modesty

For Example... A severely cognitively impaired Arab man became uncontrollably agitated in the nursing home and was admitted for evaluation. He was calm and easy to care for until the TV was turned on. Even though he was no longer able to speak, it was immediately obvious that the semi-nude women in the TV ads were the problem. He had lived all his life in a country where women only showed their hands and eyes. To see unclothed women was a placing him at risk of his soul.

Body Language

- Gestures and facial expressions communicate intent: dominance, deference, respect, fear, affection, embarrassment and so forth
- Two important aspects of body language are:
 - What you do with your eyes
 - What you do with your hands
- Personal space and facial expressions are other important aspects

Eye Contact in Body Language

- In general we think making eye contact is good, it shows you are paying attention. We interpret avoiding eye contact as either attempting to conceal something, not paying attention or possibly depressed mood. This is NOT universal
- In fact, direct eye contact can be interpreted as hostile or at least rude in some cultures, e.g., African American men, Chinese women, Native Americans of either sex
- When dealing with high status medical professionals, lowered eyes may signify respect
- If there is mistrust of medical professionals, avoiding eye contact may signify conflict avoidance
- This is something you should learn by experience
- If you are not sure what to do with your eyes, looking just past the patient's ear is usually safe

Hand Gestures in Body Language

- Hand gestures are also complex. For instance, Italian gestural language is renowned for its expressive vocabulary
- Hand gestures can easily be misinterpreted
- In general it is acceptable to point at things but not at people
- It is usually a good idea to keep your hands in sight, relaxed, resting on a tabletop, in your lap or if you are standing, holding a stethoscope, book, or pen
- As you observe your patient and family watch what they do with their hands and you can pick up the vocabulary

For Example... The gesture for thumbs up is OK in Greek, but the gesture for OK is obscene. Hands wide are welcoming in southern Europe; hands together are welcoming many parts of Asia.

- Until you pick up the “lingo”, keep your hands neutral and quiet

Personal Space

- Personal space is culturally determined
- Most people have had the experience of backing away from someone who approaches too close
- The distances that people tolerate are quite predictable
- Generally speaking, people of Northern European origins become uncomfortable in conversation at about 2 feet and begin backing up at 18 inches
- Mediterranean and southern Chinese people are comfortable until nearly touching face-to-face

Facial Expressions Are Not Universal

For Example... East and Southeast Asian people convey embarrassment by smiling and even laughing. A neutral or “impassive” expression suggests anger. It is incorrect to interpret this as concealment; these facial gestures are perfectly understood in their own communities. By comparison, an impassive expression without eye contact among most, but not all, Native Americans communicates attentiveness and respect.

Literacy

Health professionals deal in the written and electronic word. This goes well beyond just being able to sound out words on a page. We read effortlessly. We write effortlessly. Do not assume that this is true of your patients. This section contains information about:

Avoiding Assumptions about Illiteracy

- Adult medical illiteracy is a major barrier to care
- One study revealed that up to 45% of English-speaking Americans couldn’t read directions on a pill bottle or follow written instructions for care. Literacy was only partly related to years of formal schooling
- Illiteracy is often a deeply concealed secret. It is **never** directly volunteered

Diagnosing Illiteracy

- Diagnose illiteracy early and non-judgmentally
- Clues to illiteracy include:
 - The patient does not look at printed material you hand them, or does not automatically turn the page upright if it is handed upside-down
 - The patient always “forgets my glasses” and cannot read large boldface type
 - The patient has forms that “the doctor needs to fill out” that may pertain to a medical condition but do not need to be filled out by a physician

What to Do if you Suspect Illiteracy

- Never challenge the patient, “You mean you can’t read that?”
- If you suspect low vision or low literacy you can offer to read aloud necessary information. You can ask “Is it difficult for you to read this? What would make it easy for you to remember?”
- Illiterates are not unintelligent. They may come from a part of the world where women in rural areas are not educated (Bosnia). They may be refugees from a country in which the school system was destroyed in war (Cambodia). They may be U.S. born Americans with undiagnosed learning disabilities, which caused them leave school in frustration. In any case, illiterate patients have gotten by for a long time by figuring out ways to compensate. Let them teach you
- References:
 - The REALM test...citation is a rapid, validated English literacy-screening device that tests patients’ ability to understand medical written materials
 - Davis, T. C., Long, S. W., Jackson, R. H., et al. (1993, June). Rapid estimate of adult literacy in medicine: A shortened screening instrument. *Family Medicine*, 25(6), pp. 391-395.
- If you suspect that literacy is making it difficult for your patient to take medications properly there are a lot of things you can do to make it easier. For Example:
 - With medications, tape the pill or a picture cut out of the PDR on the list next to the instructions
 - Nearly everyone can read numbers and dates
 - Simple line drawings with some orienting details help. Find pictures in health pamphlets

