

A RESOURCE GUIDE FOR PALLIATIVE CARE EDUCATION

Part 4: Selected Topics in End-of-Life Care

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PREFACE

There is a pressing need to improve palliative care education. This guide was developed to assist medical educators implement educational programs in key palliative care learning domains. The guide is meant to highlight the topics of greatest educational need, as identified by clinicians.

DISCLAIMER

The information in this book is not medical advice. Health care providers should exercise their own independent clinical judgment. Some of the information in this book cites the use of a product in dosage, for an indication, or in a manner other than that recommended in the product labeling. Accordingly, the official prescribing information should be consulted before any such product is used.

LEARNING FORMATS USED IN THIS GUIDE

PRE-POST TESTS

A brief test (5 minutes), (short-answers or fill in the blank) is included at the beginning of each topic domain. Answers are provided at the bottom and can be covered when copies are made for distribution. The test can be administered in one of the following ways:

- Used at the beginning of a teaching session to heighten learner awareness of the topic;
- Used at the conclusion of a teaching session for the learner and/or the teacher to gauge effectiveness of the learning experience and to demonstrate topics for further learning;
- Used at both the beginning and the end of a teaching session for the learner and/or the teacher to gauge effectiveness of the learning experience and to demonstrate topics for further learning; Note: using the same test both pre and post may create re-test bias in the responses.

TEACHING OUTLINES

Each topic domain contains a brief outline containing the essential topic information. The outlines are designed as quick reference guides, suitable for distribution for different types of learning opportunities—either as stand-alone guides, or as written material to accompany an educational experience, such as:

- a didactic lecture—small or large group setting
- teaching time during ward rounds
- a faculty development course
- a self-study guide

CASE STUDIES

The case study format is used to complement the content outlines to help learners:

- express their own feelings toward the attitudinal issues raised in each case (see **Discussing attitudes**, below);
- reveal deficits in knowledge;

- reinforce existing knowledge.

The cases are designed for small-group discussions, ideally no more than 12-15 participants, (e.g. ward rounds teaching time, small group conference, faculty development course). Each case can be discussed in 30-45 minutes depending upon the depth of discussion. Case studies are included in the following modules: *Pain; Dyspnea; Delirium; Nausea; Constipation, Artificial Hydration/Nutrition.*

SMALL GROUP WORKSHOP-Attitude Discussions

Small groups are excellent venues to discuss attitudinal issues. To optimally explore the personal attitudes that arise in discussing end-of-life care, it is essential that the small group environment feel comfortable and safe. Have each participant introduce themselves and then set basic small group ground rules. One suggestion to help engage all participants is to break the small group into pairs; have each pair work for 5-10 minutes on the questions and then reconvene the entire group, asking each pair to report their answers to the questions. Use of a blackboard or flip-chart can be helpful in keeping track of ideas, opinions. Listed below are key teaching points concerning the subject of attitude change (1).

- Exhortation, information and rational argument have a limited role in the learning or changing of attitudes.
- Recognize that attitudes involve ego-involvement.
 - Shared group attitudes are more resistant to change
 - There must be a willingness to change
- Effective teaching capitalizes on “teachable moments” when the learner is emotionally or intellectually aroused by a question, contradiction, or problem.
- Attitudinal development is fostered in situations in which
 - concrete knowledge and skills are taught that relate to the desired attitudes;
 - the learner is able to examine personal feelings/attitudes in an open and non-threatening dialog with peers;
 - the learner can be active and can engage with others around real problems;
 - the learner has an opportunity to practice the new behavior thus making a commitment;
 - the learner has the opportunity to reflect on the meaning, difficulties and rewards of attitudinal change.
- Role-playing and role-reversal encourages the learner to take an alternative perspective and may foster an empathic awareness of the other’s experience.
- Role models and mentors are crucial to the process of learning attitudes; especially when the learner is making a transition.
- Feedback about the learners progress towards explicitly desired attitudinal objectives can help promote self-reflection and self-learning.

1. Adapted from information provided by Susan Block, MD with assistance from Luann Wilkerson, Ed.D.

ROLE PLAYING AND EXPERIENTIAL EXERCISES

Role playing exercises have been designed to help practice critical end-of-life skills, to reinforce knowledge and as learner evaluation tools. The exercises can be done with dyads (doctor and patient/family) or triads (doctor, patient/family and observer/recorder). The exercise can also be used as an example—the facilitator acting as the doctor, showing “how to do it right”.

The teacher can reduce the inevitable anxiety that accompanies experiential activities such a role playing by encouraging participants to view the role play as a time for the group to

experiment with various approaches to common clinical dilemmas. In the process of experimenting, the learners will discover some approaches that work well, and other approaches that are less effective.

Role playing exercises have been designed to help practice critical end-of-life skills, to reinforce knowledge and as learner evaluation tools.

PERSONAL AWARENESS AND SELF-CARE

LEARNING OBJECTIVES

ATTITUDES

- Self-reflect on current self-care/personal awareness practices.
- Values the importance of personal awareness in caring for dying patients/families.
- Values the importance of personal care in preventing burnout.
- Self-reflects on the impact of patient care on personal and professional roles and responsibilities.

KNOWLEDGE

- Recognizes how past professional and personal experiences can influence one's work with patients.
- Describes the basic steps in self-reflection.
- Describes the signs and symptoms of burnout.
- Describes strategies to avoid burnout.

SKILLS

- Practices self-reflection in the context of working with patients.
- Practices mutual support in the context of working with patients.

PERSONAL AWARENESS AND SELF-CARE

PRE / POST TEST

1. List two reasons why physicians may be fearful of exploring patient emotions at the end-of-life.
 - a)
 - b)
2. Name the three major components of personal awareness.
 - a)
 - b)
 - c)
3. Describe three strategies to avoid burnout.
 - a)
 - b)
 - c)

Answers

1. Fear of provoking painful emotions in a) the patient and b) themselves; 2. Awareness of self, patient and environment; 3. Take care of yourself through life balance; exercise; debrief painful events.

PERSONAL AWARENESS AND SELF-CARE

HUMANIZING PALLIATIVE CARE FOR THE PATIENT AND PHYSICIAN

Caring for dying patients and their families' present unique personal and professional challenges to the physician. In providing this care, the physician confronts his or her own mortality through the patient's. The physician also confronts the inevitability of their own personal losses through the loss experienced by the patient's family. In addition, many physicians have experienced a patient's death that is, for one reason or another, professionally difficult— making the death declaration for a patient one has never met before; facing the unexpected tragic death of a child or young person; caring for a patient who dies following a medical mistake; caring for a patient who dies following a tragic accident or assault. Standing with a patient and family as they confront death requires courage. Sustaining this courage over time requires **personal awareness and attention to self-care.**

BARRIERS TO EFFECTIVE CARE OF DYING PATIENTS

The need to improve palliative care is now well accepted by the health professions. In spite of this acceptance, medical practice continues to lag behind. What are some of the barriers that physicians and other health care providers encounter? Here is our list. If you present a workshop on self care you might ask your audience to brain-storm and generate their own list before presenting our list or your own list. Encourage participants to think beyond the more obvious training issues such as lack of knowledge and clinical skills.

1. Opening Pandora's box

- Lack of knowledge & skill in caring for the dying
- Lack of confidence-- What can I offer?
- Lack of professional support-- Modern medicine focuses on cure, but has not valued palliative care.

2. Past experience—Too close for comfort?

- Negative, inactivating experiences with death and dying
- Positive, enhancing & enriching experiences with death and dying that were not affirmed and supported by peers

3. Fear of patient & family emotions

- Anger; Depression; Anxiety; Sadness; Grief

4. Burn-out

- Emotional burn-out
- Substance abuse

5. Spiritual challenge

- Dealing with dying patients can force one to confront the big spiritual questions— From whence did I come? Why am I here? Where do I go?

PERSONAL AWARENESS

What is personal awareness? Personal awareness involves insight into how one's sensations, emotional life, past experiences, thoughts, beliefs, attitudes and values influence our life experience, including our interactions with patients, families and other professionals (See Novack, et al., 1977). Epstein (1999) talks about "mindful practice". "The goals of mindful practice are to become more aware of one's own mental processes, listen more attentively, become flexible, and recognize bias and judgments, and thereby act with principles and compassion. Mindful practice involves a sense of "unfinishedness," curiosity about the unknown and humility, having an imperfect understanding of another's suffering." (p. 835) Personal awareness includes 3 components: awareness of self; awareness of the other; and, awareness of the environment.

1. Awareness of self --Your sensations, emotions, thoughts, beliefs, attitudes & values

- What do I believe?
 - i. Are people good and trustworthy?
 - ii. Is my role as a physician a calling or a job?
 - iii. What are my cultural roots—ethnicity, gender, religion?
 - iv. What are my spiritual and religious beliefs-- Beliefs about death, Beliefs about suffering, Beliefs about what gives life meaning?
- Your experiences
 - i. How did my family deal with death, emotion, and conflict?
 - ii. "How have my personal experiences with loss and grief affected, enhanced, or limited my abilities to work with dying patients? What are my own attitudes and fears of death and vulnerability, and how do they affect my patient care? If I were dying, what would I want and need from my physician?" (Novack, 1997)
- Your emotional life
 - i. Affiliation: love, caring, attraction
 - (a) What patients elicit feelings of caring? How do I usually respond to my own feelings of caring?
 - (b) What patients elicit feelings of physical attraction? How do I usually respond to my own feelings of attraction?
 - (c) How do I establish appropriate boundaries?
 - ii. Anger & conflict
 - (a) "What sorts of patients elicit an angry reaction in me? What work situations usually make me angry and why? What are my usual responses to my own anger and the anger of others (e.g., do I overreact, placate, blame others, suppress my feelings, become super reasonable)? What are the underlying feelings when I become angry (e.g., feeling rejected, humiliated, and unworthy)? Where did I learn my responses to anger?" (Novack, 1997)
 - (b) How do I establish appropriate boundaries?

