Cultural Issues around End of Life

VA Palliative Care January 2012

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Learning Objectives:

- Find the correct care path by asking patient
- Recognize key aspects of cultural reality
- Perform step-by-step cultural assessment of patients facing the end of life
- Avoid common cultural land-mines around end-of-life
- Use scripts to ask questions about sensitive subjects
- Switch to serving cultural needs of family and community at time of death
Practical Reasons for Considering Cultural Aspects of End of Life Healthcare Practice

- **Palliative care staff** benefit from harmonious and successful engagement with patients.
- **Families** (already edgy) benefit from reduced stress when there is cultural alignment.
- **Patient** has just this one chance at final days, and greatly benefits emotionally from focused, holistic support.
- **Clinical care** flows more smoothly when all parties are working in concert. There is probably less unnecessary care provided, as only what is truly wanted is provided.
What are we paying attention to when we are being culturally sensitive?

- Personal **identity** of patient and people around him.
- **Relationships** between these people.
- Relative value and **power** of various people in the care environment, including ourselves.
- **Rituals** and **symbols** that embody meaning and help people to focus.
- **Values** that give meaning to life, and which may also give meaning to suffering and death.
Process of supporting cultural needs of palliative care patients

- **Assess**: ask patient about his goals and preferences.
- Make a **plan** based on assessment: check with patient that you got it right.
- Start to **carry out plan**, gather **feedback** from patient every day.
- Interactively and iteratively **re-assess**, **re-plan**. New problems will arise to be solved.

The trust you earn by cultural validation of patient early on helps if there are unintentional missteps later on.
Assessment:
The Patient Knows what is Needed.

Care team asks sensitive questions,
Clarifies to understand what patient says,
Offers choices, ideas.

Patient leads the way on setting goals, indicating preferences.

Care team follows the patient’s lead.

NOTE: Care team does not carry the burden of knowing what is right for a patient, only the burden of asking the questions and listening.
Assessment itself must be respectful: Sensitive questioning

- Background knowledge can help you avoid antagonizing the patient/family. Know the major friction points and tread carefully.

- Scripts make it easier to ask questions safely and fluently. Scripts tiptoe up on the topic calmly and gently. Always begin with assurance of wish to learn patient’s wishes in order to provide good care.

- Make it safe and easy for the patient to respond with the information you need to know. Assuring patient that every person has things that are important to him validates his requests ahead of time.
Clarifying what the patient says:

- When you hear what the patient says, it may be shocking to you, or difficult to understand, or it may seem to contradict the care plan as it has been developed so far.

- Your reaction can be one of supportive engagement even so. “What would it look like if things were going the way you want them to?” “Please tell me more about the way you would like things to happen.”
Next, build a plan, check with patient. Iterate.

- Write down and repeat back to the patient his main goals and preferences.
- Ask him for prioritization on these.
- Translate the goals into functional, logistic terms. (“To preserve your dignity and help you feel peaceful, we will be very quiet as we care for you, and we will do nursing care at predictable times during the day, with no visitors around. Is this what you want? Please let us know as we go along how else we can preserve your dignity and help you feel peaceful.”)
Cultural Friction Points around End of Life
Cultural Friction Points—2 levels

1) Values and preferences different from provider
   - Patient sees things differently from the way you see things, but is not apprehensive or antagonistic to the care team over these as care begins.
   - As long as patient’s values and preferences are validated by care team, good chance of successful and positive interaction.
Cultural Friction—2 levels, cont.

AND/OR

- Outright fear, anger, defensive position
  - Much more care must be exercised to assure patient of good faith effort to care for him.
  - It may help to speak frankly of patient’s fears/anger so as to lay them to rest.
  - May derive from experience of violence, sexism, racism, homophobia, ageism, poverty, colonialism.
Main Cultural Friction Points at End of Life

- Degree of acknowledgement of and respect for patient goals in care setting
- Disclosure of diagnosis
- Decision-making process in family
- Advance directive/planning vs. fear of jinx
- Acceptability of various specific options
- Norms for touching, communicating, sharing
- Role of care team relative to patient/family control
Assess Patient’s Wishes around each Friction Point
Assess: Patient goals, preferences

Ask the patient (and write down the answers):

- What is the patient’s main goal for this episode of care, his palliative care? (Pain control, dignity, peace, family presence, time to get affairs in order, longest life possible…)
- How would he describe his ideal days for the next week?
- What would make him happy and content?
- What would he like to avoid as much as possible?
- What specific values and concerns would he like us to know about?
Assess: Disclosure of diagnosis

– Avoid blunt use of terms at first (tumor vs cancer).
– Ask patient what he understands his disease to be, and what he understands his present clinical status to be.
– If patient is vague about either, ask him if he wishes to have his care team tell him about his condition in detail, or just in general terms.
– Don’t let the family dictate your approach as you do this assessment. Assure them you will have a gentle, non-specific chat with pt.
Assess: Decision-making pathways in family

- Educate patient that every day there will be information about clinical status to relay, and possibly decisions to be made.
- Ask patient who should receive the information, who should be involved in making decisions, and who has the most important voice in decision-making.
- Be alert to complicated decision-making pathways. Clarify by giving examples of issues. “If your kidneys stop working well and you have trouble thinking clearly, and we need to ask for permission for treatment, would all of your children as well as your wife need to come to an agreement about how to proceed?”
Assess: Advance Directive/Planning vs. Jinx

- Ask patient if he would like to make a plan about what the medical team should do if the patient’s condition deteriorates. (“If” is more gentle than “when.”)
- Be alert to patient indicating that this would jinx his survival or recovery.
- Be alert to patient fear that an Advance Directive is pushed on him to save your organization money or because his life is not valued.
Planning vs. jinx, cont.