Evaluation and Adaptation of Written Materials

Informational brochures and pamphlets are appreciated but may be useless as instruments of patient and family education if the patient or family cannot read them. You may wish to consider:

Translation of Written Materials into Other Languages

- What about developing some pamphlets?
- Certainly it is good to have translated materials available in languages you commonly encounter
- There are cancer-related materials available in Spanish, Polish, and Chinese in most large urban centers. But they may not convey what you want
- If you wish to develop your own materials...
 - Work with a professional literacy expert to develop the text and with professional translators
 - Select carefully the key ideas you need to convey. Too much information will lose the important message for low literacy readers
 - Never distribute such materials without a pre-market test with several of your own established patients and others in their community
- If you have low literacy materials, do not assume that simple translation is all that is needed. Again, work closely with communities and professional translators to be sure the message and not the just the words are translated. Immigrant and minority patients may need different information

Evaluating Written Materials for Readability

- Most versions of Word for Windows98 6.0 will offer you a literacy score for readability and grade level. The document you are now reading rates 53, low on readability. It should be 70. It rates a grade level of 8.9. It should be around 7.0.
- Literacy scoring programs are readily available only in Spanish and English
- The National Institute for Literacy has a website and health listserv: nifl-health@literacy.nifl.gov

Medicine as a Subculture

- As a health care professional you are a member of a subculture with a shared vocabulary that is likely unfamiliar to outsiders
- The subculture is further divided by discipline. Much of the rub between physicians and nurses for example is due to slightly different vocabularies, different skills and different JOBS, which members of the other profession may not completely understand. Why else do we have team meetings? So much the more for patients

Clues to Cultural Misunderstanding

- The following clues may signify that a cultural misunderstanding is taking place:
 - Repetitious questions from a mentally competent patient or family member
 - Unexplained refusals
 - Polite resistance and “non-compliance”
 - Repeated demands or requests for treatments that are not indicated
- Remember that the concept of palliation itself, which seems universal, may not be so. People come to doctors and to hospitals in expectation of cure. They may seek palliative care outside the setting of formal medical care. Therefore it is important to ASK every patient about his or her expectations of outcome for their illness and their goals for care
- Understand that some patients actively engage from the start, while others do not. Non-U.S.-born, limited-English and limited literacy patients may not be so assertive out of respect or intimidation or an unrealistic expectation of medical or miraculous cure

Life Experiences Contributing to Distrust of Medicine

- Ethnic and racial minority patients may be deeply and justifiably suspicious of health professionals who seem to be withholding care. It is very important to understand the life experience of patients who seem uncooperative
 - African-American men were used as unwitting subjects for unethical research (the Tuskegee Study)
 - Soviet hospitals were used as places of internment for political prisoners
 - Holocaust survivors may be very upset by some medical and nursing procedures
 - Former POWs and refugee survivors of torture may have re-emergent trauma in times of stress

Communicating Bad News: Issues and Values to Consider

- Communicating bad news is a burden and an art about which much has been written in the medical literature lately
- It is intimately associated with issues of truth telling and patient autonomy
- It is important to remember that truth telling and patient autonomy are highly time- and culture-bound values that are not necessarily shared by your patients

Truth-telling

- As recently as the 1960's physicians in this country were routinely taught to withhold disclosure of terminal diagnoses out of kindness
- This is still the common, ethical practice in many countries (such as Italy and Japan)
- You do not need a list of cultures.... The same basic set respectful questions asked of all patients would obtain the information you need to proceed. This has been called “Talking in pieces”

Patient Autonomy

- The concept of patient autonomy is an outgrowth of ideas floating around Western Europe and English-speaking North America since the Reformation on the one hand and the French Revolution on the other
- However, it is a foreign and even abhorrent idea in many cultures. Permitting patients to choose among treatments may be perceived as avoiding responsibility on the part of the health care practitioner. It may be interpreted as lack of professional knowledge and skill. In any case, a rigid or abrupt approach to decision-making may put the patient in an untenable position, especially if family or group decision-making is the norm

TELLING THE WHOLE TRUTH ...in pieces

- ASK the patient what they know about their illness, the name of it, how does it affect their life, what do they expect to happen over the next few weeks or months
- You can start, if you are not the treating physician, by asking, “What did your doctor tell you about your sickness?”