2. Awareness of the other, your patient--Their sensations, emotions, thoughts, beliefs, attitudes & values

- Awareness of the patient's illness experience (Stewart, et al., 1995). The distinction between disease and illness reminds us that our medical understanding of a pathological process is different from the individual patient's understanding and experience of illness: Disease refers to a biological, pathophysiological, understanding the pathological process while illness refers to the patient's experience of the process. The acronym FIFE guides us through an assessment of the patient's experience of illness:
 - i. F = Feelings, especially specific fears and hopes. "Do you have any specific fears or concerns that I should know about? What hopes do you have?"

- ii. I = Ideas about what is going on. “What do you think this pain means?”
 - iii. F = Function: Impact upon functioning. “How is your illness affecting daily activities? Are there things you want to do that you can not do?”
 - iv. E = Expectations. What are your expectations...of the disease process; of your self; of others; of care-takers; of your physicians; of me?
- Awareness of the patient as a whole person in the context of family and community (Stewart, et. al, 1995)
 - i. Where is the patient in the cycle of life (childhood, adolescence, young adulthood, parenthood, older adults, dementia)
 - ii. What has been important to them—career, family, service in the community, etc.
 - iii. What are the person’s spiritual beliefs and resources?
 - iv. Does the patient have unfinished personal business?
 - v. Who are the family and friends? What role have they played in the past, and what role are they playing now?
 - vi. Where does the patient live? What are their physical surroundings like? Do the physical surroundings meet the patient’s needs now? Will this change as illness progresses?
 - vii. Does the patient belong to a religious community or other community organizations?

3. **Know the environment**

- What is the local professional environment regarding palliative care? What are my colleagues’ attitudes? What is the local skill level? In what ways will my work be supported or undermined?
- Are there clinical systems in place to support my palliative care work? Does my hospital and clinic have resources for pain and symptom management? Are nurses well trained in palliative care? Do the quality assurance mechanisms include palliative care outcomes?

THE PATHWAY TO PERSONAL AWARENESS THROUGH SELF-REFLECTION

Effective self-awareness requires a specific set of psychological and social skills that involve reflection upon of one’s own thoughts and feelings, awareness of others’ thoughts and feelings, and the practice of acceptance and curiosity. The specific skills or tasks involved in self-reflection are described below.

1. **Self-awareness of sensations, emotions, thoughts, and actions:** Recognize and maintain awareness of your own sensations, emotions, thoughts, and actions when working with patients. One’s sensations, thoughts and feelings are often quite automatic. The interconnections between one’s sensations, thoughts, feelings and actions often go unnoticed.
2. **Self-acceptance:**
 - Accept your emotions, sensations and thoughts openly, without judgement--These emotions, sensations and thoughts are a natural part of your response to the world.
 - Accept ownership of your emotions, sensations and thoughts--These arise from your self; they are a part of you. They are not caused by anyone else. You alone are the source of your thoughts, sensations, and feelings.
3. **Other-awareness:** Recognize and identify the emotions, sensations and thoughts of your patients.
4. **Other-acceptance:** accept the patient's emotions and thoughts openly, without judgements-- These emotions and thoughts are a natural part of their response to the world.
5. **Increase understanding by identifying cognitive and emotional schemas:**
 - Personal schemas: By studying your automatic sensations, emotions and cognitions over time you can become aware of patterns-- in what doctor/patient scenarios do you tend to feel angry?

Happy? Depressed? Satisfied? Frustrated? Identifying personal schemas involves a process of sustained self-observation, curiosity and hypothesis testing.

- Other schemas: By studying another's emotional and cognitive responses over time you will become aware of patterns in their responses. In what scenarios do they tend to feel angry? Happy? Frustrated? Demoralized? Identifying another person's schemas also involves a process of sustained observation, curiosity and hypothesis testing.

8. Increase understanding by identifying patterns of interaction over time: You do not live in isolation. You are always interacting with others. Your sensations, emotions, cognition and behaviors influence others, while the emotions, cognition and behaviors of others influence you. This process is constant and mutually reciprocal. You are linked with others in a constantly changing, dynamic web of interactions. The highest level of personal awareness involves awareness of your engagement in this web of interactions. How do your emotions, cognition and behaviors influence those around you? How do their emotions, cognition and behaviors influence you? What patterns of interaction play out over time with a specific patient? As you explore interactions over time you will be challenged to move from awareness to acceptance to understanding.

THREE PATHWAYS TO SELF-CARE

1. Balance personal & professional life

- What are my goals for work, play, family, community and personal development?
- Am I achieving my goals in each domain? Where I am falling short, can I accept responsibility for the choices I am making or do I feel like a victim? Can I move from a victim stance and instead set proactive goals?
- "What would be an ideal distribution of time between work, play, family, and personal growth and development? What are the barriers to achieving balance in my life? In what ways could my assumptions and beliefs be a barrier to change? In what ways is the current imbalance benefiting me and would I be willing to give that up?" (Novack, 1997)

2. Lead a healthy life-style

- Diet-Exercise-Sleep
- Fun-Social support
- Meaning-Diverse goals-Optimism

3. Prevent burnout

- Stress occurs when there is a mismatch between the resources a person has available and the demands the person is facing. This includes internal psychological resources and demands, and external social and environmental resources and demands. Burnout results from chronic stress.

KNOW AND RECOGNIZE THE SIGNS AND SYMPTOM OF BURNOUT

- Emotional exhaustion: demoralization, irritability, withdrawal, depression, drug and alcohol abuse, marital conflict, family problems;
- Depersonalization: Feeling emotionally separated and numb, cynicism, erosion of empathy, hostility, control and manipulation of others;
- Perceived professional inadequacy: loss of control, dissatisfaction with gains;
- Substance abuse: Use and abuse of controlled substances, illegal drugs, alcohol;
- Social isolation & withdrawal: Backing away from colleagues or family; immersing oneself in work to the exclusion of family and colleagues.

FACTORS THAT INCREASE RISK OF BURNOUT

1. **Irrational beliefs that promote excessive responsibility and place one at risk for burnout--**
 - Limitation in knowledge is a personal failing
 - Responsibility is to be borne by physicians alone
 - Altruistic devotion to work and denial of self is desirable
 - It is “professional” to keep one’s uncertainties and emotions to oneself.
2. **Tragic clinical situations--**
 - An untimely death: child; young adult; unexpected death; death before an important event can occur
 - A patient suffering in spite of my best interventions
3. **Physician mistakes--**
 - “What was the nature of my mistake? What are my beliefs about the mistake? What emotions did I experience in the aftermath of the mistake? How did I cope with the mistake? What changes did I make in my practice as a result of the mistake?” (Levinson, W, Dunn, PM. Coping with fallibility. JAMA. 1989;261:2252.)
4. **Abuse--**
 - Recognize abusive situations--Harassment and abuse based upon gender, race, ethnicity, religion, sexual preference or other factors is a significant source of distress and burnout in medical settings.

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PERSONAL AWARENESS AND SELF-CARE

TEACHING WORKSHOP

Faculty Guide

1. Introduce self-care by talking about the ways in which caring for dying patients and their families can be personally and professionally rewarding as well as demanding.
2. Share two or three examples from your own career. Ask others to share a rewarding or challenging experience.
3. Identify the gap between palliative care recommendations and actual practice (calls for greater use of opioids for pain vs. reality—physicians fear of prescribing), then ask participants to brainstorm about why this gap exists. What are some of the barriers that physicians and other health care providers encounter (in addition to training issues such as knowledge and clinical skill)? Why do you think we haven't done a better job?. (write answers on blackboard or use an overhead projector.)
4. Review the **Personal awareness** section of the outline.
5. Divide participants into groups of 3 or 4. Hand out the **“Professional and Personal Experiences With Death and Dying” worksheet** and ask each person to work through this alone in the next 5-10 minutes. Give a 2 minute warning then ask the group to share their responses within their group (to the extent they are comfortable). After another 5 to 10 minutes debrief the entire group by asking them what they learned by comparing their experiences with varied experiences of others. In what ways do their past personal and professional experiences enhance their work, or present a challenge?
6. Review the **Pathways to self-care** section of the outline.
7. Talk about local resources for participants who are feeling burnout, anxiety or depression.
8. You will want to prepare a resource sheet that lists appropriate local resource numbers, for example the number for resident mental health services and/or EAP program, the office to contact in case of abuse of discrimination, the hospital's physician impairment committee, etc. Encourage participants to use these resources, and to refer colleagues to these resources.
9. Give participants the handout titled **“Inventory of Personal and Professional Goals”**.
10. Ask participants to take 5-10 minutes to begin filling in this worksheet. As a large group or in smaller groups, ask people to reflect upon their goals. Do they have diverse goals or are they all in one category? Which goals are most important? Which goals are receiving the most time and energy? How are they doing at valuing and pursuing those goals that are most valued? Ask participants to take this handout with them and review their responses with a spouse or close friend. As an alternative activity you can ask participants to complete this worksheet on their own time, discuss it with a spouse, family member or close friend, and come prepared to discussion the worksheet at the next meeting.
11. As a follow-up to this module, faculty and residents should identify ways to continue a discussion of personal awareness and self-care in the residency. One approach to continue this dialogue is to devote several case conferences or discussion groups each year to talking about the challenges and rewards of palliative care. Another approach is to create a resident support group that focuses upon personal awareness, self-care and professional growth. Yet another approach is to build self-reflection into the daily work of caring for patients so that faculty and residents can discuss these issues while discussing patient care.

INVENTORY OF PERSONAL AND PROFESSIONAL GOALS ¹

Take the next five minutes to reflect upon your personal and professional goals. Use the chart below to record your thoughts.