Scripts:
“Would you feel comfortable giving us an idea about whether you would want us to use certain types of treatments or machinery to keep you alive, if your body started to have more problems?”

“Your family will have less stress if they know that your wishes have been clearly expressed.”
Assess: Role of care team vis-à-vis patient, family

Ask the patient how he would like his care team to work with him.

- Does pt. want to determine how his final time is organized, and just have the care team support his clinical needs, or
- Does pt. want the care team to be highly active in managing his situation and organizing his environment?
- Give examples: Who determines who can visit, which activities OK around patient, optimum level of clinical intervention?
Assess: Acceptability of options around specific issues

Ask patient if he has strong opinions or worries around:

- Being asked about organ donation.
- How his need for care affects his family financially.
- The issue of withholding care to avoid painful interventions which cannot cure him.
- Anything at all. "Is there anything you worry about that we might do or not do?"
- Anything else you have heard him or the family mention. (Taking blood every day hurries my death.)

NOTE: Introduce each item with assurance that our aim is to empower the patient to make choices that fit his values. These are edgy issues for many patients.
 Assess: Norms around touching, communicating, sharing, naming

- Patients, families, and care team members read huge meaning into others’ styles of touching, communicating, and sharing.
- Watch what the patient does spontaneously.
- Ask “Is it comfortable for you to be hugged or touched by your care team? Do you prefer that we greet you each time we come in your room, or that we let you make the first move in case you wish to not be disturbed?”
Background cultural info to help avoid putting foot wrong at the beginning:
Consider the Patient’s History and Reality

- Care providers have the responsibility of avoiding gratuitous insults to dignity. Be well informed.

- With any patient, consider what injuries to dignity and identity he or his family have endured, and go out of your way to avoid deepening these injuries.
Adult children may need to be seen to be taking good care of parents

Children of patient may be under pressure to:
- not worry pt. by discussing the condition bluntly, certain words taboo;
- not allow pt. to lose hope;
- not consider the cost of continued care;
- deny inconvenience to self around caring for parent;
- not jinx pt. by making plans for physical decline or death.

These cultural pressures are common in traditional cultures. Ask: “Taking care of your parent is a big responsibility. Please let us know your concerns.”
Will of God, destiny, or fate may be factor in patient’s decision-making.

- Patient or family may be unwilling to make decisions or to engage in care, citing fatalism or God’s prerogative to determine outcome.
- All issues may be seen through lens of submission to external power.
- Some issues may be very disturbing to even think about, such as “prematurely” stopping life.
- Organ donation may be repugnant concept.
- Suffering may be seen as necessary or acceptable.
- Ask: “Do you have beliefs that you want us to know about, so that we can take care of you as you wish?”
Patient may see his own needs as subservient to those of family

- Patient may worry that his care will eat up family resources if he lives longer, so he may stop eating in order to hasten his death;
- Patient may defer to dominant family members in order to avoid family discord.
- Patient may have low status in the family and therefore not feel comfortable asking for attention or resources.
- Ask “Do you have concerns about how your family is coping with your illness or your need for care?”
- Reassure “It is OK to ask us for what you want, without needing permission from anyone else. We are here to support you in every way. It is fine to not share information about every aspect of your care with family members."
Community interface, expectations may be important for patient

- Patient may see himself, or family may see patient, as having certain status or meaning in community, may need to maintain an image as dignified, wise, able to do without pain meds,…
- Patient may need to have public religious ritual or visitation.
- Ask patient if he wishes to receive members of the community in his room and whether he needs to be dressed or prepared in a certain way to receive people.
- Ask patient if there are things he needs to do to show leadership or to follow community norms.
Personal grounding work may be patient’s main need

- Patient may focus on inner space for last period, perhaps fasting, perhaps meditating, perhaps making amends for past mistakes or reconciling with family.
- Patient may want religious leader or chaplain.
- Patient may want special environment for this: music, meaningful items, photos, access to phone or computer or writing materials.
- Ask whether he would like any special items, time alone and quiet, help contacting anyone, quiet time with a religious leader or chaplain.
Shift from patient as main cultural client to family as main cultural client, when patient is no longer lucid.
When patient is not conscious

- Once the patient is no longer conscious, the family’s culture comes to the fore. Assess (tell us your wishes), plan, check (is this what you would like?).
- If there is tension between factions, elicit what each faction values, in those words. Refer back to the stated values when talking to them about logistics: “We are respecting your value of doing nothing to hasten death.”
- Test “Are you feeling able to talk with us about how to manage arrangements once the patient passes away?”
- Ask ”Who is the best person to speak with about arrangements?” The person who has been the contact so far may now feel too vulnerable to receive more bad news or to make decisions.
New Problems Arise at Death

- Because many patients and families will not discuss plans about death before it happens, many new problems arise quickly. Identity and relationships have just shifted forever.

- Ask the key family or designated community leaders what the most important considerations are for them now (modesty/gender, access to body, religious rituals, community participation...).

- Ask who it is appropriate to approach to discuss necessary arrangements, including care for the body. In some cultures it is not acceptable to ask the spouse, in others one must ask the spouse.
Cultural Issues at Death

- Autopsy
- Organ donation
- Visitation
- Care of body
- Ritual at site of death
- Proper/acceptable expressions of sympathy

Ask “Around the issue of X, what values does the family/community have? What expectations does the family/community have?” “We want to express our sympathy with you at your loss. We may not know the best way to express it to you, but please accept our condolences and best wishes.”
Recap

- Patient knows what is needed
- Care team:
  - asks goals and preferences
  - avoids stepping on cultural landmines by using scripts
  - makes plan, checks with patient
  - iterates steps as new problems come up and client changes from pt. to family
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