- Invite the patient to ask questions. If the patient wants to know, or wants to know FROM YOU, the patient will ask you questions, volunteer information and engage you. This is also a good way to ascertain what the patient heard and compare it to what the doctor said
- Alternatively, volunteer information a little bit at a time like the layers of an onion

For Example... “We have found an abnormal growth in your... The mass is rather large... The tumor is in a difficult place for surgeons to reach... There is some tumor in your liver as well... I am afraid that the tumor is probably malignant, that means it could spread even more.... There are several kinds of treatment we can offer you...” The patient will signal when you should stop unwrapping the bad news. S/he will change the subject, ask for a negative confirmation or tell you to stop until a family member comes.

- If the patient is aware of the prognosis and expecting a visit from the palliative team, it is still a good idea to verify their understanding and clarify the nature of the care you will provide

For Example... “I am from the palliative care service. Dr. Blank asked us to consult with him about your care. We are the doctors and nurses who specialize in comfort care for patients with serious illnesses such as yours. Has Dr. Blank explained to you about your illness and what can be done for you?”

Family Disclosure: Determining Whether, Who, and When to Tell

- Who should you talk to? Generally, whoever asks to talk to you, provided you have the patient's permission
- An assertive patient may tell you in advance, “Don’t tell my family anything until we talk”
- Families may approach you in advance asking you to talk to them before you talk to the patient or insisting that you not tell the patient
- Whatever the case, it is important that you anticipate
- If the terminal diagnosis has been made you may ask the patient, “Would you like me to talk about it with you alone or would you prefer that I talk to your family first or would you like to talk about it all together?”
- If the family is chosen, ask whom in the family the patient designates. You may confirm this by asking the family who should be contacted for medical matters, and who is “head of the family” for decisions
- Learn the authority hierarchy of the family. Then ASK how to proceed. “We will have to make a lot of decisions about treatment for your (wife) as things go along. Who should we call first? Who second? Would you like to have regular meetings?”

Family Decision-Making

- Family decision-making is more the norm than the exception
- Once the “command system” is agreed upon, you can begin to explore the specific care needs and beliefs of the patient
- It may be that you will “lie” to the patient if the difference is between total disclosure and negotiated discretion

How Do People Make Sense of Illness?

- People always try to make sense out of experience
- Illness in particular causes people to question the meaning of their own life, life in general, the place of suffering in life
- You can approach it from a variety of frameworks, as a spiritual challenge, an existential challenge, and a challenge to ego integrity
- The point is, in all cultures people have ideas about why they get sick, the significance of specific illnesses, the value of suffering, who is responsible for it and who should be involved in the care and cure
- Senseless suffering is far more of a problem than understandable suffering
- Spiritual and psychological distress will adversely affect your ability to provide care. This section is more secular. But you should go to the module on spiritual care for a full discussion

Common Concerns that May Arise from Meanings Attributed to Illness

Patients may have many disease specific concerns that they do not express unless you ask them. Here are some common ones:

- Cancer may be believed to be contagious
 - The patient may isolate herself or may actually be abandoned by friends and neighbors who fear contagion
 - Children may be sent away to protect them
 - Address and refute the misinformation directly and definitively
- Lingering illnesses may be believed to be a sign of bad luck or ill fate that affect the individual and even entire household
 - Illness could be the result of active malevolence (witchcraft, voodoo) or just “bad vibes”... the evil eye of jealous relatives or neighbors
 - You probably cannot change this belief, but you must clearly convey that you and your team will not abandon them
 - Volunteers and friendly visitors may have to be recruited from outside the cultural community
 - Especially in small communities, support groups may be culturally unacceptable for these reasons
- In some cases patients are anxious to conceal the illness because they wish to protect the household from being labeled as unlucky and therefore ostracized in the community
 - Many language communities are small, local neighborhoods where gossip gets around fast. Regular nursing visits may not go unobserved. An unfortunate family may have difficulty doing business or finding marriage partners for their children
 - ASK if they fear that their illness may be harmful to the family in anyway besides the cost of care

Guilt vs. Shame in the Context of Illness

Guilt and shame are not the same. In assessing a patient's concerns related to the meaning of illness, it is important that you hear the difference between guilt and shame. Cultures tend to emphasize one or the other