Individual goals	
Spouse/Significant Other (If single, think about what your goals may be in the future)	
Children	
Social network: Friends; church; clubs; organizations; etc.	
Professional	

¹Bruce Ambuel, PhD

FACULTY STRATEGIES FOR ENCOURAGING PERSONAL REFLECTION AMONG TRAINEES¹

Strategy	Tactic
Incorporate self-reflection into each case presentation.	Ask residents to comment on the doctor-patient relationship each time they present a case. See the outline <i>A Patient-Centered Approach to the Medical History</i> for an example.
Faculty model self-reflection when working with residents	Share your own emotional reactions. Reflect aloud with the treatment team about what was satisfying for you. What was emotionally challenging. What you might do next time to be more effective. What you have learned from working with this patient and what has been
Pose questions that prompt self-reflection when staffing palliative care patients with residents.	<p>What is most challenging about working with this patient and family?</p> <p>What is most satisfying about working with this patient and family?</p> <p>How are you reacting emotionally to this patient? In what ways are you showing those feelings?</p> <p>How did the patient benefit from working with you? How did the family benefit from working with you?</p> <p>Have your past experiences in any way enhanced or hindered your work with this patient and family?</p> <p>What gives this patient a sense of meaning and purpose?</p> <p>Based upon your work with this patient, what have you learned about yourself and about your strengths and weaknesses? What are your learning goals for the future?</p>
Ask residents to reflect upon their work with each palliative care patient and respond in writing.	See the <i>Palliative Care Episode of Care Resident Education Documentation</i> page for one example of self-reflective questions.
Create regular residency meetings to discuss the doctor-patient relationship	Offer a resident support group or Balint group 2-4 times per month
Assign structured self-reflection during a palliative care rotation.	<p>Read and discuss stories or novels that deal with death and dying.</p> <p>Keep a written journal.</p>

¹ Bruce Ambuel, PhD

ARTIFICIAL HYDRATION AND NUTRITION

The public is increasingly concerned that death not be artificially prolonged. In the absence of a clear advance directive, the placement and long-term maintenance of feeding tubes in patients with late-stage cognitive loss and other terminal illnesses has become common practice. Recent evidence indicates little benefit, but substantial burden, to this practice.

These guidelines provide a framework for decision-making about the use of non-oral feeding and hydration in late-stage dementia and related conditions, taking into account current medical evidence, legal and ethical principles, cultural and religious values.

DEFINITIONS

Non-Oral feeding--provision of food by nasogastric tube (NG), gastrostomy tube (G-Tube) or Gastrojejunostomy (G-J tube) or Total Parenteral Nutrition (TPN).

Artificial Hydration--provision of water or electrolyte solutions by any non-oral route (intravenous, hypodermoclysis, NG/G/GJ tube)

Advanced Cognitive Loss--a progressive, terminal illness, caused by one of a number of conditions including Alzheimer's disease, cerebrovascular disease, congenital or acquired neuro-degenerative diseases, brain tumors, AIDS, Parkinson's diseases, etc.; Diagnostic features include:

- Loss of higher cognitive function including memory and judgment;
- Loss of intelligible speech;
- Inability to interact meaningfully with family/friends;
- Inability to maintain oral nutrition due to loss of swallowing reflex;
- Inability to ambulate;
- Increasing need for medical attention due to complications of dementia;

Natural History⁵ — **progressive cognitive loss is a terminal illness**; when patients can no longer eat, speak or ambulate, the median survival is approximately 6-12 months, depending on the level of medical intervention for intercurrent illnesses (e.g. urosepsis).

DATA CONCERNING THE MEDICAL EFFECTIVENESS OF NON-ORAL FEEDING / HYDRATION IN ADVANCED DEMENTIA

Benefits --- Psychological benefits for family members and caregivers include:

- Maintaining appearance of life-giving sustenance
- Maintaining hope for future cognitive improvement
- Removal/avoidance of guilt about making a decision to withdraw/withhold non-oral feeding and hydration.
- May alleviate caregiver burden associated with time-consuming oral feeding

Unproven benefits --- There is no medical evidence to confirm that provision of non-oral feeding or hydration in patients with late-stage cognitive failure will meet the following goals:

- Reduction in aspiration pneumonia
- Reduction in patient suffering
- Reduction in infections or skin breakdown
- Improved survival duration (in a population of similar patients)

Burdens

- Risk of aspiration pneumonia is the same or greater than without non-oral feeding
- Increased need to use physical restraints
- Wound infections, abdominal pain, and tube-related discomfort
- Loss of pleasure in eating
- Patient isolation, due to decreased contact time with care providers

ETHICAL PRINCIPLES

1. There is no mandate to provide non-oral feeding/hydration to a patient with a terminal illness when the burden/risk of feeding is greater than the benefit.
2. As with any medical procedure, decisions to institute, withhold, or withdraw non-oral feeding should involve patient or designated proxy and include full informed consent discussion regarding the benefits/burdens associated with the action.
3. Non-oral feeding/hydration is considered a medical treatment, not “ordinary care”. “Ordinary care” includes provision of oral food and water, bathing, dressing, keeping a patient safe, warm and comfortable.
4. The decision to withhold or withdraw non-oral feeding/hydration in this setting is **not euthanasia** (the active administration of a drug/procedure by a physician to induce death).
5. The decision to withhold or withdraw non-oral feeding/hydration in this setting is **not assisted suicide** (the provision of a lethal drug/procedure to a patient, with their full knowledge that the drug/procedure can be used by the patient to induce death at the time/place of the patient’s choice).
6. Patients who lack decision-making capacity (non-decisional) may have non-oral feeding/hydration withdrawn or withheld. However, different states have different documentation standards regarding prior expressed wishes in advance care planning documents, check with your hospital social worker or ethics consultant.

RELIGIOUS/CULTURAL VALUES CONCERNING FOOD/WATER

1. The act of eating and the provision of food to the sick are important cultural symbols signifying life and hope. Thus the withdrawal or withholding of food often appears contrary to normal societal values. Families will often mistakenly equate withdrawal or withholding of food with *starvation, euthanasia or murder*.
2. Many, but not all, religions recognize that death is a normal aspect of life and that non-oral feeding/hydration may be discontinued when the burden exceeds the benefit. However, this is not a universally held religious belief; when in doubt, clinicians should consult with a hospital chaplain or spiritual leader.
3. Physicians themselves have deeply held cultural and religious values surrounding the issue of feeding. Such personal feelings must be respected, but not allowed to interfere with the presentation of all reasonable facts and options to families or surrogate decision-makers.

INFORMATION FOR PHYSICIANS WHEN COUNSELING FAMILIES OR SURROGATE DECISION-MAKERS.

- In the absence of non-oral feeding, food and fluids can be offered by mouth, as tolerated, in a manner that will lessen aspiration risk (e.g. thickened liquids).
- There is no data that a lack of fluid or nutrition in patients with late-stage dementia causes suffering. **Note:** The dying patient typically has no or little appetite. moistening the lips and good mouth care will alleviate the symptom of a dry mouth. There is good data that provision of non-oral hydration, by itself, will not correct the symptom of dry mouth among the terminally ill.
- Aggressive comfort measures will always be provided;
 - Pain and symptom management
 - Moistening agents to lips and mouth
 - Frequent change of body position
 - Family support

DISCUSSIONS WITH FAMILY AND SURROGATES—KEY POINTS

1. An advance directive should be completed by patients at the earliest onset of cognitive loss, at a time when patients are still deemed to have decision making capacity.
2. Once a medical determination has been made that adequate oral nutritional intake to sustain life is not possible, and there are no prior expressed wishes, all reasonable options must be discussed with families/surrogates. Present the medical data for and against tube feeding, citing benefits, burdens and alternatives.
3. The option of withholding/withdrawing feeding must be done *in a manner that minimizes guilt upon the family/ surrogate*.
 - If available, review patient wishes expressed in an advance directive with family/surrogate; Consent by the surrogate is required, although it may be useful to frame the decision by the surrogate as one of *honoring* previously expressed patient preferences. It may also help to point out that you, as the clinician, share responsibility in any decision as to its medical appropriateness.
 - Inquire about patient and family religious or cultural values;
 - Ask the family/surrogate, “what would (name) want if he/she could tell us?”;
 - Give permission, if you believe it is appropriate, to withhold/withdraw feeding—families/surrogates will be looking to the physician for clear permission and leadership to make this decision;
 - Offer consultation input (Geriatrics, Neurology, Palliative care, Ethics, Chaplaincy, Psychology);
 - Offer families/surrogates time to make a decision; suggest they contact their spiritual leader, friends or other family for further discussion;
 - Provide patient/family with education material;
4. If a decision is made to begin non-oral feedings, establish a time frame (e.g. 4-8 weeks) for re-evaluation, to establish if the goals of feeding are being met (e.g. weight gain, improved function). Reassure families/surrogates that if goals are not being met, non-oral feeding can be discontinued.
5. If a decision is made to discontinue/not begin non-oral feedings, and hand-feeding is not an option (e.g. diminished level of arousal), and intravenous hydration is not started, families/surrogates should be advised that death will likely ensue within 14 days, and that all comfort measures will be continued.

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ARTIFICIAL HYDRATION/NUTRITION LEARNING ACTIVITY

TEACHING WORKSHOP

Faculty Guide

Small Group Discussion

The attitudinal issues surrounding this topic lend themselves to a group discussion of attitudes and cultural beliefs. Some suggested activities include:

1. Have learners read one of the following references:
 - Finucane TE, Christmas C and Travis K. Tube feeding in patients with advanced dementia. JAMA 1999; 282:1365-1370.
 - McCann, R. Lack of evidence about tube feedings – food for thought. JAMA 1999; 282:1380-1381
 - Gillick MR. Re-thinking the role of tube feeding in patients with advanced dementia. 2000; 342:206-209.
2. Engage a discussion of the major points in the article.
3. Ask learners to discuss their feelings about ANH from the perspective of their own cultural background.
4. Ask learners to reflect on how these values impact their clinical decisions and discussions with patients and families.
5. Practice role-playing a discussion with a family member; in particular, practice responses to these common questions:

“I don’t want my mother to starve to death” “Won’t it be painful if she doesn’t eat” “Isn’t this suicide?”

DISCUSSING SPIRITUAL ISSUES & MAINTAINING HOPE--TEACHING OUTLINE

RELIGION & SPIRITUALITY

RELIGION refers to a socially and culturally grounded system of beliefs concerning the cause, nature and purpose of the universe and individual human life. Because religion is culturally and socially grounded, an individual generally practices their religion within a defined religious community. Most of the world religions, including the religions of Christianity, Buddhism, Islam, Judaism, Hinduism, and Taoism, include 6 common elements described by Smith (1994):

- **Explanation**—of life's big questions, where do we come from, why are we here, where do we go?
- **Tradition**—passing knowledge and practice from one generation to the next;
- **Ritual**—gatherings of celebration and bereavement;
- **Authority**—individuals recognized as religious advisors and counselors by virtue of talent, wisdom, study or experience;
- **Grace**—believing that in some sense “reality is on our side and can be counted on.” (Smith, 1994)

Each religion has specific practices that pertain to illness, healing, the dying process, death, and the period after death, which are rooted in the religion's explanations, traditions, rituals and authority. An individual patient may or may not ascribe to all the practices and beliefs of their chosen religion.

SPIRITUALITY is a broader term than religion, referring to one's personal understanding of the relationship between one's self as a human being—one's spirit, one's soul—, other people, and the universe. Spirituality often encompasses one's personal explanations of big questions-- Where do I come from? Why am I here? Where do I go? What gives my life meaning? What is the meaning of my relationship with other people, and with the earth and universe? Is there meaning to my illness and suffering?

Sulmasy (2006) describes the distinction between religion and spirituality in a similar manner: “Spirituality is about one's relationship with the transcendent questions that confront one as a human being and how one relates to these questions. A religion, by contrast, is a set of texts, practices, and beliefs about the transcendent, shared by a particular community. Spirituality, in this respect, is broader than religion. While not everyone has a religion, spiritual issues, in this wider sense, arise for almost all dying persons.”

WHY MAKE A DISTINCTION between the *spiritual* and the *religious*? The distinction between the *spiritual* and the *religious* helps the physician and palliative care team understand and support the patient's needs by reminding the care team to attend to both the personal (spiritual) and social-cultural (religious) dimensions of an individual patient's sacred experience. For some patients, spirituality is experienced within the context of an organized religion. Some patients do not practice a religion, and yet have spiritual beliefs and practices.

WHY ADDRESS SPIRITUAL AND RELIGIOUS ISSUES?

1. Understanding a patient's spiritual and religious beliefs helps the doctor understand the whole person.
2. A majority of patients want physicians to ask about spiritual and religious issues, to make referrals to appropriate sources of religious and spiritual support, and to incorporate the patient's spiritual and religious concerns into the plan of care, as appropriate.
3. Patients and families may have specific preferences regarding the treatment plan and the dying process which are rooted in their spiritual and religious beliefs and practices. This may include specific needs related to religious rituals and traditions.
4. Dying patients often confront fundamental spiritual questions—Why did this happen to me? Has my life been worthwhile? What value do I have now? What happens after I die? For what may I hope? Why do I suffer? The patient may look to the physician “at the bedside” for support. When a physician stands with a patient as they face death, the physician inevitably supports the patient's inquiry into these fundamental questions. The physician can affirm the worth of the patient,

encourage the patient to express their concerns and questions, and connect the patient to other people such as chaplain and family members.

5. Spiritual pain may cause physical symptoms, particularly pain.
6. Addressing spiritual and religious issues may increase the physicians' self-awareness of how their own belief system and experience of the sacred may influence their interactions with patients and families.
7. Integration of spiritual and religious dimensions is considered a standard of care (e.g. Davidson, et al.,2007).

PHYSICIAN'S ROLE IN SPIRITUAL AND RELIGIOUS ISSUES

Appropriate roles for the physician

The physician's role in the spiritual care of patients is grounded in the spiritual dimensions of the doctor-patient relationship including the fact that the physician will be present with a patient as they encounter some of the most profound moments of their life. The physician:

- sees and treats the whole person, not merely a disease;
- responds to the patient with compassion;
- affirms the patient's unique worth and dignity;
- stands by the patient who is facing suffering and death.

Two appropriate and important roles for the physician in facilitating the patient's spiritual and religious coping are **Catalyst** and **Guide**.

1. Catalyst

When the physician assesses spiritual and religious issues, this inquiry acts as a catalyst for the patient and family to explore spiritual and religious questions that have meaning at this time in their life. The physician's inquiry and resulting dialogue may encourage the patient and family to keep sacred space open for exploration. Thus the physician encourages and supports the patient's personal discovery and dialogue with family, friends, chaplain, and religious teachers.

2. Guide

Once spiritual and religious issues have been assessed, the physician serves a guide to:

- make sure that the health care team integrates spiritual and religious issues into the plan of care
- encourage the patient to obtain support from their own social network.

The physician does not need extensive knowledge about the patient's religion or spirituality. Instead the physician's role is to support the patient in finding resources to address their spiritual and religious concerns.

Inappropriate roles for the physician

As the physician explores the patient's experience of the sacred, there is potential to assume an inappropriate or unethical roles with the patient. Two inappropriate and unethical roles are:

1. Spiritual or religious teacher/leader

The physician can encounter ethical difficulties if they assume the role of spiritual advisor, teacher or leader. This creates a dual relationship between the physician and patient (physician-patient & teacher-seeker). There will inevitably be conflicts between these roles which compromise the physician's ability to provide medical care for the patient.

2. Proselytizing to convert the patient to the physician's religious beliefs

The physician should not attempt to convert a patient to their religious perspective. Maintaining appropriate boundaries in the physician-patient relationship may be particularly challenging when the patient is struggling with fundamental spiritual and religious questions.

FOUR TASKS FOR INCORPORATING SPIRITUALITY AND RELIGION INTO THE CARE OF PATIENTS:

Assessing a patient's spiritual and religious beliefs then incorporating these into EOL care may seem like a daunting task. However, integrating the patient's spiritual and religious beliefs and practices into the plan of care is an accepted standard in palliative care. This goal can be achieved by accomplishing four manageable tasks.

Task #1: Take a spiritual history to assess spiritual and religious issues

There are various guides for physicians in taking a spiritual history (see page 140). Maugans (1996) spiritual history is perhaps the most comprehensive and practical approach.

- SPIRIT. Maugans (1996).
- FICA Spiritual History. Puchalski & Romer (2000)
- HOPE. Anandarajah & Hight (2001)
- Existentially Focused History. Okon (2005).

Task #2: Communicate the spiritual history to the treatment team, document the spiritual history in the record, and incorporate the spiritual history into treatment planning.

- Document the spiritual history appropriately and respectfully in the patient's record;
- With guidance from the patient, and based upon the spiritual history, incorporate specific activities and outcomes into the interdisciplinary treatment plan for the patient;
- Don't assume that the patient and family ascribe to specific religious beliefs and practices of the religion they belong to; confirm this with the patient and family.

Task #3: Continue a dialogue regarding spiritual and religious issues. Foster realistic hope and affirm the worth and value of the person.

- Spiritual support occurs in the context of a meaningful human relationship where patients can feel accepted, valued and respected. Continue to invest in fostering this relationship and continue to engage the patient on issues related to spirituality;
- Take time to sit with your patient, practice active listening and appropriate touch;
- Continue to nurture your relationship with the patient with honesty, availability, active listening, and reassurance;
- Learn the patient's language of meaning as you take the spiritual history and return to important themes;
- Follow-up on the treatment plan, and revise as needed;
- Engage the entire treatment team, and ask the patient whether they wish to consult with clergy or other religious advisors;
- Ask if the patient has encountered any barriers to the practice of their spiritual or religious life.

Task #4: Recognizing common spiritual dilemmas

Patients may express feelings and thoughts that evoke one or more of the following themes involving the past (guilt, painful memories); the present (isolation, anger, unfairness) or the future (fear, hopelessness). Common verbal expressions include:

- Unfairness--*Why me?*
- Unworthiness--*I don't want to be a burden.*
- Hopelessness--*What's the point?*
- Guilt & punishment--*My disease is a punishment. But I have led a good life.*
- Isolation & anger--*No one understands me.*
- Confusion--*Why is this happening to me?*
- Vulnerability--*I am afraid.*
- Abandonment--*My God (or my family) doesn't care about me.*

When you hear these themes, reflective listening and normalizing can highlight the dilemma in a manner that helps the patient recognize the issue and accept their feelings. For example:

Patient: *Sometimes I feel like I'm being punished*

Physician (reflective listening): *You feel like you are being punished.*

Patient: *Yes, I do.*

Physician: *Tell me more about that*

Patient: Describes feelings in more detail.

Physician (normalizing): *Many patients that I have worked with have had similar feelings. Is there someone you can discuss these feelings with?*

Highlighting, recognizing, and affirming emotions in this manner often guides patients towards healing. For some patients, a brief discussion with their physician will be sufficient. For others, this type of discussion with their physician will prompt them to further discuss their feelings with friends, family or religious advisor. When the physician sees that a patient continues to struggle with an issue, the physician will want to make an referral to a psychotherapist and/or religious advisor.

MAINTAINING HOPE

Maintaining hope in the face of terminal illness is one of the great challenges facing people near the end of life. Most dying patients both want and need honesty from their physicians regarding their disease and prognosis. Sometimes health care providers fear that in the face of terminal illness, honesty is cruel because it will force the patient to lose hope. However, one may be honest with patients and still maintain hope through a change in focus, away from hopes that are long-term, to hopes that are either short-term or spiritual. Maintaining hope through realistic short-term goals is extremely important for patients and families.