Guilt... Is internal

- Causes the patient to feel personally to blame for their own misfortune and the burden they feel they are causing their families
- Often has a religious overtone of sin
 - Patients may feel they are being punished for past sins
 - A familiar model is the biblical Job, who could not figure out what sin he had committed to bring such suffering

Shame... Is external

- Causes the patient to feel inadequate and that their inadequacies bring more shame on the household
- Is not exactly embarrassment, but it is more like embarrassment than guilt
- Is social and interpersonal in nature

Meanings of Suffering

Victor Hugo wrote, “Men die and they are not happy.” It is hard to imagine that suffering does not drive out happiness. This depends on the meaning of suffering. In the section of this module that focuses on spirituality, you can get some sense of how various religious traditions attempt to explain suffering

Suffering -- and pain -- may be perceived as:

- Something positive, as the way to earn a place in heaven
- The morally neutral but unavoidable fate of all mortals

- The punishment for past sins
- The revenge of an angry god
- The random mistake of an indifferent god

People bear suffering with courage, good cheer, quiet resignation, stoicism, depression, rage, and panic depending on how they interpret it

Expressions of Suffering

- Cultures generally do lay out an ideal model for how suffering **should** be borne. However, do not **generalize** from cultural stereotypes
- Some families, some cultures, permit and encourage the sufferer to express their anguish and pain. It is this cultural permission that is sometimes misinterpreted as “excitability” by outsiders
- Emotional expressions of pain and suffering may be shameful in some cultures
- Failure to express pain would deny the patient’s claim for care and support in others. For them, dependency is a legitimate component of the sick role
- U.S. medical culture does not accept dependency graciously. Patients are expected to “work” at getting better. In palliative care, this may mean “working” at feeling better. Physical therapy, for example, may make little sense to someone who interprets dependency as a legitimate right for someone in the sick role
- Passivity and dependence may be appropriate in your patient’s culture. If the family accepts it, so should you. You cannot change it in any case

What is Fatalism?

- Fate can be secular or spiritual
- Fatalism means that people feel that their actions either cannot influence the future or that the future has already been determined
- This does not imply passivity and beliefs about pre-determination do not imply a paralysis of will
- Invoking fate, the will of God, in God’s hands, not playing God may reflect a positive adaptation to a situation in which patients or families feel helpless. Better God’s will than chaos
- Hoping for miracles is tactically similar
- Although free will is a Western, Protestant concept, neither are all Protestants in a frame of mind to seize initiative at the end of life
- Conversely, Buddhism and Islam have both been described, as the reason for “fatalism” but it is well to remember that both religions have sustained their believers through great feats of will

Negotiating Fatalism and Choice When Decisions Must Be Made

Specific circumstances, experience, knowledge and belief determine whether patients make active or passive choices about medical care. Fatalism is only a problem if the palliative care team feels thwarted in providing appropriate care by what appears to be obstruction or unwillingness to decide. If it is necessary to get a decision...

- Present the options clearly
- Be certain that the options are understood

For Example... “Just to be sure we’re on the same wavelength, could you explain to me what artificial feeding means to you?”

- Explain your opinion
 - Explain clearly and truthfully why you believe a certain course of treatment is futile
- Be receptive to second opinions
 - There is never any reason to object to a second medical opinion
 - Help the family obtain a second opinion. Most of the time it will confirm your assessment

- Encourage spiritual support-seeking
 - You may invite the family to discuss it with their spiritual advisor (imam, monk, priest)
 - This may or may not help your case
 - In small communities there are few alternatives to the local religious leader. Sometimes this person is willing to work with you. Sometimes not. Do not antagonize him/her. Over time you may build a good relationship with him/her
- Help the family to build on past successes
 - It is useful sometimes to review with the patient and family times when they did make active choices that helped them to survive and succeed
 - Remember that it took enterprise and courage for immigrants and refugees to survive long journeys, internment camps, hardship, and danger to get here and to start over in a strange place
- Address fears of making the "wrong" choice
 - Sometimes it is useful to suggest that fate or God provide the choices. Consequently, the choice that they make is the one that is intended. They cannot fail
- Empower the patient
 - Even within a family there be differing perspectives on fate

What is Alternative Medicine?

- Alternative medicine refers to popularized cures, the variety of "natural healing" modalities including:
 - Reflexology
 - Naprapathy
 - Healing touch
 - Herbals
 - Aromas
 - Massages and so forth...
- It is largely unsystematized and unregulated
- Alternative medicine is quite different from traditional medical systems
- Some of these therapies may actually be helpful. Herbals can be effective; placebos are in some cases harmful. It is important to either become knowledgeable about them or find someone, e.g., a pharmacist, who is. Some can cause interactions with necessary drugs

What Should I Do If My Patient Is Using Alternative Medicine?