Some strategies for beginning a dialogue about short and long term goals include:

1. Ask the patient, *"Do you have long term hopes and dreams that have been threatened by this illness?"*

Identifying loss is the first step in grieving. Support the patient in recognizing and grieving the possible loss of these hopes:

- Validate and recognize feelings of anger, sadness and denial;
- Encourage the patient to talk with others about this loss, especially if these hopes and dream included others.

2. Ask the person if there are upcoming events they wish to participate in--a wedding, birth, trip, etc.

3. Encourage the patient to make short, medium and long range goals with an understanding that the course of terminal illness is always unpredictable.

- to attend a family gathering (dinner, wedding, birth)
- to walk again
- to feel better tomorrow
- to be at home
- to visit with close family or friends
- to be remembered
- to have a future beyond physical existence

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DISCUSSING SPIRITUAL ISSUES & MAINTAINING HOPE

TEACHING WORKSHOP

Faculty Guide

1. Ask participants to generate examples of patients for whom religion and spirituality have been important resources. Ask them to identify patients where the health care team has responded effectively to incorporate religious and spiritual issues into the treatment plan. Ask them to also identify patients where the health care team was not as effective as one would hope.
2. Review the outline.
3. Divide the group into pairs and ask each pair to practice taking a spiritual history with the other person using the **Spiritual History and Documentation Outlines** as a guide. After about 5-10 minutes, prompt the pairs to switch roles.
4. Ask each person to work by him or herself and write a brief spiritual history chart note summarizing the history they just took. Use the outline provided.
5. In a large group ask for feedback on the interview. How did it go? What challenges do they anticipate incorporating this into their interview? Does anyone have a particular way of asking a question that they want to share with the group?
6. Homework: Ask each participant to practice taking and documenting a spiritual history on 3 inpatients or outpatients. Staff these histories with a palliative care faculty member.

Spiritual History Tools and Sample Questions¹

SPIRIT	
Spiritual belief system	“Do you have a formal religious affiliation?” “Do you have a spiritual life that is important to you?”
Personal spirituality	“Describe the beliefs and practices of your religion or spiritual system that you personally accept.” “Describe beliefs and practices that you do not accept.”
Integration with a spiritual community	“Do you belong to any spiritual or religious group or community?” “Is it a source of support? In what ways?”
Ritualized practices and restrictions	“Are there specific practices that you carry out as part of your religion/spirituality (eg, prayer or meditation)?” “Are there certain lifestyle activities or practices that your religion/spirituality encourages or forbids? Do you comply?”
Implications for medical care	“What aspects of your religion/spirituality would you like me to keep in mind as I care for you?” “Are there specific elements of medical care that you forbid on the basis of religious/spiritual grounds?”
Terminal events planning	“As we plan for your care near the end of life, how does your faith impact on your decisions?” “Are there specific aspects of care that you wish to forgo or have withheld because of your faith?”

Reference: Maugans, TA. The SPIRITual History. Arch Fam Med 1996 5:11-16

FICA Spiritual History	
Faith	“What is your faith? Do you consider yourself spiritual or religious?”
Importance/Influence	“What importance does your faith or belief have in your life?”
Community	“Are you part of a religious community?”
Address/Apply	“How would you like me as your provider to address these issues in your care?”

Reference: Puchalski CM and Romer AL. Taking a spiritual history allows clinicians to understand patients more fully. J Palliat Med 2000 (3):129-137

HOPE	
H sources of hope	“What gives you hope (or strength or comfort or peace) in the time of illness?”
Organized religion	“Are you a part/member of religious or spiritual community? Does it help you? How?”
Personal spirituality and practices	“What aspects of your spiritual beliefs do you find most helpful and meaningful personally?”
Effect on medical care and end-of-life issues	“How do your beliefs affect the kind of medical care you would like me to provide over the next few days/weeks/months?”

Reference: Anandarajah G and Hight E.. Spirituality and medical practice: Using HOPE questions as a practical tool for spiritual assessment. Am Fam Physician 2001;63:81-89.

Existential Focused History	
Meaning	“What brings purpose to your life? What is it like to go through this illness? What brings comfort to your life?”
Hopes, identities, and continuity	“What do you hope for? What are your dreams and goals? What is still possible?”
Legacy	“How would you like to be remembered (by people you care about)? What are you especially proud of?”

Trust, support, and caring relationships	"Who are you the closest to? What role have you been playing in your family? What brings fun and laughter to your life?"
Life review: pain & forgiveness; estrangement & reconciliation	"Are there conflicts you wish to resolve? Do you feel in need to reconcile with somebody? Do you feel burdened by a sense of guilt?"
Resilience and self-efficacy	"What makes you strong in the midst of this illness? What can you do to still make a difference in your life?"

Reference: OkonTR. Palliative Care Review: Spiritual, Religious, and Existential Aspects of Palliative Care. *Journal of Palliative Medicine* 2005 8;2, 392-414

Spiritual History Documentation -- Outline

S—spiritual belief system

P—personal spirituality

I—integration with a spiritual community

R—ritualized practices and restrictions

I—implications for medical care

T—terminal events planning

CROSS-CULTURAL ENCOUNTERS

LEARNING OBJECTIVES

ATTITUDES

- Develops appreciation for the prevalence of cross-cultural encounters and common barriers that arise.
- Values the importance of cultural competence in palliative care.
- Gains insight into one's own culture and values and how these affect beliefs about palliative care.

KNOWLEDGE

- Defines culture and its impact on palliative care.
- Describes the explanatory model and its use in understanding cultural influences.
- Identify various death related activities and how they may be affected by culture.
- Define ritual and explain it's role in palliative care.

SKILLS

- Demonstrates the ability to respond appropriately to a request to withhold information from a patient.
- Demonstrates the ability to assess beliefs and practices about death and dying in a patient and family of a different background.
- Demonstrates the ability to enlist resources that will assist in understanding and working with people from different cultural backgrounds.

CROSS-CULTURAL ENCOUNTERS

PRE/POST TEST

1. Define culture: _____

2. List two attributes that contribute to an individual's cultural identity:
 - a)
 - b)
2. Name two death-related rituals that vary across cultures:
 - a)
 - b)
3. Write two questions you might ask someone from a very different culture to help you understand how they view and understand an episode of illness:
 - a)
 - b)

Answers

1. a set of guidelines that individuals acquire from their society. 2. Burial practices; Preparation of the body; 3. What do you call the problem? Why do you believe the problem occurred.

CROSS-CULTURAL ENCOUNTERS

Most things that don't make sense from the outside DO make sense if understood from the inside...

WHAT IS CULTURE?

Definition: "A set of guidelines (both explicit and implicit) which individuals inherit as members of a particular society, and which tells them how to view the world, how to experience it emotionally, and how to *behave* in it in relation to other people, to supernatural forces or gods, and to the natural environment." Helman, CG, *Culture Health and Illness*, 3rd Ed. 1994:2.

Culture is more than just ethnicity, skin color or religion. A variety of other attributes contribute to our cultural make-up including: national and geographic origin, current home, gender, sexual orientation, age/generation, marital status, family, professional and community roles. It is important for all clinicians to remember that we too have our own cultures. Our cultural make-up significantly influences our interactions with patients and families and the care we deliver. We can better serve those we work with by gaining insight into our own cultural make-up.

CHALLENGES IN WORKING ACROSS CULTURES

- **Language**
Try to avoid using family members as translators, as they may filter communication. Use professional translators where possible.
- **Misunderstandings**
Misunderstandings occur when something is said or done with one intent or meaning and it is interpreted to have a different intent or meaning. This is particularly a problem in EOL care, as many cultures (including our own) rely on indirect, symbolic communication around illness and dying.
- **Differing values, meanings**
Values and the meaning invested in certain behaviors or rituals may vary dramatically across cultures and even within cultures. It is difficult to avoid extremes of cultural stereotyping on the one hand and ignoring real differences, where they exist, on the other hand.
- **Imposed relationships**
As people approach the end-of-life, regardless of socioeconomic class, they are more likely to become dependent upon others from very different cultural backgrounds. There is little if any choice about this; these relationships are *imposed*. The nature of such imposed relationships makes misunderstandings more common and conflict, based both on misunderstandings and differing values, more likely.
- **History and prejudice**
People carry with them their history. Sadly, the historical relationship between members of many groups is characterized by distrust, prejudice and even hatred. Clinicians may like to think that they are immune to the effects of such distrust or prejudice- either in their patients or themselves, as we imagine ourselves to have only beneficent intents. It is difficult to acknowledge that history and prejudice may themselves pose a significant challenge for our patients and ourselves.
- **The power of ritual**
Ritual is a process of making *human* that which is *biological*. Ritual can be defined as repetitive behavior for a non-technical purpose, which is imbued with meaning. Ritual is particularly important in life-transitions, such as birth, puberty and dying. Clinicians tend to underestimate the power and importance of ritual. If dying is understood primarily as a biological or medical event, ritual for patients, families and clinicians will be devalued. It is also natural for people to have little insight into their own rituals; most people when asked why they do something a certain way will say, "because that's how it is done." Clinicians cloaked in science have trouble recognizing the importance of rituals in others, but may have even greater difficulty recognizing ritual behavior in which they themselves are engaged.

THE EXPLANATORY MODEL

Developed by Arthur Kleinman, a medical anthropologist, this is a method of exploring another's way of understanding a particular illness. Explanations of how one became ill, what the consequences of the illness are (indeed what the illness is) and the roles of various parties in relating to the ill patient vary dramatically across cultures. Getting to the patient's and the family's explanatory model (and developing insight into one's *own* model) can go a long way toward promoting understanding. Such understanding is often critical when dealing with people from very different backgrounds and when encountering a serious disagreement- where the other side's position makes no sense. Remember: *Most things that don't make sense from the outside usually DO make sense if understood from the inside...*

QUESTIONS TO ASK TO EXPLORE THE EXPLANATORY MODEL:

What ...

- Do you call the problem?
- Do you think the sickness does?
- Do you think the natural course of the illness is?
- Is it you fear?

Why ...

- Do you believe this problem occurred?

How ...

- Do you think the sickness should be treated?

Who ...

- Should one turn to for help?
- Should be involved in care and decision making?

EXPLORATION OF DYING AND DEATH RELATED BELIEFS AND PRACTICES

Exploration of EOL dying and death related practices is particularly important when encountering a patient or family from a group with which the practitioner is unfamiliar. Examples of various styles of beliefs and practices that may have cultural tones are in parentheses.

Beliefs and practices that may be explored:

- How are people informed or communicate about a serious/terminal illness? (direct, indirect)
- Preparation/approach to dying? (fighting, fatalistic, accepting)
- Symptom/medical management? (stoic or vocal approaches to distress, self-care practices/home remedies, complementary therapies)
- Approaches to feeding/nutrition of dying patients?
- Desired location of dying? (home, hospital)
- Spiritual/religious needs/rituals?
 Before death; At time of death and Following death
- Care of the body, following death? (washing, placement of body (directional, Islam), speed in moving the body (Buddhist- slow, Jewish- fast), desired clothing)
- Grief practices? (restrained, demonstrative, ritual behavior and anniversaries)
- Attitudes toward organ donation, autopsy? (Accepting, non-accepting)
- Funeral practices?

NOTE: Especially when asking questions regarding death it may be wise to initially *detoxify* questions, by stating that you are NOT inquiring about the patient, but about general cultural practices, as many cultures have taboos against speaking explicitly about the dying of a sick patient- as it is believed this may hasten death. If the person with whom you are speaking continues to speak indirectly ("in our culture this is how things are done..."), continue *not* speaking directly about the dying person. If the person begins to talk more openly, ("when he dies, this is what we want") you have probably been given permission to address more directly what will happen within that family.

In exploring beliefs and practices you may consider the following general approach and types of questions:

- **Statement of respect, desire to learn.**
Example: *I know very little about how people from East India deal with things at such a time. I understand and respect the fact that different people handle things in very different ways. I would very much appreciate it if you would teach me what I need to know to be of help.*
- **What is important?**
For the dying person to do.
For caregivers/families to do.
For the dying person.
At the time of death.
Following death.
- **Are there important things that we should know NOT do?**
At the time of death.
Following death.
- **Do you have any special concerns or fears that we should know about?**
- **How could we be most helpful to the patient and family?**
In the dying process.
At the moment of death.
After death.
- **Reaffirm intent to help.** Give permission to let us know if we make a mistake.

DEALING WITH A REQUEST FOR NON-DISCLOSURE

Key points:

- A request for non-disclosure (don't tell grandmother she's dying) is often rooted in cultural beliefs and practices of the family. Such beliefs and practices are very common.
- A belief system wherein the dying is not told and others make healthcare decisions is not necessarily wrong. The prevailing belief system in Western healthcare that the "patient has a right to know" is not necessarily right.
- Skilled communication and negotiation is required to broker between those who desire non-disclosure and a healthcare system that is overtly based on disclosure and the patient's 'right to know'.

Suggested steps in exploring a request for non-disclosure:

- **Statement of respect**
Examples: *"I respect that different people have different opinions/beliefs about how such things are handled. Thank you for letting me know of your concern."*
- **Why has this request been made?**
Example: *"Is there some particular reason you would prefer to handle things this way or do you have a special concern about what might happen if I talked directly with her?"*
- **Where do they think the patient would stand on this issue?**
Example: *"Do you think or know that grandmother would agree with this? Have you discussed this approach with her? How has she dealt with similar situations (prior deaths if any) in the past?"*
- **Statement of own values:** This should be done in a non-coercive manner, simply as a matter of explanation, both explaining common practice and personal values.
Example: *"In the United States most people believe a clear-thinking patient should make their own decisions..." "It is important to me to tell the truth, when speaking with people..."*
- **Propose a negotiated approach:**
Example: *"I've heard what you've said and respect where you are coming from. What I would like to do is to simply confirm with your grandmother that she is OK leaving the details to you."*

- **Set ground rules for discussion:** Most physicians, I think, would like it clearly understood that if the patient says, “No, I want to be in charge. Tell me the whole truth” that it violates the physician’s ethics to lie.
Example: “Assuming your grandmother agrees, I’m fine not talking with her about details of her disease and having you make decisions. However, if she asks me to tell the truth or that she wants to be in charge, I cannot lie. Do you understand and agree to this?”
- **Talk with patient**
Example: “I understand in your family that the details regarding your medical condition and care are usually discussed and decided upon by the family (or specific member). Is this the way you would like me to handle things?”
If yes, then there is no problem. **To defer one’s autonomy is itself an act of autonomy.**
If no, then it is suggested that this response be discussed with the family members prior to proceeding to further discussion with the patient.

RESOURCES

Resources in your health care setting can include translators and/or *cultural guides*, individuals that can assist you in understanding patients and families from different backgrounds. Other local resources include healthcare workers from a similar background in your institution, who can help facilitate understanding between the ‘system’ and the patient or family. Local community and religious groups may also be great resources in providing guidance and support to the patient and family.

Books

- Braun KL. *Cultural Issues in End-of-Life Care*. Sage Pub. 2000. This book provides a good overview and addresses specific issues in specific sub-populations, such as African Americans, Hispanics, Disability Groups and patients with AIDS.
- Crawley LM, et al. Strategies for culturally effective end-of-life care. *Ann Int Med* 2002; 136:673-679.
- Fadiman A. *The Spirit catches you and you fall down*. Noonday. New York. 1997. A superb description of a Hmong girl with a seizure disorder and the cultural conflicts that arose between Western medical practitioners and the Hmong people in trying to care for her.
- Helman CG. *Culture Health and Illness*. (3rd Ed.). Butterworth Heinemann. London. 1994. A superb introduction to medical anthropology, not specific to EOL care.
- Irish D, Lundquist K. *Ethnic Variations in dying, Death and Grief*. Taylor and Francis. Washington, DC. 1993. A more focused book on death related practices of major ethnic groups in the United States. However, this does not have the breadth of Lipson’s book.
- Lipson JG, Dibble SL, Minarik PA. *Culture & Nursing Care: a pocket guide*. UCSF Nursing Press. SF. 1996. Perhaps best pocket reference. Has detailed descriptions of death related practices for 23 ethnic groups.

Articles:

- Blackhall LJ, Murphy ST, et al: Ethnicity and attitudes toward patient autonomy. *JAMA*. 274; 1995:820-825. Useful in considering issues, such as disclosure.
- Dula, A. The life and death of Miss Mildred. *Clinical Ethics*. 10(3); 1994:419-430. Useful in teaching, as it illustrates cultural differences between a poor, elderly African-American woman and the healthcare system with which she interacts. Skillfully allows the reader access to the perspective of the patient and how she views her situation and the healthcare system.
- Hallenbeck JL, Goldstein MK, Mebane EW. Cultural considerations of death and dying in the United States. *Clinics in Geriatrics*. 12(2); 1996:393-406. Identifies different types of cultural misunderstandings that can arise in EOL care.
- Hallenbeck JL, Goldstein, MK, Decisions at the end of life: cultural considerations beyond medical ethics. *Generations*, 1999; 23(1):24-29. Considers the cultural relativity of Western

medical ethics and problems that arise when different value systems are not understood in addressing common ethical problems at the EOL.

- Kleinman A. Culture, illness and cure: Clinical lessons from anthropologic and cross-cultural research. *Annals Int Med.* 1978; 88:251-258. From the creator of the "explanatory model"- a classic paper introducing this concept to the medical community.
- Loudon RF, Anderson PM, Singh Gill, P, Greenfield, SM. Educating medical students for work in culturally diverse societies. *JAMA.* 282(9); 1999:875-880. Excellent recent systematic review, covers other papers that have examined this issue.
- Orona CJ, Koenig BA, Davis AJ. Cultural aspects of non-disclosure. *Cambridge Quarterly of Healthcare Ethics.* 1994; 3:338-346.

Websites

<http://www.xculture.org/> Focus on cross-cultural healthcare. Vast resources and links available. Excellent start-site for web searches on the topic.

<http://www.ama-assn.org/ethic/diversity/contents.htm> Acrobat file of 460 page AMA report entitled, Cultural Competence Compendium. Excellent reference work with reviews of major articles and resources in the field. Also can be purchased from the AMA. For purchase see information on the website.

CULTURE AND END-OF-LIFE CARE
TEACHING WORKSHOP—ROLE PLAYING EXERCISES

Faculty Guide

Five different exercises are included to explore different aspects of culture and end-of-life care:

1. Explanatory Model – Role playing exercise
2. Explanatory Model – Personal exploration exercise
3. Exploring death-related practices - Role playing exercise
4. Exploring a request for non-disclosure exercise ('Don't tell grandmother') –
Role playing exercise
5. Finding cultural resources exercise

1. Explanatory Model – Role playing exercise

Purpose: To practice the skill of eliciting an explanatory model and to gain insight into one's own explanatory model of illness. The learner will practice asking *what, why, how* and *who* questions.

Method: One learner takes the part of the clinician and one the part of a person from a different culture (either patient or family member). While the learner playing the family or patient role may play his or herself, it is helpful if the explanatory model is significantly different from the Western medical model in order to highlight differences. Faculty and learners may decide prior to the role play what particular illness is to be explained. The illness may or not be terminal in nature. The script below is for a patient from a non-Western culture with a brain tumor, who is experiencing seizures. **Note:** After the role play, highlight differences between answers from a Western clinician and a person from the culture of the patient with a brain tumor to the same questions.