- Remain open-minded about it so that the patient will continue to tell you what they are doing
- Do not make the patient choose between your team and the other healers
- Have the patient bring in samples of things they are taking so you can have them analyzed if necessary
- Remember that going to these healers represents either a life long practice or a desperate search for cure when our treatments fail. Regard it as the patient taking an active role. As long as there is no interference with necessary care there is little reason to oppose it

What is Traditional Medicine?

- Long before the marriage of science and medicine, there were doctors and other practitioners. Several of these traditional systems of healing are ancient and quite systematized, e.g., Chinese and Ayurvedic medicine. Some are not in written texts, e.g., Navaho singers. But these are standardized systems of knowledge
- Practitioners in these traditional systems have undergone years of training and apprenticeship. There may be specialties within them, such traditional bonesetters, psychiatrists, or women's ailments
- Patients usually combine allopathic (US) and traditional medicine. Again, patients see the value in both. The traditional healer brings an empathic component and vocabulary of illness and symptoms that are familiar to the patient whereas technology based medicine is foreign and strange

What Should I Do if My Patient is Using Traditional Medicine?

- There is no reason to oppose and many reasons to support the patient in seeking traditional care
- Again, samples of regularly ingested herbals should be obtained so that they can be analyzed if necessary
- The healer should be welcome at the bedside
- Some treatments such as coining, moxibustion, sucking or tattooing may leave bruises and marks on the skin that do not represent abuse

Surgery

All people fear surgery. Fear is normal. Your team is probably expert at managing fears of patients. Surgery may have other meanings for some patients. For Example...

- Opening the body may cause the soul to fly out
- The idea that air makes cancer spread is widely held and reasonable if you realize that poor people often present with advanced malignancies at open and close laparotomies
- Fear of mutilation or sexual abuse while under anesthesia is not uncommon
- The loss of body parts may render the body unclean and not fit for burial in sacred ground

Pain: Meanings Attributed to Pain

- For most people in most of the world, pain and loss of function precipitate the search for care when home remedies fail
- For patients with terminal diagnoses, pain is the reminder of imminent death
- How they bear pain may be interpreted as a measure of character if stoicism is an important value
- If pain represents impending incapacity, the patient may not admit it due to fear of death, fear of loss of status and respect, loss of power and authority, loss face (shame) and indignity. Patients may conceal pain for many reasons

When a Patient Refuses Analgesics: Patients may refuse analgesics for many reasons, including:

- Fear of loss of mental capacity
- Fear of addiction
- A realistic desire not to have narcotics in the house if there are drug problems in the family

It is important to emphasize that analgesics (and antidepressants) are medicines intended to improve function, that the doctors and nurses carefully monitor them. They are under the patient's control

A Language for Assessing Pain

- In describing pain, think of a common kind of pain, like a toothache, like a pinch, like a stabbing knife, like a sticking needle
- For women severity is relatively easy to grade. You can ask her to compare it to the pain of childbirth
- For men, you might ask what was the worst pain they ever had. What caused that pain? How does this compare? Is it much worse, about the same, not as bad, not bad at all just there?
- The pain analog scale with smiley faces, neutral faces and weeping faces may take some explanation since smiling face can represent embarrassment, neutral face anger and weeping face sorrow. These emotions do not scale

Depression

- We identify depression mainly by listening to patients talking about emotional and psychological states. This is a relatively unusual expression of what is a universal pathology
 - Many languages do not have words that describe emotions and psychological states

- Even in English, it is a fairly sophisticated patient who says, “I feel anxious and helpless”
- We believe it is helpful to say these things out loud. That may not be universally true
- The language of anxiety and depression may appear in dream images, the language of the body (somatization) or idioms of speech we do not recognize.

For Example... The Cambodian expression, which translates “thinking too much” represents depression probably associated with PTSD. In Amharic, to complain that “my stomach is too wide” also represents a depressive equivalent.

- Generally, a long list of somatic complaints with no obvious physiologic basis is likely to be depression
- Depression is undertreated among terminally patients at large. It is very likely under-recognized among ethnic and cultural minorities
- Spiritual and pharmacological modalities should be tried

Food: General Considerations

- Medical professionals tend to regard food as nutrition
- Food is love. Food is comfort
- Unless there is a very good reason to restrict a diet, and I can only think of two, sodium and water for end-stage heart and kidney disease, patients should be allowed and encouraged to eat whatever they like
- Bringing home cooked food to hospital should be encouraged.
- If there are food restrictions, e.g., kosher, halal, vegetarian, ask the family what to do. Do not assume that you know what is acceptable

When a Patient Refuses to or is Unable to Eat

- In terminal care the patient may not be able to eat for a variety of reasons. Refusal to eat or inability to eat may signal the end of life
- Families may become extremely anxious and demanding about feeding. They may demand intravenous or tube feeding; they may try forcibly to feed a choking dysphagic patient. They may resist the withdrawal of feeding and hydration
- A useful metaphor is to describe how you go around the house shutting off lights as you prepare to leave on a long journey. The loved one is preparing for a long journey. One by one the systems for this life are shutting down. The loved one does not eat because s/he does not need to sustain this body anymore. If we try too hard to keep him/her here we are just preventing him/her from going on to the next place
- If death is anticipated, a few days or even weeks of hydration and tube feeding are unlikely to change the outcome. It may comfort the family. It is important to pick your battles. This may not be the important one

For Example... It has been described that upper caste (Brahmin) Hindu families may withhold food from a dying family member, since the food is no longer relevant to their needs. This may be upsetting to Western Health professionals. As before, it is important to ask the purpose of practices and to be clear in your communication about prognosis of imminent death

Imminent Death

Expectations and Preparations Around the Time of Death

Star Trekkers are familiar with Klingon death rituals. For a Klingon warrior, death in battle is desirable. Otherwise the warrior death is ritualized at the deathbed. At the moment of death, a comrade (Lt. Worf) holds open the eyes of the dying warrior so he may enter the afterworld courageously, eyes open. A chorus of war-like howling accompanies the moment of death. We don't see many Klingons, but cultures have different practices and beliefs about the last hours of life, the moment of death and the time period immediately following.

- When death is expected within a few weeks or days it is appropriate and considerate to ask the patient and/or family what they expect to happen and what is needed to prepare

- The Victorians clearly had etiquette if not a ritual for the good death. These practices are intended to reassure the patient and insure that they do not die alone. How many relatives constitute NOT ALONE is variable. It can mean immediate family (spouse and children) or the whole family (out to second cousins)
- Preparations may take awhile, so it is important to know how soon the family needs to be notified of imminent death
- Sometimes the patient, if conscious, needs to be informed of imminent death in order to say certain prayers, make bequests and give instructions to heirs

What to Do when Cultural Practices Conflict with Hospital Routine

- Sometimes practices conflict with hospital routine

For Example... Some Hindus believe that death must occur in contact with the mother earth. The patient will need to be on the floor or have earth in the bed. There may be burning of candles, incense or fragrant herbs. Such practices may be in conflict with institutional routine.

- If there is no actual danger, such as lighting fires around oxygen tanks, bending the rules is preferable to stressing the family
- If death is imminent, reconsider the necessity for oxygen or move the patient to a safer area
- If hospital rules cannot accommodate the patient it may be better to arrange for death at home
- Bedside purification rituals are common. It may be necessary to wash or anoint the body. Obviously a few hours can be accommodated. If the length of time needed exceeds institutional regulations it is best to have home transfer worked out in advance of the death. Few public health authorities will permit transport of a cadaver to a private home

Definitions of Death

- Medical professionals define death different ways. Cessation of brain cortical activity OR cardiac asystole. Others may define it as cessation of breathing, which is difficult to demonstrate for a patient on a ventilator
- Establish early with the family how you will define death of the body
- Medical professionals view death as instantaneous. Alive one minute, your heart stops and you are dead
- Death occurs in stages to other people

For Example... In some cultures, death has not occurred until the soul leaves not just the body, but the building. The soul may stay around for several hours or days after the death of the body and must be assisted on its journey or it will stick around to harass the survivors. Some belief systems allot several souls per person, each with it's particular travel requirements.

- You need not have detailed knowledge of these beliefs, but be aware that even though you may believe the patient has died, the family may believe the patient is not alive, but not quite dead either. You have heard inklings of this when autopsies are requested and the family refuses because s/he "has suffered enough." (Also see the section on surgery)

National Cancer Institute grant (R25 CA76449) to Sara J. Knight, Ph.D., at the Robert H. Lurie Comprehensive Cancer Center provided the funding for the development of this program.