Clinician Role: You have just admitted a patient with a glioblastoma multiforme, who has begun having recurrent seizures. The family appears distressed by the seizures, but also looked unhappy when the patient is given IV and oral medications. The nursing staff describes the family as uncooperative and the patient as non-compliant with medications. Upon entering the room, you notice a strange, herbal odor. The patient's gown is open at the front and a greasy, foul-smelling ointment has been applied to the chest. You ask to speak to the patient to try and elucidate the explanatory model for this illness.

Patient role: You are a recent immigrant to the United States. A few months ago you began having pains in your head and feeling strange. Two weeks ago you were admitted when you had a spell. After you woke up, the doctors told you they had to drill a hole in your head. You were scared, but hoped that by drilling the hole, whatever spirit was trapped in your head would be released. After that they told you that you had something bad in your head. Releasing the bad spirit didn't work- it was too big. Recently, the spirit has been possessing you more frequently. You are afraid that the spirit might take your soul away. If that happened, you would not only die, but be unable to find your way to the afterworld. The Western medicine you have been given hasn't helped, so you are reluctant to keep taking it. Your family connected a medicine man, who told them to apply a special herbal lotion to you chest, which will irritate the spirit and make it leave.

2. Explanatory Model – Personal exploration exercise

(This exercise can be performed more rapidly than the role play (Exercise 1.)—it is especially good for self-reflection on how the medical model is itself an explanatory model, but does not allow skill practice.)

Purpose: To understand how different cultures have different ways of explaining medical phenomenon.

Method: Distribute the worksheet (following page), ask the group to explain *their* explanatory model for seizures, asking the group, *what, why, how* and *who* questions. (e.g. “*What is a seizure?*” An electrical discharge in the brain...). After this, read the excerpt below from, *The Spirit Catches You and you Fall Down*. This book is about a young Hmong girl with seizures. The Hmong are a mountain people from Laos, who settled in large numbers in the area of Fresno, California. Note how different the explanatory models and the potential for misunderstandings and confusion.

From *The Spirit Catches You and You Fall Down* ¹:

1. *What do you call the problem?*
Qaug dab peg. That means the spirit catches you and you fall down.
2. *What do you think has caused the problem?*
Soul loss.
3. *Why do you think it started when it did?*
Lia’s sister, Yer slammed the door and Lia’s soul was frightened out of her body.
4. *What do you think the sickness does? How does it work?*
It makes Lia shake and fall down. It works because a spirit called a *dab* is catching her.
5. *How severe is the sickness? Will it have a short or long course?*
Why are you asking us those questions? If you are a good doctor, you should know the answers yourself.
6. *What kind of treatment do you think the patient should receive? What are the most important results you hope she receives from this treatment?*
You should give Lia medicine to take for a week but no longer. After she is well, she should stop taking the medicine. You should not treat her by taking her blood or the fluid from her backbone. Lia should also be treated at home with our Hmong medicines and by sacrificing pigs and chickens. We hope Lia will be healthy, but we are not sure we want her to stop shaking forever because it makes her noble in our culture, and when she grows she might become a shaman.
7. *What are the chief problems the sickness has caused?*
It has made us sad to see Lia hurt, and it has made us angry at Yer.
8. *What do you fear most about the sickness?*
That Lia’s soul will never return.

1. From: Faidmans A. *The spirit catches you and you fall down*. Noonday Press, NY, NY. 1997, pgs. 260-261.

WORKSHEET—EXPLANATORY MODEL EXPLORATION

How do you explain the phenomenon of seizures? Write your answers below.

What is a seizure?

Why does a seizure occur?

How does a seizure occur?

Who experiences seizures?

3. Exploring death-related practices -- Role playing exercise

Purpose: To practice the skill of learning about another cultures death related practices.

Method: One person will be the physician, the other the relative of a dying patient of a cultural background with which the physician is unfamiliar. Prior to the role play clarify the relationship of the relative to the patient and give a very rough sketch of the cultural background of the family being represented (perhaps race, national origin and/or religious background). The person playing the relative may choose to act the part of someone from his/her own background or may alter the background as desired. Encourage learners playing the part of the family member to answer as his or her own family was involved, if comfortable doing so, as this promotes self-reflection.

Scenario: The scene is a peaceful one. There is no immediate medical crisis. It appears that the relative is well aware that the patient is dying.

Physician Role: You have just admitted a patient from a very different background than your own. You are unsure how to approach the patient or the family and to be of help relative to patient's impending death, which may happen in a matter of days. You ask to speak to a relative in order to get some understanding of dying and death related practices so that you can understand their needs.

Relative role: Your relative (fill in the blank – relation to you) has been admitted to the hospital and is obviously dying. The doctor asks to speak with you for a few moments.

4. Exploring a request for non-disclosure exercise ('Don't tell grandmother') – Role playing exercise

Purpose: Practice the skill of dealing with a request for non-disclosure.

Method: One person will be the physician, the other the relative of a dying patient of a cultural background different from the physician. The person playing the relative may choose to act the part of someone from his/her own background or may alter the background, as desired. Encourage learners playing the part of the family member to answer as his or her own family was involved, if comfortable doing so, as this promotes self-reflection.

Physician role: You are meeting with the son (or daughter) of a patient, who is dying. He (or she) has requested to talk with you. You are considering a hospice referral. Normally, you would discuss hospice as an option with the patient. However, you are stopped you in the hall and told you that the family does not want you to tell his mother that she is dying. You meet to discuss this.

Son or daughter of patient role: You are meeting with your mother's physician. You know your mother is dying, but believe it would destroy her hope if she knew. You think she might in fact know it already, but it would not be proper to speak of such things. You have never discussed directly your mother's wishes, but you believe this is consistent with your cultural and family values. At a certain age the oldest child becomes the family spokesperson and makes decisions. It is not proper to speak of death with the dying. When your father died seven years ago of cancer, your mother also believed it was best not to tell him.

5. Finding cultural resources exercise

Purpose: Practice finding resources to manage specific cross-cultural patient needs.

Method: This exercise can be given as “homework”, perhaps as a treasure hunt competition with a ‘prize’ for the learner with the most comprehensive resource list. Select one or more specific cultural groups (e.g. Hmong, African American)—have trainees research specific resources that will help promote understanding of that cultural group:

- Books
- Articles
- Websites
- Cultural guides
- Individuals within your healthcare system that could help support a patient from a particular group.
- Agencies or individuals outside your healthcare system that could help support a patient from a particular group.

HOSPICE CARE

LEARNING OBJECTIVES

ATTITUDES

- Self reflect on the meaning of referring a patient for hospice services—what attitudes come to mind
- Understands that physicians need to take a leadership role in referring patients for hospice care.
- Understands that physicians need to continue to have an active presence in patient care once a patient is in enrolled in a hospice program.

KNOWLEDGE

- Describes the meaning of the term hospice.
- Describes the benefits to patient and family of being in a home hospice program.
- Describes the members and functions of the hospice core team.
- Describes the patient care responsibilities of the referring physician and the hospice medical director.
- Describes the role of the referring physician in developing the “plan of care” with the hospice team.
- Describes the key features of the Medicare Hospice Benefit including eligibility criteria, physician role, covered services, care settings, and revocation rules.
- Describes prognostic factors for cancer, end-stage heart disease lung disease and dementia.
- Describes common patient/family reactions to the concept of hospice care.

SKILLS

- Demonstrates communication skills in discussing hospice care with a patient/family.
- Demonstrates how to respond to patient/family concerns raised by a hospice referral.
- Demonstrates how to contact a home hospice agency for the purpose of patient referral.

HOSPICE CARE AND REFERRALS

PRE / POST TEST

1. Describe the meaning of the term "hospice care":

2. The most common setting where patients in the United States receive hospice care is in
(hospital, nursing home, home, inpatient hospice, etc.):

a (n): _____

3. List two eligibility criteria for hospice care under the Medicare Hospice Benefit:

a)

b)

3. List two prognostic factors in cancer patients that predict a 3 months or less prognosis:

a)

b)

c)

Answers

1. A program of interdisciplinary care to support patients and their families through the dying process. 2. Home; 3. hypercalcemia, carcinomatosis meningitis, ECOG ≥ 3

HOSPICE CARE AND PROGNOSIS

DEFINITION

Hospice is a philosophy of care for dying patients and their families--focusing on control of distressing physical symptoms, psychological and spiritual support for the patient-family unit and bereavement care after the patient's death. Hospice is not a physical place. Hospice utilizes the concept of interdisciplinary care--realizing that no single health care professional can meet the needs of dying patients and families.

WHO PROVIDES HOSPICE SERVICES AND WHERE

- Medicare certified home hospice agency most common setting in US--often combined with a home health agency; a Medicare certified hospice agency must provide 80% of total care days per year in the home setting (all agency patients combined); under the Medicare benefit, patients are eligible for inpatient care for symptoms that cannot be managed in the home (e.g. pain that out-of-control) or for respite care (up to 5 day inpatient stay);
- non-Medicare certified home hospice agency; typically small, rural hospice programs;
- inpatient beds within an acute care hospital; a) these may be beds used by a Medicare certified home hospice agency for inpatient or respite care, or b) an acute care hospital may provide non-Medicare certified hospice services, often by staffing a dedicated geographic nursing unit for care that follows the hospice philosophy;
- a nursing home may serve as a patient's primary place of residence and provide Medicare certified hospice care when a contract for services exists between the nursing home and a Medicare certified home hospice agency;
- free-standing dedicated inpatient hospice facility.

ELIGIBILITY FOR HOSPICE SERVICES

To be eligible for hospice services under the **Medicare Benefit** (see below), patients must meet the following criteria:

- physician-certified prognosis less than 6 months assuming "*the terminal illness runs its normal course*"; any terminal diagnosis is appropriate;
- treatment goals are palliative rather than curative
- a physician is willing to be identified as the physician-of-record

NOTE: Other eligibility criteria **may** exist, determined solely by the particular hospice agency (see below: **Miscellaneous Care Issues**).

NOTE: Medicare certified hospice agencies **may not** use DNR status as a criteria for hospice admission per the Health Care Financing Administration (HCFA).

HOSPICE SERVICES

- physical symptom control--pain, nausea, dyspnea, etc.
- home health aide services for help with bathing, dressing, feeding
- psychological counseling--patient, family, community
- preparation for death--completion of advanced directives, wills, funeral planning
- spiritual support--for patient and family before death and family after death
- volunteers to assist patient and family
- bereavement program for family after death

HOSPICE REIMBURSEMENT

Medicare Hospice Benefit

1. When eligible (see above), a patient “signs off” of Medicare Part A (hospital payment) and signs on (elects) the *Medicare Hospice Benefit*.
2. There are 3 hospice benefit periods: the first two periods are each 90 days; the third benefit period is indefinite, consisting of unlimited 60 day periods. At the start of each benefit period, the patient must be re-certified as hospice eligible—they must meet the criteria listed above by two physicians, one of whom is typically the hospice medical director. During any benefit period a patient may revoke their Hospice benefit and return to Medicare Part A; they may subsequently return to the Hospice Benefit if they meet criteria (see above).

NOTE: the Medicare-certified hospice agency is responsible for the *Plan of Care*; all treatment decisions must be discussed and approved by the hospice care team, which includes representatives from the following mandated services:

- hospice physician medical director
 - skilled nurse (typically serves as overall case manager)
 - social worker and chaplain
 - volunteer program coordinator and bereavement program coordinator
3. The Medicare Hospice Benefit **does not** provide 24 hour custodial care;
 4. Patients may continue to utilize services of their primary physician for in-office or at-home visits; the primary physician can bill for services under Medicare Part B. The hospice physician medical director is available for consultation but does not assume direct care responsibilities and cannot bill Medicare for services to individual hospice patients.
 5. Each day the patient is enrolled in the Medicare Hospice Benefit, the hospice agency receives reimbursement (approx. \$126/day). This is used to support the salaries of the core team and the additional services listed below:
 - home health aide visits, as often as daily
 - all drugs related to the terminal illness
 - all durable medical equipment (bed, commode, etc.)
 - any ordered physical therapy, dietary counseling, etc.
 - payment for other medical services approved by the hospice team such as: palliative radiation, parenteral hydration, etc.

Other Payment Sources

- most states administer a Medicaid Hospice program that is similar to the Medicare Benefit;
- many private health insurers / HMO's have a hospice benefit which may include some or all of the features of the Medicare Benefit; for insurers without a hospice benefit, payment for per diem hospice services to a hospice agency can usually be negotiated on a case by case basis.

MISCELLANEOUS CARE ISSUES

Beyond good physical, psychological and spiritual care, there are a number of "gray" areas of palliative support services which can arise. These include the use of expensive and/or invasive treatment approaches for which the palliative value is often not clear. Each hospice agency is free to develop its own policy regarding the acceptability of these services for its patients. These services include:

- blood products; cancer chemotherapy or hormonal therapy
- non-oral feeding (NG tube, G-tube, TPN); parenteral hydration
- kidney dialysis or mechanical ventilation
- antibiotics--oral or parenteral
- use of anti-retroviral HIV medications

PROGNOSTIC INDICATORS TO ASSIST IN DETERMINING HOSPICE ELIGIBILITY

< 14 DAYS—aka Actively Dying or Syndrome of Imminent Death

- Anuric--No Dialysis planned
- Delirium
- No or minimal oral intake
- Cheyne-Stokes Respirations / Mottled Skin /cool extremities
- Pooled oropharyngeal secretions (death rattle)

3 MONTHS OR LESS

- In Bed > 50% Time (Perf. Status: ECOG \geq 3, Karnofsky < 50)
- Hypercalcemia (Ca) (except newly diagnosed Myeloma or Breast Cancer)
- Dyspnea (HIV, Ca)
- Carcinomatous Meningitis or Malignant Pericardial Effusion
- Liver Metastases with Jaundice

6 MONTHS OR LESS

- Multiple Brain Metastases
- Metastatic Solid Cancers—No treatment planned or none effective (except breast/prostate cancer)
- Malignant Ascites or Pleural effusion
- Severe Dementia -- No Speech, Bed Bound, Incontinent
- CNS Lymphoma (HIV)
- CHF / COPD
 - Symptomatic Despite Maximal Treatment
 - Weight Loss
 - Frequent Hospitalization
 - Rest Dyspnea / Tachycardia

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- *Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases.*, 2nd Edition. National Hospice Organization. 1996.
- Turner R. Medicare Hospice Benefit I-III. Fast Facts and Concepts #82,87,90. www.eperc.mcw.edu

HOSPICE CARE AND PROGNOSIS
TEACHING WORKSHOP/ROLE PLAY EXERCISE

Faculty Guide

1. Ask participants to list three common reasons why a patient or family would be resistant to enrolling in home hospice care?
2. Ask participants to list three reasons why it is beneficial to the physician, for his/her dying patient to be enrolled in a home hospice program.
3. Review the outline—**Hospice Care and Referrals**.
4. Divide the group into triads (patient, wife and physician) and ask each pair to practice discussing a hospice referral using the **Role Playing** case; after about 5-10 minutes, prompt the pairs to switch roles.
5. In a large group ask for feedback on the interview. How did it go? What challenges do they anticipate incorporating this information into their interview? Does anyone have a particular way of discussing hospice care they want to share with the group?

CASE BLUEPRINT

Purpose of Case: Discussing the option of home hospice care

Training Level: Medical students, post-graduate trainee, or faculty

Simulated patient name: Mr./Mrs. Adams

Diagnosis: Pulmonary Fibrosis

Setting: The patients' hospital room

Reason for Visit: To discuss home hospice care.

Time allotted: 7 minutes

PATIENT PROFILE

MEDICAL HISTORY

I am Mr./Mrs. Adams, a 68 y/o patient in the hospital for the past four days—admitted with end-stage pulmonary fibrosis. This is my fourth hospital admission in the past three months, all for dyspnea. With high-dose steroid treatment and respiratory treatments I get a little better, but only for a short time. My functional ability is bed to chair with assistance. I've lost twenty pounds in the past four months. I have previously expressed a wish to my doctor for No Code status and no ICU admissions.

SOCIAL HISTORY

I live at home with my spouse of 41 years who is in good health; I live in a two-story home. I have two grown children, both married with children, who live in the metropolitan region. I am a non-observant Catholic, not connected with a church. I am a retired accountant, my spouse works part-time at a hardware store.

SETTING

I am in a chair, next to the hospital bed, my spouse is with me when the doctor comes in the room.

TASK

Your doctor will be coming to discuss a referral for home hospice care. Some questions you may pose to the doctor:

- Does this mean you will no longer care for me?
- Does this mean I can not come back to the hospital?
- What happens if my breathing gets bad at night—do I just call 911?
- I'm not sure I want someone coming into my home.

As the physician talks to you about hospice care, think about these questions:

1. what emotional reactions are elicited by the term *hospice*?
2. what are your concerns / fears about home hospice care?

INFORMATION FOR PHYSICIAN

MEDICAL HISTORY

Mr./Mrs. Adams is a 68 y/o patient on your inpatient service for the past four days—admitted with end-stage pulmonary fibrosis. You have cared for him/her for the past seven years. This is his fourth hospital admission in the past three months, all for dyspnea. He/she has severe hypoxemia and mild hypercarbia. With high-dose steroid treatment and respiratory treatments there is some short-term improvement in the dyspnea. His/her functional ability has declined over the past six months dramatically—currently it is bed-to-chair with assistance; there has been a twenty pound weight loss in the past four months. The patient has previously expressed a wish for No Code status and no ICU admissions.

SOCIAL HISTORY

The patient lives at home with his spouse of 41 years who is in good health. When you last spoke with the spouse he/she was very anxious, asking about newer experimental treatments. They live in a two-story home. They have two grown children, both married with children, who live in the metropolitan region. They are non-observant Catholics, not connected with a church. The patient is a retired accountant, the spouse works part-time in a hardware store.

SETTING

The patient will be sitting in a chair in the hospital room, the spouse is with him/her.

TASK

You will role-play the physician who enters the patient room to discuss home hospice care. Your task is to bring up the subject of hospice care, tell the patient/spouse that you think it is time to begin home hospice services and answer any questions they have.

HOSPICE DISCUSSION ASSESSMENT FORM

Make an "X" if the resident did this without prompting; "✓✓" if the resident did this only after prompting, and leave blank if this was not done.

- _____ Greet the patient member and introduce self
- _____ Explain the purpose of the meeting
- _____ Ask the patient member to describe their understanding of the illness
- _____ Describe the current medical condition succinctly without jargon
- _____ Allow the patient to digest the information, use silence
- _____ Offer an opportunity for the patient member to ask questions
- _____ Respond to questions using plain language, no jargon
- _____ Discuss prognosis and treatment options
- _____ Ask patient to describe goals
- _____ Discussed the role of hospice care within the context of the particular case and prognosis
- _____ Provided a clear recommendation about hospice care
- _____ Summarize discussion

Communication Skills - Please check ONE box per question using the following rankings: 3=Excellent, 2=Good, 1=Marginally Satisfactory, or 0=Unsatisfactory (either poorly done or not done at all)

	3	2	1	0
Assures comfort and privacy				
Assumes a comfortable inter-personal communication distance				
Maintains an open posture				
Reflects emotional meaning				
Displays empathy through words, expression or touch that was appropriate to situation				

Please provide your overall assessment:

- ___ Competent to perform independently
- ___ Needs close supervision
- ___ Need basic instruction

Do you believe the physician able to discuss hospice with compassion in a manner so as to do no harm? YES OR NO

If you feel additional training is needed, please indicate what problems need to be addressed (circle all that apply):

- basic communication skills (eye contact, rate of speech, excessive use of jargon, personal space)
- professional attitude (sullen, not empathic, angry, giggles) other:
please describe:

- other: