electr

TAKING SIDES: Clashing Views in Death and Dying

Instructor's Resource Guide:

First Edition

William J. Buckley
Karen S. Feldt

Instructor's Resource Guide:
TAKING SIDES: Clashing Views in Death and Dying
First Edition

Taking Sides® is a registered trademark of The McGraw-Hill Companies, Inc.
Taking Sides is published by the **Contemporary Learning Series** group within the McGraw-Hill Higher Education division.

ISBN
MHID

Our digital Instructor's Resource Guides are conveniently provided as a *Microsoft Word* document that you can manipulate for academic purposes. Once you save this file to your desktop or storage device, you can use it to generate tests for your students by printing directly from the file, or by modifying and reformatting the file using a word processor. You will need a word processing application or a test-generating application to open and manipulate this file. Please note: McGraw-Hill Contemporary Learning Series does not supply software applications for generating tests; we only provide the digital content from our Instructor's Resource Guides.

We welcome and appreciate comments from instructors who have used McGraw-Hill Contemporary Learning Series in the classroom. Should you wish to make recommendations for new issues, selections, or improvements, please write to:
McGraw-Hill Contemporary Learning Series, Attn: Editorial Dept., 501 Bell Street, Dubuque, IA, 52001. If you are looking for general information or wish to request a desk copy of any McGraw-Hill Contemporary Learning Series title, please contact your McGraw-Hill Sales Representative (locate your rep online at www.mhhe.com) or our Sales Support staff (800-338-3987, prompt 3).

To learn more about our series and view a complete listing of our titles, please visit the McGraw-Hill Contemporary Learning Series website (www.mhcls.com).

CONTENTS

UNIT I. END OF LIFE DECISION-MAKING

UNIT II. CARE-GIVER END OF LIFE DECISION-MAKING

UNIT III: TREATMENT REQUESTS AND DECISIONS: PAIN AND FUTILITY

UNIT IV: ASSISTED SUICIDE

UNIT VI. DETERMINING DEFINITIONS OF DEATH

UNIT VI. HOSPICE, POLICY AND COSTS OF DYING

UNIT VII. DYING AND DEATH AS CULTURAL PERFORMANCES

Instructor’s Resource Guide:

ISSUE 1 Does Depression Make End of Life Decisions Untrustworthy?

YES: Brody, B. (2009). Who Has Capacity? *New England Journal of Medicine, 36(3)*, 232-233.
NO: National Ethics Committee of the Veteran’s Health Administration. (2002).
Ten myths about decision-making capacity.
http://www.ethics.va.gov/docs/necrpts/NEC_Report_20020201_Ten_Myths_about_DMC.pdf

1)Synopsis

Brody, a psychiatry resident physician, offers a discussion of cases he was called to evaluate for depression because other physicians had concerns the depression might impair decisions related to end of life care. He demonstrates each case must be uniquely approached and that, in some cases depression can impair decisions related to end of life care. The National Ethics Committee of the Veterans Administration warns against using a single diagnosis as criteria for the lack of decisional capacity. Instead they provide guidelines on what persons should be able to understand about their specific treatment in order to have decisional capacity.

2) Discussing the Issue

The course of dying for most people includes dozens of decisions made along the way. Choices are offered about starting a treatment, trying a treatment, continuing a treatment, or withdrawing treatment. This chapter confronts the common problem of depression in patients who are dying. Because end of life decisions greatly impact care approaches and treatment choices, health professionals are cautious about psychological problems that could impair decision-making (Brody, 2009; Werth, et al, 2004). Patients who decide against treatments at the end of life are sometimes labeled as depressed even though they are making a rational decision based on information given. Family members worry that patients who are depressed may be inclined to “give up” too soon.

After reading the essays, students should develop an understanding of differences between decisional capacity and competence. They should understand that competence is a legal term and is conferred by the court system. Decisional capacity in dying patients is based on evaluations by physicians. Reliable decision-making, or decisional capacity requires that the patient has the capacity to understand and relate back the relevant treatment information, is able to identify the each of the choices available, can appreciate the benefits and the burdens of each of the treatment choices, and is able to state the likely outcome of the treatment. It is true that severe depression may impact decisions at the end of life. However, some depressed patients are able to grasp treatment information, identify choices and related back the benefits and burdens of those choices. By the end of the readings, students should grasp that decisional capacity is more of a continuum rather than an either/or capacity. Patients make be able to make some health care choices and not others, based on their decisional capacity and health literacy related to those choices.

The essay by the National Ethics Committee provides a clear discussion of the issues relating to decisional capacity. A review of each of these myths will help students to understand that people can make bad choices, or unwise choices and still have good decisional capacity.

3) Web Questions

1. Which of the following statements is most accurate?

a. All depressed patients are mentally incompetent to make end of life decisions.
b. It is common for patients with terminal illnesses to have some degree of depression
c. Dying patients under treatment for depression should have someone else make decisions for them.
d. Depression does not generally affect decisions about end of life care.

2. Complete this statement with the most accurate ending. Decisional capacity:

a. is the ability to understand and appreciate the nature and consequences of health decisions and to formulate and communicate decisions concerning health care. (Natl Ethics Committee, pg. 11)
b. is the ability for someone to make correct and wise health care decisions
c. is only evident in patients who meet the criteria for legal competancy
d. means that persons will be able to make all decisions related to their health care or living situation.

4) Multiple-Choice Questions

3. Which of the following is NOT required for reliable decision-making capacity at the end of life?

a. the patient has the capacity to understand and relate back the relevant treatment information
b. the patient is able to identify the each of the choices available
c. the patient scores a perfect score on tests of cognitive function (NEC, pg 13)
d. the patient can appreciate the benefits and the burdens of each of the treatment choices
e. the patient is able to state the likely outcome of the treatment

4. Which of the following statements is most accurate?

a. Once a patient loses decisional capacity it permanently applies to all decisions
b. A person may have decisional capacity for some decisions but not others.
c. Persons who lose decisional capacity will all eventually be declared incompetent by the courts.
d. People who have some cognitive impairment automatically don't have decisional capacity.

5. When a dying patient needs to have decisional capacity assessed, which health care provider can do this?

a. Only a psychiatrist
b. Any mental health provider
c. Social workers
d. Any primary care provider who knows the patient well.

6. Brody discusses the conversation that the attending physician initiated with a patient who was refusing a transplant. Brody was concerned the patient may have been depressed, but was somewhat surprised about how the attending physician directed questions to the patient. These questions:

a. Tested the patient's cognitive status
b. Simply focused on the patient's life, accomplishments and whether he had talked about this decision

with anyone else

c. Included a special exam for hallucinations and delusions
d. Use specific standardized tests for depression

7. The NEC article discusses ten myths or falsehoods that are thought to be true by health professionals. Which of the following is NOT a myth about decision making capacity:

a. Decision making capacity is an "all or nothing" phenomenon
b. Lack of decision making capacity can be assumed if patients refuse to follow medical advice
c. Patients who are involuntarily committed lack decision making capacity for all medical decisions
d. Decision making capacity and competency are not the same thing

5) Essay Questions

8. A friend of yours is discussing her grandmother who was recently hospitalized. Although her grandmother is in the early stages of Alzheimer's disease, she has some clear ideas about not wanting any life prolonging therapies. Her uncle is demanding that everything be done for her, and the doctor is following the uncle's wishes because "he's the one that can sue me later". Discuss this problem from the patient's, the granddaughter's and the uncle's viewpoints. How would understanding the grandmother's decisional capacity help or complicate this issue?

9. You are working as a nursing assistant in a long term care facility. An older patient with dementia has recently had severe chest pain and the family and physician are sending her into the hospital for care. The patient is screaming as the paramedics load her onto the gurney. "Get me out of this thing! I'm not going to the hospital! I want to die in my own bed!" How would you know if this patient had decisional capacity? Discuss this case from the patient, family and paramedic's point of view.

Answers:

1. b
2. a
3.c
4.b
5.d
6. b
7. d

<u>Instructor's Resource Guide</u>:

ISSUE: 2 Do Advance Directives Improve Care for Those Unable to Make Decisions?

YES: Silveira, M. Kim,S.K. & Langa, K.M. (2010). Advance Directives and Outcomes of Surrogate Decision Making before Death, *N Engl J Med*, *362*;13

NO: Hertough, C.P. (2011). The misleading simplicity of advance directives, Editorial, International Psychogeriatrics, 23:4, 511-515.

1) Synopsis University of Michigan physicians Maria J. Silveira, Scott Y. H. Kim and Kenneth M. Langa argue that for the 25% of older adults who require surrogate decision-making because of decisional incapacity, care is improved because the outcomes of decision-making reflect their treatment preferences. These are known with respect to life-sustaining treatment (such as living wills) or selection of surrogate decision makers (such as durable power of attorney for health care) or both (such as in advanced directives). These authors provide evidence that having advance directives make a difference. Geriatric Ethicist Hertough from the Netherlands argues that the history and North American culture of "prospective autonomy" have shown some of the limits of ADs. Despite their history in enabling "prospective autonomy," many problems include low frequency, low compliance, low adherence, changing preferences, unstable health and a "disability paradox" that people change their minds as their minds change. Such low usage and problems in interpretations signal better alternatives in that third stage of pre-commitments that are future-oriented and collaborative among care-givers and patients. To resolve potential conflicts between prior values of a competent person and best interests of one later incapacitated, he suggests patients shift instead to dialogic doctor patient communication.

2) Discussing the Issue

THREE DIFFERENT QUESTIONS: How is good care measured or chosen when one is incapacitated by dying? Few disagree about the importance of three key questions at the end of life even while different answers are offered for each:(1) who decides (patients-valid surrogates, Issue I) (2) how (informed consent-decisional capacity, II), (3) what measures or outcomes determine a good decision (first generation living wills, second generation advance directives, third generation, future-directed values documents, Issue II).

But do discussions about end of life care for decisionally incapacitated risk abandoning patients or denying necessary care? Should Advanced Directives be revived or allowed to die? Is there really any perfect prescription for improved care for those unable to make decisions at the end of life?

Ask readers to cite specific examples from essays, cases from the newspaper or personal stories that demonstrate how popular fears and the three questions above pose different issues for different persons at the end of life. Who decides? Might a treatment decision based on "informed consent" change for the well-being of one who no longer has "decisional capacity"? How do we help our dying family members who change their minds as their minds change? Do we examine documents, processes or shape outcomes as events? Different tools that express decision-making each have a history of meaning (legal and medical).

Invite readers to consider how terms matters. Both essays and the Introduction and Conclusion describe different key terms that are helpful to discuss these examples, cases, and stories. For example, how is informed consent different than decisional capacity in an elderly person who is dying? What are the key advantages and disadvantages of living wills (helpful planning like disposal of property but limited by vagueness); advanced directives (good delegating decisions about treatments but limited by changing conditions and technologies); pre-commitments and values histories (helping caregivers, but limited when prior autonomous decisions must be re-calibrated for evolving patient well-being). No instrument is perfect; all tools are interpretated by different audiences and jurisdictions. In the past century, "care ethics" has become professionalized in Anglo-American worlds of demand-based health care that distinguish care as personal affect, solicitude, skilled competence and personal regard (See Issue XVIII).

THREE GENERATIONS OF DOCUMENTS: "Living wills" were modelled on property law (in 1969) and provided written evidence of prior wishes regarding patient treatment decisions if they are terminally ill. Based on family disputes regarding property of legal incompetents, in 1983, a Presidential Commission recommended decisionmaking for the currently incapacitated in real time according to substituted judgment (what the patient would want or patient self-determination) and best interests (patient welfare) (Deciding to Forego Life-Sustaining Treatment, 1983:132). Future-directed (e.g. "values") decisions are addressed by the USA Congress 1991 "Patient Self-Determination Act" (PSDA). This requires many health care institutions to provide information (notification) for adult patients about "advanced health care directives"—without requiring usage. These include who decides (durable power of attorney or health care proxy) and what treatments (health care directives). These include many different kinds of of prior and emerging documents (e.g. POLST, MOLST, Five Wishes).

Testing on the Issue

3)Web Questions

1. Physicians Maria J. Silveira, Scott Y. H. Kim and Kenneth M. Langa, believe that having advanced directives improves care for dying persons by enabling outcomes of decision-making to reflect their treatment preferences. They argue that care is improved because

a.one quarter of elderly adults need surrogate decision-making
b.living wills have little effect on decisions to withhold or withdraw care and do little to increase consistency between care received and patients' wishes
c. incapacitated subjects who had prepared a living will were less likely to receive all treatment possible; subjects who had assigned a durable power of attorney for health care were less likely to die in a hospital or receive all care possible
d. when decision-making capacity is lost, data shows agreement is rare between dying patients and appointed surrogates.

2. Geriatric Professor CEES M. P. M. HERTOGH from the Netherlands believes that advanced directives have failed to improve the final stages of life. These require less advance planning than sensitive day to day dialogue among physicians and patients. What does Hertogh see as their biggest weakness that challenges Silveira's claims about improved care?

a. "prospective autonomy" called "auto-paternalism" restricts one from changing one's mind in the future
b. there is a conflict between the prior values of the still competent person and the welfare interests of a later incompetent person
c. a "disability paradox" shows people change their minds as their minds change to adapt to new realities
d. advance directives have many problems of underusage, improper interpretation, low compliance, low adherence, changing preferences, unstable health

4) Multiple-Choice Questions

3. With which one of the following statements would both authors *disagree* concerning Advance Directives?

a. Advance directives are legal documents and clinical guidelines
b. Advance directives can indicate who decides (valid proxy) and what treatments should be offered for incapacitated (treatment directives)
c. Honoring Advance Directives to refuse treatment improves care for incpacitated who are dying

c. The 1991 Congressional Patient Self-Determination Act required notification about Advance directives but not their use

4. Physician Orders for Life-Sustaining Treatment (*POLST*) and Medical Orders for Life-Sustaining Treatment (MOLST) are examples of :

a. living wills for terminally ill
b. best interest standards for valid proxies
c. advance directives indicating who must decide (durable power of attorney) and what treatment should be provided (treatment directives)
d. initiatives to insure decisions to withdraw or withhold life-sustaining treatment are made in accord with patients' wishes or best interests

5. Those who lack decision-making capacity and require end of life decision-making, but who do not indicate their wishes regarding a surrogate-proxy decision-maker or treatment decisions at the end of life

a. most often only receive comfort care that physicians and nurses judge is appropriate
b. most often receive all care possible including aggressive care

6. During the health care reform legislation in 2010, physicians asked Medicare if they could be reimbursed for the lengthy conversations that are required when doing advance care planning with patients. Which position might Hertogh support?

a. The debate raised concerns that advance directives would lead to denial of necessary care.
b. Opponents characterized this as interference with personal decisions by government bureaucratic "death panels".
c. Critics rebutted that objections to reasonable planning with health care professionals as "killing Grandma" were a "lie of the year".
d. Well-done planning doesn't ration care—it avoids litigation by resolving conflict through enhanced dialogic communication.

7. With which one of the following statements would both authors *agree* concerning communication of end of life decisions regarding goals and a plan of care at the end of life (cure and restoration; stabilization of functioning; preparation for a comfortable, dignified death)?

a. clinical conflicts are typically legal disputes
b. many conflicts are resolved by timely communication among stakeholders including one-on-one dialogue among patients, family and interdisciplinary caregivers
c. legal conflicts are best litigated in courts not mediated
d. most clinical conflicts are disguised ethical conflicts

8. With which one of the following statements concerning communication of end of life decisions would both authors *disagree*?

a. one must determine and document a patient's decision-making capacity
b. a key task is to identify the the appropriate decision maker, either a patient with decision making capacity, or a patient's valid surrogate
c. instruments or documents for determining end of life wishes for incapacitated patients have demonstrably evolved in better ways to improve care for the dying
d. instruments or documents for determining the end of life wishes of patients are only as good as the process in which they are used

9. With which one of the following statements concerning communication of end of life decisions for incapacitated would both authors *disagree*

a. patients underutilize advance directives
b. advance directives resolve all disputes among families about who are valid proxies
c. advance directives are seen as "foreign" to health systems of socialized medicine (in Europe) characterized by caregiver paternalism ("doctor knows best")
d. advance directives seem second nature to demand-based (consumer) healthcare in which patients seek a role in healthcare decisions ("patient autonomy")

10. Since 1975 there have been a number of high profile court cases regarding the rights of proxies to make decisions for incapacitated; e.g. Quinlan (1975-1985), Cruzan (1993-1990), Schiavo (1990-2005), Wanglie (1989-1991) and Finn (1995-1998). With which one of the following statements would both authors *agree?*

a. Litigation shows that the only way to protect the interests of incapacited patients is through the court system
b. Cases concerned refusal of life-sustaining therapies for persons whom everyone agreed were unquestionably near death
c. None of the cases featured an advanced directive, but in each, some family members represented incapacitated as proxies
d. Advance directives would have improved care for those unable to make decisions

5. Essay Questions

1. HOW IS YOUR CARE IMPROVED BY WHICH BEST USE OF AN ADVANCED DIRECTIVE? AD/POLST ROLE PLAY: Should Advanced Directives be revived or allowed to die? Divide into dyads (partners) and role play being both the patient and health care professional in the following scenario. Use arguments from each essay to interpret these documents and your experience—e.g. do advanced directive improve your care? You are being seen by a health care professional at your local hospital for your first admission after being diagnosed with cervical/testicular cancer and incapacitated. The health care professional should use the forms below to 1) clarify DNR status upon admission and 2) help the patient to complete an advance directive/POLST from either Washington State (or your home state). When playing the role of the patient pay attention to the health care professional's behavior and provide feedback at the end of the experience about what was helpful and not helpful. Each role play should take about 20 minutes. (Adapted from Center For Clinical Bioethics, Georgetown University, Washington, D.C.)
http://www.wsma.org/patient_resources/advance-directives-qa.cfm
http://www.wsma.org/Files/Downloads/PatientResources/POLST-PrintDownload.pdf

2. HOW IS A CONFLICT RESOLVED FOR TREATMENT FOR END OF LIFE INCAPACITATED? Not all advance planning need be conflictual, nor need every practical conflict be ethical much less legal. Using essay authors and POLST, describe two positive and two negative behaviours for successfully resolving conflicts in the following scenario: Your elderly father in assisted living just became incapacitated; medical staff and social workers disagree about treatments; you and your siblings disagree about who should decide, and whether to tell your mother.

3. WHAT IS MY MOST IMPORTANT QUESTION AS I DIE? From the list of twenty-four, use essay authors to explain why you chose the two most important and least important Questions for Your 'Living Will' or Advance Directive for Medical Care from James Park, Your Last Year: Creating Your Own Advance Directive for Medical Care
(Minneapolis, MN: Existential Books: www.existentialbooks.com, 2006). See
http://www.tc.umn.edu/~parkx032/Q-L-WILL.html

4. DEBATE AND DISCUSS: Do you think that time set aside for advanced directives should be reimbursed by

insurance or federal subsidies? Do you think discussion of care approaches for an incapacitated person should be viewed as a “Death Panel”? Are Advanced Directives for incapacitated a “Death Panel”? Debate the PROS (Yes—they encourage pre-commitments regarding withholding and withdrawal of ineffective, burdensome, costly treatment called futile Issue 11) and CONS (no, they are positive about goals of care and end of life, Issue IX)

ANSWERS
1. C , 2. D, 3 C, 4. D, 5. B, 6. D, 7. B, 8. C, 9. B, 10. C

Instructor's Resource Guide:

ISSUE 3. Do Dying Persons Without Advocates Get a Different Quality of Care?

YES: Pathak, E. B., Casper, M. L., Tanner, J. P., Reader, S., Ward, B. (2010). A multilevel analysis of absence of transport to a hospital before premature cardiac death. *Preventing Chronic Disease, 7(3)*, 1-11.

NO: Wasserman, L. S. (2008). Respectful death: A model for end of life care. *Clinical Journal of Oncology Nursing, 12(4)*, 621-626. doi:10.1188/08.CJON.621-626

1. **Synopsis**

Elizabeth Barnett Pathak, Jean Paul Tanner, Steven Reader, Beverly Ward, of the University of South Florida, and Michele L. Casper, from the Centers for Disease Control and Prevention, found that people who are unmarried and live alone are vulnerable to dying from cardiac events without medical aid or a witness. Linda Wasserman, an advance practice nurse proposes a "respectful death" model of care that would be used as an approach to all patients, regardless of whether they have an advocate. The model includes identifying a caregiver for dying patients, with or without advocates.

2. **Discussing the Issue**

This chapter focuses on the unique problems that arise when a dying person does not have an advocate as decisions for end of life care are made. Much of the chapter addresses research on the needs of dying homeless individuals who are alienated from family or individuals who other patients who have no advocate or other supportive resources. Readers should be able to relate the findings of studies on end of life care in homeless persons without identified family or surrogates. They should also recognize that there are many other persons living in the community who may not have advocates that would be able to help make decisions. Readers should think about someone they know who lives alone and does not have a family member within that region or area. Readers should picture an older neighbor, or a single person who has no living relatives. Once readers have this person in mind, ask them to consider what the physician or other health professional should do if that person arrives in the emergency room with a terminal condition. If there is no advance directive (see Issue 2), or surrogate designated, how can the physician best serve the interests of the patient? Remind readers that research shows that approximately 5% of patients who die in the intensive care units at hospitals lack a surrogate decision maker and an advance directive (White et al., 2007). This is a common occurance.

The essay by Pathak, et al (2010), is a study of timing of transport to the hospital after a cardiac event. That study showed that persons who lived alone or had no surrogate, were more likely to die of the cardiac event because of the delay of transport. For those readers who are living alone, this research may be somewhat startling. It should raise discussions about whether they have friends or relatives who know their wishes. This reading may also raise discussions about how connected or disconnected we are with others in our daily lives. Readers should be asked to think about solutions to this issue or recommendations they might make to persons living alone. If a patient arrives in an emergency room or the hospital without expressed wishes and without an advocate, physicians are legally required to provide the standard of care that they would offer to other patients in similar circumstances. However, laws about who can make decisions about care withdrawal from these types of patients vary from state to state. Some states allow physicians to issue a do not resuscitate order if the medical care is seen as futile and the physician receives written agreement from another physician (NY state law, Texas state law) (White, et al.

2007). However, other states require a guardian to be appointed to represent the patient and still other states have no explicit law regarding how end of life care should be handled for patients without surrogates or advance directives. Readers should be encouraged to find out what the laws in their states require.

The Wasserman essay proposes an approach to ensure quality of care to all dying patients regardless of whether they have an advocate. Although the author writes from a sound theoretical viewpoint, research shows that there are many dying patients without advocates whose care is decided by others who do not know them. The likelihood of a patient receiving more aggressive care at the end of life is much greater when there is no written guide or advocate to suggest otherwise. Overall the essays speak to the need for all persons to develop advance directives that can guide the care of dying patients regardless of whether an advocate is available.

Testing on the Issue

3. **Web Questions**

1. Which of the following was the strongest predictor of dying without transportation to a hospital after a cardiac arrest in the study reported by Pathak, et al?

   a. Persons of a minority culture.

   b. Persons who lacked insurance or financial means to obtain transportation to the hospital

   c. Persons who delayed seeking medical treatment because of fear

   d. Persons who were unmarried.

2. Which of the following would make it **most possible** to implement the respectful death model as proposed in the essay by Wasserman?

   a. The patient is dying rapidly and his/her wishes are largely unknown to the nurses and physicians.

   b. The patient has been frequently readmitted to the oncology unit and has frequently discussed their dying views with the health care staff.

   c. The patient is unable to express their views or their wishes because of long standing psychiatric issues and dementia.

   d. The patient is non English speaking and has no family advocate.

4. **Multiple Choice Questions**

3. Which of the following is NOT an issue that complicates end of life care for homeless persons?

   a. Lack of a caregiver to assist with hospice care

b. Insurance plans that restrict where end of life care can occur.
c. A reluctance to contact family members because the homeless person is estranged from the family.
d. A reluctance by physicians to prescribe strong analgesics to a person who may have a history of substance abuse.

4. Which of the following statements is most accurate?

a. The laws about who can make decisions for somewhat with no advocate are federally designated and the same in every state.
b. By law, physicians must always give the most aggressive care to patients who have no advocate
c. In some states the law allows physicians to withdraw futile treatments in patients who have no advocates.
d. There are no laws in any state that allow physicians to make end of life decisions for terminal patients without advocates.

5. Pathak, et al (2010) acknowledges that cardiac deaths can occur before transportation arrives as a result of 3 possible scenarios. Which is **not** one of these scenarios:

a. The patient dies in the ambulance on the way to the hospital .
b. The patient delays or avoids seeking treatment and death occurs hours later
c. The onset of symptoms is so severe, there is unsufficient time to solicit an ambulance.
d. The patient desires transport to a hospital, but is unable to access transportation before death.

6.Pathak acknowledges that many people delay seeking treatment for cardiac symptoms which result in higher cardiac death rates. The primary reason for this delay is:

a. The patient has no knowledge about cardiac symptoms.
b. The patient lives alone
c. There is not one primary reason, the cause of delay is due to many causes.
d. Family members encourage the patient to ignore symptoms.

7.The respectful death model is based on intimate and personal relationship with the dying patient and their family members. For which groups of patients might this model be ***MOST*** difficult to implement?

a. Nursing home patients who plan to die in long term care.
b. Hospice patients who die at home
c. Disabled patients who have lived in a residential facility for years.
d. Emergency room patients who die from trauma.

5. **Essay questions:**

1.Identify two possible conflicts and two possible benefits when estranged or distant family members are called upon to make decisions for a relative with chronic alcoholism and end stage liver failure.

2. Your aunt lives alone in a rural area. “If I had a heart attack, it would be days before anyone knew I was dead” she tells you. Provide one or two solutions to this dilemma that would not require her to move out of her comfortable home.

1. d 2. B 3. B 4. C 5. a. 6. c. 7. d

Instructor's Resource Guide:

ISSUE 4. Compassion Fatigue: Does burnout occur in all caregivers of dying patients?

YES: Bush, N. (2009). Compassion fatigue: Are you at risk? *Oncology Nursing Forum, 36(1)*, 24-28. doi:10.1188/09.ONF.24-28

NO: Dunn, D. J. (2009). The intentionality of compassion energy. *Holistic Nursing Practice, 23(4)*, 222-229.

1) Synopsis

University of California School of Nursing assistant clinical professor Nancy Jo Bush, identifies the phenomena of compassion fatigue in nurses. She discusses caregivers at risk for emotional exhaustion related to their work. Risk factors of empathic engagement are similar and different among compassion fatigue, burnout, secondary trauma stress and vicarious trauma. Bush recommends problem-solving coping mechanisms, the need to establish empathetic boundaries and to have self-awareness and self-forgiveness. Using ideas from her 2009 dissertation on interpretive experience and care, Florida Atlantic University's Clinical Faculty and Nurse Practitioner Dorothy Dunn describes compassion energy as the converse of compassion fatigue. She believes that nurses and other caregivers can grow and thrive if they understand how to prevent burnout by self-generating vigor as compassion energy. Her view interprets compassion as energy in a field of care. "Nurses initiate the experience of compassion energy when they answer the call from a patient. The 3 attributes of compassion energy are compassionate presence, patterned nurturance, and intentionally knowing the nursed and self as whole."

2) Discussing the Issue

NAMING BENEFITS AND RISKS IN COMPASSION AND CARE: Dying incapacitates patients; empathic caregiving risks incapacitating caregivers. Illness and dying all too often converts beloved families into sometimes ill-prepared caregivers always on call (Levine). But does a clinically worthwhile goal of good dying require caregiver exhaustion? Must empathy with a fragile or dying person always be experienced as a threat to human flourishing of caregivers? Or is sharing human vulnerability (care-giving generativity) a basic value for humans and communities? Answers depend in part upon larger cultural cultural assumptions about control over imminent death events (autonomy) and best interests or well-being during dying processes as either end stage, terminal conditions, expecting death or in the face of medically futile treatments (beneficence). Answers also rely upon whether vulnerability connects us in positive ways without debilitating dependence—and professionalizations of nursing, ministry and many kinds of care.

Bush asks caregivers to focus on their own needs; Dunn invites nurturers to see compassion as an intentional "energies" of interconnectedness that prevents fatigue. Bush writes: "Compassion fatigue is a complex phenomenon that escalates gradually as a product of cumulative stress over time, often when caregivers ignore the symptoms of stress and do not attend to their own emotional needs." Dunn writes, "Compassion energy is the converse of compassion fatigue. Nurses will grow and thrive if they understand how to self-generate vigor as compassion energy, preventing compassion fatigue or burnout."

Four different considerations help readers frame stories of empathic caregiving. First, how do larger cultural assumptions about empathic caregiving as tragic (western) and nontragic (eastern) influence both families and professional understandings? Second how is empathic caregiving related to understandings of self-regard (self-nurturing called egoism not overweening pride called egotism) and other-regard (generative altruism)? Third, what research demonstrates how compassion fatigue is defined, progresses, can be positively engaged or negatively worsened as well as distinguished from related experiences (emotional burnout, vicarious trauma, post-traumatic stress). Fourth what risk factors are recurrent attitudes and behaviors?

Humans are care-givers and care-takers; care is not confined to physical health. Compassion fatigue is a term first coined by Joinson (1992) to describe the unique stressors that affect people in caregiving professions (e.g., nurses, psychotherapists, ministers)—it is also applicable to informal caregivers such as family and caregivers (Bush, 2009; Dunn, 2009). A century and a half of humanistic and social sciences distinguish such other-directed empathy from other-caused sympathy, and both are different from self-oriented perceptions that make me feel bad or cause personal distress. One tool for "interpreting experience" is "hermeneutic phenomenology" (Dunn).

IDENTIFYING PRACTICAL RESOURCES: Risks of empathic care-giving are real--decades of outcomes based research confirm common sense. Yet data gives new practical advice for transforming experience into wisdom about how healing can care when cure is gone amidst suffering. The loss of self in compassion fatigue is different from the emotional exhaustion of burnout, symptoms similar to post-traumatic stress disorder and cognitive changes from vicarious trauma (Bush, 2009). Longer life spans bring complex demands for care among fragile elderly and near dying.

Ask readers to cite specific categories and examples from essays, cases from the newspaper or personal stories that identify emotional burnout, vicarious trauma, post-traumatic stress and compassion fatigue. Bush discusses the case of 35 year old oncology staff nurse E.P. who experienced each. Popular stores and fears can be helped with working definitions. Who diagnoses each? What are practical ways of recognizing and coping with each among professionals and family members? For example, what might family members giving hospice care learn from professionals about risks of empathetic care for the different stages of dying persons? For example, imminently dying, those in end stage illnesses, terminally ill, expecting to die, those for whom treatments are ineffective, too burdensome or too costly called futile (e.g. Issue 11) Do empathic care-givers document changes, participate in processes or shape outcomes as events? Different tools that express and measure empathy continue to be debated.

Invite readers to consider how terms are understood by different audiences. Both essays and the Introduction and Conclusion describe different key terms that are helpful to discuss these examples, cases, and stories. For example, how are different kinds of compassion, distinguished from different meanings of care as anguish, general solicitude (other-regard), skilled competence or specific care for particular persons. What are the key advantages and disadvantages of positive coping attitudes, behaviors and guideline-directives? Needs change and no instrument is perfect; all tools are interpretated by different audiences. Which advice has stood the time of "best pactices" regard self-nurturance (diet, exercise, social support) and generativity (solve practical problems, one day at a time). The professionalization of "care ethics" offers many resources for families and colleagues(See Issue XVIII).

CONNECT IDEAL WITH REAL: Cross-cultural communities and plural traditions are rediscovering nonwestern (non-tragic) and western (tragic) interpretations of compassion. Debates about merits and limits of caregiver involvement with patients is vibrant, including discussions about "Wounded Healers" as "counter-transference." It is less laws than outcomes based social and human sciences that are leading reflection on how to balance self-nurturing and other-directed generativity that improves care for the dying.

Testing on the Issue

3) Web Questions

1. University of California assistant professor Nancy Jo Bush identifies risk factors of empathic engagement which leads to compassion fatigue and useful coping skills. Which of the following are the most effective responses?

a. identifying a specific plan for dying or clear goal for end of life care
b. problem solving mechanisms and empathic boundaries
c. clearly distinguishing compassion fatigue, burnout, secondary trauma stress and vicarious trauma.
d. self-awareness and self-foregiveness

2. Florida Atlantic University's Dorthy Dunn argues that too much compassion talk focuses upon other-directed empathy rather than self-regarding sustainance. She argues for self-generating vigor as compassion energy that includes all but which of the following:
a. listening and hearing what patients experience
b. compassionate presence
c. patterned nurturance
d. intentionally knowing the nursed and self as whole

4) Multiple-Choice Questions

3. Which one of the following statements would Bush identify as *evidence of compassion fatigue*? Family members privately caring for hospice patients who can often do the physical work but may experience

a. exhaustion called *emotional burnout* by being overwhelmed with work and demoralizing personal stressors
b. a change in cognitive awareness from prolonged exposure to trauma causing acute fear and hopelessness similar to *vicarious trauma*.
c. secondary stress with symptoms similar to *post-traumatic stress disorder (PTSD)*
d. cumulative and progressive processes from early manifestations of discomfort, to the secondary stages of stress, to eventual exhaustion.

4. Who would both Bush and Dunn *agree* are at *greatest risk* but often use the *least resources* for compassion fatigue?

a. formal caregivers such as health professionals who are physicians, and nurses and well as spiritual guides such as therapists, ministers, counselors, social workers
b. *informal caregivers* such as family, partners and friends
c. *nonformal caregivers* whose roles are episodic and temporary but potentially influential; co-workers, extended families, social networks, financial advisors, educators
d. different persons who are *dying* need different kinds of care; including imminently dying, those in end stage illnesses, terminally ill, expecting to die, those for whom treatments are ineffective, too burdensome or too costly called futile (e.g. Issue 11)

5. What would both Bush and Dunn agree have been shown to be the *least effective practices* to prevent the development and progression of compassion fatigue?
a. effective screening of professional caregivers
b. good training with well-understood directives
c. incentivized guidelines that encourage caregiver respite, leave of absence, reduction of shift time and support groups to discuss stressors
d. warnings and threats about worst practices that are discouraged with
fear, shame and sanction in civil or criminal terms

6. What would both Bush and Dunn *agree* has the *least impact* on "emotional burnout"
a. workplace stressors, role ambiguity, workload
b. gender, employment status, educational preparation
c. age
d. cumulative losses in the face of idealism and high motivation

7. What would both Bush and Dunn agree is the *first priority* families can learn from caregivers about how to avoid two extremes: caregiver emotional over-involvement with those who are dying or the other extreme of distance or burnout?

a. use effective problem solving including positive reappraisal, managing sadness in growth-enhancing rather than destructive ways
b. be generative in care for the other
c. balance empathy in nurturing positive care for the self
d.include exercise and relaxation; maintain adequate sleep and nutrition; reach out for support from others

8. With which one of the following statements would both authors *disagree* concerning the risks of being a "Wounded Healers"

a. "counter-transference" risks (over-)identifying with the patient ("Only wounded doctors heal")
b. wounded healers with compassion fatigue risk losing empathy
c. care for self (nurturance) and others (generativity) requires recognition of vulnerability by communities, not only individuals
d. "healing" after the end of "cure" focuses primarily on patients not healers

9. With which one of the following statements would Bush and Dunn dis*agree* about strategies of empathic care that "interpret experience"?

a. Best nurturers focus on immediate tasks of making sure here and now biomedical needs are met (hunger, thirst, pain, rest)
b. True nurturers connect with psychosocial needs such as accompanied presence and communication of meaning-filled stories and hopes
c. Caring-for-self strategies include relaxation and stress reduction
d. Persons can learn to self-generate vigor as compassion energy, preventing compassion fatigue or burnout

10. Who would criticize the other's position in the following terms? Compassion energy is a caring process of exchange that is like a field of identification fostering interconnectedness between nurturing

and nurtured. But this risks over-identifying nurtured with nurturer (“Wounded Healer”)

a. Dunn of Bush
b. Bush of Dunn

5) Essay Questions

1. HOW DO CLASSIC STORIES OF COMPASSIONATE CAREGIVING FUNCTION AS POSITIVE AND NEGATIVE RESOURCES? Ask readers to identify the most moving personal example (ideal type), classic story (narrative), image, symbol or music that illustrates a “model of” (descriptive) or “model for” (normative) or anti-model (against) compassionate caregiving. Is this classic an “impossible ideal” (the “Pieta”) or tacit norm (maternal/paternal memories of nurturing)? What kinds of communities nurture caregiving (Hauerwas)? Classic parallel stories disclose distinct kinds of compassion in eastern and western traditions such as Buddhism (Lotus Sutra IV, Lost Heir), Judaism (Deut 4:30) and Christianity’s Parable of the Prodigal Son (Luke 15.11–32) with complex notions of departure, return, affliction and reciprocal generativity. Whalen Lai, “The Buddhist Prodigal Son: A Story of Misperceptions,” Journal of the International Association of Buddhist Studies 4:2 (1981): 91-98.

2. TAKE SIDES ON A SURVEY: Select and take a compassion fatigue survey such as Varner, Joyce M "ASNA Independent Study Activity - Compassion Fatigue. How would Bush and and Dunn answer each of its following questions 1. Describe the phenomenon known as compassion fatigue.
2. State at least five signs common to compassion fatigue.
3.Describe at least four ways to cope with compassion fatigue.
4. State three prevention strategies that can be used to avoid compassion fatigue.

3. WHO CARES? HOW HAS THE HISTORY OF CARE SHAPED UNDERSTANDINGS OF COMPASSION? How do Bush and Dunn show different understandings of compassion that have been influenced by distinct meanings of care (See Issue XVIII)? Notions of care refer to traits, affects, interactions and interventions. Four historical meanings of care include (1) care as affect: trouble, grief, modern anxiety or contemporary anguish, etymologically derived from Middle High German word *kar* and more remotely in the Common Teutonic word *caru.* (2) Care as solicitude for or concern for people, discourses, groups of practices as institutions and organizations. (3) Care can also refer to care-filled, responsible specific attention to precise competencies or exact skills. (4) Caring about concerns a particular person and her growth (Reich, 1995; Jecker and Reich, 2004). Warren Reich’s archaeology of care in western European traces how “[t]he Myth of Care suggestively offers a care-based genealogy of morals that is deeply ingrained in human psychology, anthropology, religion, and altruistic service” (Reich, 2004: 359). From the Nightingale Pledge (1893) to the International Council of Nurses (1899) through the Codes of the International Council of Nurses (1953, 2005) to the American Nursing Association (1985, 2001), Nursing ethics has grown from hygiene rules to health promotion, illness prevention, restoration of health, alleviation of suffering and advocacy for social change (Fry, 2002, 2004). Post World War II shifts from early gendered etiquette and deference to patriarchal authority evolved to competence-based criteria for increasingly independent clinical practitioners. Transnational mid century “Codes” of nursing ethics shared five care-based commonalities; practical competence (Care as competence); good relations with co-workers (caring with); respect for the life , dignity, and beneficence of the patient (care for, Pellegrino, Shiber, Larson, Valentine), protection of patient confidentiality (carefulness with); and the ethical responsibility not to discriminate against patients on the

basis of race, religious beliefs, cultural practices, or economic status (caring about, Sawyer, 1989).

4. DISCUSS MERITS AND LIABILITIES OF MODELS AND ANTI-MODELS OF “WOUNDED HEALERS” FROM LITERATURE AND POPULAR MEDIA. Harriet Ross Tubbman (1820-1913); Florence Nightingale (1820-1910); Henri Nouwen (1932-1996); Scott McPherson, “Marvin's Room” (1992 book and 1996 film); Iris (2001 film about Iris Murdoch based on her spouse’s book, “Elegy for Iris”); “House,” “Margaret Houlahan, MASH,” John Coffey “The Green Mile;” “Dying to Live: The Journey into a Man's Open Heart” (2008 Documentary by Ben Mittleman).

ANSWERS
1 (B), 2 (A), 3 (D), 4 (B), 5 (D), 6 (B), 7 (C), 8 (C), 9 (D) 10 (B)

Instructor's Resource Guide:

ISSUE 5. Does a Dying Person With Severe Pain Have A Right to Effective Pain Management?

YES

Tucker, K. (2004) Medico-legal case report and commentary: inadequate pain management in the context of terminal cancer. The Case of Lester Tomlinson. *Pain Medicine, 5(4), 214-22. Responses by Brushwood and Johnson*

NO

Syme, R. (2009) Necessity to palliate pain and suffering as a defense to medical homicide *Journal of law and medicine, 17*, (3) 439-451.

1) Synopsis

Attorney Kathryn Tucker, the Director of Legal Affairs for the Compassion and Choices in Seattle, discusses the case of Lester Tomlinson, an 85 year old patient dying of cancer whose family were successful in reaching an agreement after a lawsuit against the hospital and health providers for inadequate pain treatment. Tucker explains how the settlement of her court litigation among different jurisdictions (State Medical Board, State Health Services, Center for Medicare/Medicaid)—reveals there were violations of standards of care among hospital, providers and nursing home. University of Florida Professor of Pharmacy David Brushwood argues that holding physicians accountable through elder abuse or medical negligence won't improve pain management due to structural flaws (training, patient fears, insurance, regulatory and law-enforcement missteps). St. Louis University Professor of Health Care Ethics Sandra Johnson argues that this case fell within "safe harbor guidelines" of permissible aggressive care, but variable state policies may limit compensation for substandard care. Australian surgeon Rodney Syme argues that it is surprising that under current laws, more physicians are not prosecuted for homicide when delivering high doses of pain medications at the end of life. He suggests that a better law should focus on palliation and consent, rather than criminal law of causation focused on intention and cause of death.

2) Discussing the Issue

NAMING ISSUES: Several distinct issues are at stake. Pain is rarely a singular phenomenon or experience. How and for whom is pain defined? How (well) is pain diagnosed? How adequately is pain managed or relieved? Who is responsible and according to what measure of accountability (ethical, professional, legal-criminal; legal-civil)? What access or coverage of effective diagnosis and treatment is available?

Common incorrect forms of reasoning called fallacies include assuming answers to any one of these questions are simple or singular rather than multiple. That is, assuming all pain is the same or self-evident to caregivers and patients—or that it doesn't change over time or vary by individuals as diseases evolve. Some assume pain is easily diagnosed, managed, relieved according to universally administered medicines everywhere about which there is undisputed agreement. Consensus is not unanimity. Others presume that clear responsibility rests with health care professionals rather than shared with informal caregivers or patients in pain relief (prescription-administration more than adherence-compliance). Some presume that cultural agreement exists about ethical justifications among professional and legal categories (utilitiarianism, duties, rights, duties, justice).

Do you think it is appropriate to precisely locate issues in end of life pain? For example, can collaboration among a team avoid incorrect blame or poor conflict resolution? To blame dying persons or caregivers for a medicalized culture incorrectly identifies only part of the entire cause of the effect—hence is a fallacy of "complex cause" ("Everyone is dying! Everyone suffers! All pain has been medicalized!").

BENEFITS AND RISKS IN ADEQUATE PAIN RELIEF: Good pain diagnoses and management works best with continuity of care and clear communication. Multiple, specialized caregivers, exhausted families and complex causes of dying present challenges to effective pain management. Tucker places responsibilities on health care professionals to monitor and treat pain effectively or face risks; "The settlement by all four defendants of the tort suit prior to the start of a trial reflects awareness in the defense bar, and among health care providers, that a case involving failure to adequately treat the pain of a dying patient carries great risk and exposure for defendants….This is appropriate because knowledge of how to treat pain is available. The problem is that, without outside motivation, physicians fail to acquire and apply the available knowledge." Alternatively, Brushwood argues "The threat of liability for undertreating pain will not produce a rational, consistent, caring response from doctors. There are too many other variables affecting the quality of pain management. We have to..improve [education in] interdisiplinary pain management…[and]…mini-residencies for law enforcement personnel to teach them that pain management is not about drugs, it is about people who suffer and who seek caring, respectful medical treatment. The small number of settlements and judgments of liability for undertreating pain over the past several years are outliers. They do not constitute even the hint of a legal trend, and they should not be used to coerce desired behaviour from those responsible for providing services and products to patients." Johnson argues "Such litigation does something that no other legal remedy can do: it provides compensation to victims. It also clearly establishes a legally enforceable duty to the individual patient to treat pain in accordance with professional medical standards." Syme argues "by manipulation of the law, and by illogical application of causation, an unacknowledged defense for doctors has been created…in the form of [a benign conspiracy] that [permits doctors to hasten death by causing and intending it for dying patients with such forms as terminal sedation]."

Different considerations help readers frame issues: are these matters of personal coping, civil versus criminal law, of regulatory administration and oversight? But different agencies claim jurisdiction: disciplinary-professional groups such as State Medical Boards, and State-Federal Centers for Medicaid-Medicare Services, FDA for drugs; State Departments of Human Services. Who best looks out for patient and caregiver interests?

IDENTIFYING PRACTICAL RESOURCES: Various national and international organizations listed in our online web resources list continuing education regard pain and pain management. Ask readers to cite specific categories and examples from essays, cases from the newspaper or personal stories that identify positive and negative accounts of effective pain management. Tucker discusses Berger (2001) and Tomlinson (2001). Popular stores and fears can be helped with working definitions. Who diagnoses each? What are practical ways of recognizing and coping with each among patients, family and professionals? For example, what might family members giving hospice care learn from professionals about pain? Different tools that measure and manage pain continue to be debated.

Invite readers to consider how terms are understood by different audiences. Both essays and the Introduction and Conclusion describe different key terms that are helpful to discuss these examples, cases, and stories. For example, how are different kinds and meanings of pain understood. Pain changes and no instrument is perfect; all tools are interpretated by different audiences. Which advice has stood the time of "best pactices" regard pain diagnosis and management (see websites). These offer many resources for families and colleagues.

CONNECT IDEAL WITH REAL: Cross-cultural communities and plural traditions are rediscovering nonwestern (non-tragic) and western (tragic) interpretations of pain.

Testing on the Issue

3) Web Questions

1. Attorney Kathryn Tucker, the Director of Legal Affairs for the Compassion and Choices in Seattle argues that treating physicians, hospital and nursing homes for an end-stage cancer patient

a. *should be held accountable* for inadequate pain management because they did not pay enough attention to the patient's pain or family requests
b. *reached a confidential settlement* that acknowledged responsibility among caregivers including mandatory retraining and regulatory-sanctions that serve as correctives for inadequate pain treatment
c. *were shown to be legally negligent* after his death because they neither assessed pain adequately, nor initiated pain management, nor prescribed adequate pain relief thereby causing unnecessary suffering

d. *were successfully sued* by the family in California under laws of elder abuse that showed "recklessness" in failure to due a duty in treating obvious pain

2. University of Florida Professor of Pharmacy David Brushwood argues that holding physicians accountable "sets up" doctors to fail in their provision of adequate pain relief to their patients. Which of the following *hurts* the effort to distinguish criminal misconduct outside medicine from malpractice within medicine?

a. Pain management *training is inadequate or unproductive* in medical schools, residency ("start low and go slow") and Continuing Medical Education ("Telling-Showing" but no "Doing")
b. *Under-resourced*: Agency rules don't financial support needed staffing for good pain support
c. Patient fears of addiction cause *under-compliance* with prescriptions
d. *Over-regulation* is not addressed by "safe harbors of legitimate use" in the face of legal surveillance and adversarial expert witnesses paid to find mistaken prescriptions

3. Some see the threat of litigation for pain treatment as "you're damned if you do and damned if you don't." St. Louis University Professor of Health Care Ethics Sandra Johnson argues

a. the Tomlinson case (and Bergman before it) fell within "safe harbor" guidelines that permit the most aggressive pain treatments as a matter of law and policy (e.g. nondisputed diagnosis, control by institution)
b. it is wrong to use civil courts to advocate for improved pain management
c. variable state laws don't limit the recovery of noneconomic damages ("pain and suffering") which make them attractive
d. DEA needs to meet with State Medical Boards to balance medical use of painkillers with efforts to stem their illegal diversion

4. Australian surgeon Rodney Syme argues that the clearest laws regarding pain relief should focus on

a. medically objective criteria about the effective dosage of pain relief for an end stage illness
b. a benign conspiracy among lawmakers and prosecutors who overlook how doctors frequently and deliberately hasten the death of patients
c. palliation and consent
d. criminal law of causation focused on intention and cause of death

4) Multiple-Choice Questions

5. With which one of the following statements would Syme *disagree* with Tucker?

a. undertreated pain at the end of life is common
b. courts can advocate for improved pain management
c. it is usually possible to determine effective relief in dosages of pain medicine by consulting patients and families
d. barriers to undertreatment are more practical than theoretical

6. Which of the following would both Tucker and Symes *agree* are not related to a "culture of underprescription"

a. provider fears of regulator sanctions for over-prescriptions of narcotics
b. laws to prevent diversion
c. delayed hospice referrals
d. patient reluctance to take medicine for fear of sedation or addiction

7. Clinical practice guidelines everywhere agree that improved pain management is a worthwhile public health goal. What does *Tucker rather than Syme* argue is the best *kind of right* to achieve adequate end of life pain relief?

a. a general *human right*
b. a matter of state jurisdiction to determine blameworthy causes for death in *criminal law*
c. a *civil duty* subject to a standard of care of negligence or reckless abuse in civil law
d. a *civil liberty* restraining or protecting one against improper government action such as "cruel and unusal punishment"
e. a *civil right* imposing an obligation on the government to protect citizens against restrictive painkiller classifications due to a "right to palliative care"

8. What would Tucker, Syme, Brushwood and Johnson *agree*?

a. end-stage cancer patients do not usually have cognitive capacity to accurately report pain
b. wealthy get pain relief, poor and working class get pain management
c. effective models ("best practices")of pain management exist to guide improvements
d. litigation improves palliation

9. What would Tucker, Brushwood and Syme *agree* are the keys to effective improvements in end of life pain relief?

a. increasingly sophisticated pharmacology
b. education of health care professionals, peer mentoring, law enforcement and public understanding about "undertreated pain"
c. recognizing that failure to acquire and apply available knowledge about adequate pain relief results in legally and financial significant exposure to claims for blameworthy harm
d. Better practical connections ("education") than silver bullets ("litigation, regulation, administration") among different groups involved in pain relief

10. Why does Syme rather than Tucker argue there have there only been a handful of cases of successful prosecutions of physicians for deliberately hastening death in relation to treatment of pain?

a. there are very few published articles about practices of physicians aiding patients in death
b. police, prosecutors, coroners, and the law benignly conspire to overlook all but the worst cases of end of life practices by doctors
c. evidence of harm is hard to gather because because end-stage patients in pain cannot offer truly informed consent nor have enough decisional capacity
d. criminal laws of causation focus on intention and cause of death.

5) Essay Questions

1. HOW DO CLASSIC STORIES OF RESPONSES TO PAIN FUNCTION AS POSITIVE AND NEGATIVE RESOURCES? Ask readers to identify the most compelling responses to pain that are a moving personal example (ideal type), classic story (narrative), image, symbol or music that illustrates a "model of" (descriptive) or "model for" (normative) or anti-model (against) responses to it. For example, what do readers think of the agonizing illness and death of Leo Tolstoy's 1886 The Death of Ivan Illych? How does some pain cause those who experience it to question meanings in life? Having emerged in eras of pandemic epidemiologies, every major religious tradition has conflicted stories and tales about pain as punitive and educative (e.g. Book of Job; Ayyub in Qur'an). Most likewise have therapeutic traditions (e.g. Buddha, Jesus as curers; traditional, complementary and alternative medicines such as Hindu Ayurvedic that continue to be tested for effectiveness and safety).

3. WHAT DO YOU THINK ARE THE THREE MOST IMPORTANT ELEMENTS OF NEW STANDARDS OF PAIN RELIEF THAT ARE EMERGING (PERSONAL, PROFESSIONAL, POLITICAL?): Discuss differences

between adequate diagnosis, administering pain relief, managing pain and relieving pain. What are some of the chief opportunities and challenges in developing a model policy? To lessen undertreatment, what models of success have worked (IPTA, Intractable Pain Treatment Act, Pain and Policy Studies Group, http://www.painpolicy.wisc.edu/index.htm)? That is, how have fears of high regulatory scrutiny, potential penalties (despite rare prosecutions), professional shame, continued and widespread lack of understanding about relative risks of prescribing opiods shaped perceptions? How have threats, actual cases of civil liability (Bergman, Tomlinson) and outcomes of disciplinary action shifted the conversation from pain relief as a risk of homicide to a civic duty to care? (Tucker, 2004; Burt, 2007)

Recognizing the inadequate management of pain and barriers to appropriate treatment;

- Emphasizing the dual obligation of government to develop a system that prevents abuse, trafficking and diversion of controlled substances while ensuring their availability for legitimate medical purposes;
- Revising definitions of addiction, chronic pain and physical dependence to reflect current consensus and expertise in the medical community; and
- Updating criteria for evaluating the appropriate management of pain.

http://www.fsmb.org/pain-model-policy.html

4. TO WHAT BASIC MESSAGE ABOUT PAIN MANAGEMENT DO YOU HAVE WHAT KIND OF RIGHT? Is a belief in total pain control overstated?

- Your pain **can** be managed.
- Controlling pain **is part** of your cancer treatment.
- Talking openly with your doctor and health care team will help them manage your pain.
- The best way to control pain is to stop it from starting or keep it from getting worse.
- There are many different medicines to control pain. Everyone's pain control plan is different.
- Keeping a record of your pain will help create the best pain control plan for you.
- People who take cancer pain medicines as prescribed rarely become addicted to them.
- Your body does **not** become immune to pain medicine. Stronger medicines should not be saved for "later."

http://www.cancer.gov/cancertopics/coping/paincontrol/page2

5. WHAT ARE THE KEY LESSONS FROM THE HISTORY OF PAIN? WHAT IMAGES EXPLAIN MY EMBODIED PAIN? What words would you use to describe the worst pain that you ever had? In clinical terms, *suffering* is a subjective appropriation and interpretation of a grammar of affliction. Cassell descriptively distinguishes the *stimulus response* of pain, *traumatic* events, specific *injuries*, resulting *disabilities*, morally and legally blameworthy *harm*, objective disease *epidemiologies* that are chronic, acute, terminal, including subjectively perceived *sickness* and *illness*, as well as challenges to *mental wellness (Cassell, 1991, 1999)*.

Descriptions of pain have shifted from pain as a merely passive "perception" that is "received" like "touch" to a functionally active and emotional construction that is cultural and embodied (Aydede, 2009). What *lessons* have we learned about the history of *pain relief*? Historically, the analgesic effects of many elements have been known for millenia--*opium cultivation* reaches to neolithic era of 9500 bce. Yet the isolation of opium alkaloid morphine occurred in 1803 but was not industrially produced until the 1820's in Germany and 1830's in America. Pain relief elements used in surgery evolved from 1846 (ether), 1847 (chloroform) and in the 1880's (cocaine). When patients became clients, pain became embodied pains against which there were struggles using images of war, crime, conflict, game and industry (Foucault, 1973; 1977; Scarry, 1981; Morris, 1991, Baszanger, 1998; Graham and Herndl, 2011). An era of sustainable cost containment shaped new outcomes based questions: "How do you feel?" became "Where does it hurt" and "How does does it hurt?" (Fitzpatrick, 2000: 124, 159) Clinical professionals, regulatory bodies and insurance guidelines shaped some two dozen self-reporting, observational and physiological pain measures or protocols called "pain scales" (indices, questionnaires, scores, inventories) that interpreted pain in two key physiological and psychological categories. Decades of questions (taught patients to) categorise pain using two important practical metaphors for intensity, duration and locale that diagnostically mapped acute and chronic pain as peripheral, central or mixed sites. These metaphors were *trauma biomechanics* (damage such as "lacerating") and *electrico-physiological transmission* (pain "sensation-impulses" by neuronal conduction called nociception as thermal, mechanical and chemical) (Melzack and Wall, 1996; Stahl, 2008; 2011). Contrary to the implied passivity of their etymologies, few contemporaries agreed that that pain is "punishment" (poena, Latin and Grk, *poine*)—much less magical or tritely educative—nor that a "patient" is merely "one who suffers, endures" (Latin, "patiens"). Murat Aydede, "Pain," Stanford Enclopedia of Philosophy (2009);EJ Cassell. Diagnosing Suffering: A perspective. Annals of internal Medicine 1999;131:531-534; Ibid., The Nature of Suffering and the Goals of Medicine. Oxford University Press, 1991

ANSWERS
1 (B), 2 (D), 3 (A), 4 (C), 5 (B), 6 (D), 7 (C), 8 (C), 9 (D) 10 (D)

<u>Instructor's Resource Guide</u>:

ISSUE 6. Should Pain Be Alleviated if It Hastens Death?

YES: Mularski, R. A., Puntillo, K., Varkey, B., Erstad, B. L., Grap, M., Gilbert, H. C. et al. (2009). Pain management within the palliative and end-of-life care experience in the ICU. *CHEST, 135(5)*, 1360-1369. doi:10.1378/chest.08-2328

NO: Sprung, C, L., Ledoux, D., Bulow, H., Lippert, A. Wennberg, E., Baras, M. et al. (2008). Relieving suffering or intentionally hastening death: Where do you draw the line? *Critical Care Medicine, 36(1)*, 8-13.

1. Synopsis

Richard Mularski, a physician from the Center for Health Research at Kaiser Permanente Northwest, and colleagues from around the country discuss palliative care and end of life care in the intensive care unit. They identify that the intent of pain medications in this setting is the relief of pain and suffering, even if the possibility exists that these treatments will hasten death. Charles Sprung, MD, JD, a physician, lawyer and professor at Haddasah University Hospital, in Jerusalem, writes with colleagues from around the world about their concerns with treatments and medications in the ICU that actively shorten the dying process. They raise concerns about the lack of distinction between alleviating suffering and active euthanasia and that inappropriately large doses of pain medications may be given to hasten death "in the guise" of relieving pain and suffering.

2. Discussing the issue

The essays for this chapter focus on pain relief for dying patients. For these patients who are suffering, the relief of pain at the end of life is one of the few treatments that provides for a truly comfortable death. Hospice care has greatly improved the management of symptoms for dying patients (pain, restlessness, difficulty breathing, loss of appetite, etc). However, for some patients pain remains severe or intolerable, even after high doses of medications are offered. This kind of pain, called "intractable pain" and is quite different than other types of pain. Discussions with students should include differentiating intractable pain (pain that is not relieved from maximum doses of pain medication) from pain that could be treated appropriately with current medications but insufficient amounts have been given. Also, students should consider the ethical concerns of overtreating and oversedating patients at the end of life. The articles in the reference list are good resources to help with this class.

Physicians and nurses have developed pain management clinical practice guidelines to improve the possibility of good pain management for most dying patients. But research shows that between 26% and 50% of patients are reported to have pain that was undertreated at the end of life (Fineberg,Wenger & Brown-Saltzman, 2006; Smith et al., 2010; SUPPORT, 1995) Aggressive pain treatment practices for dying patients can provide relief and comfort. One recent study showed that the use of high dose opioids for cancer patients had no effect on mortality, indicating that those patients receiving higher doses of pain meds did not die sooner than those without high doses of pain meds (Azoulay, Jacobs, Cialic, Mor & Stessman, 2011).

Health care professionals and bioethicists routinely use "Double effect" reasoning to distinguish actions that are intended to do good (relieve pain), but that have a foreseen bad outcome (a hastened death). By invoking the rule of double effect in the cases of palliative sedation, physicians focus on relieving or controlling suffering, and not the secondary outcome of shortening a dying patient's life (Billings, 2011; Boyle, 2004; Olsen et al., 2010). However, when very aggressive interventions are used for pain management, colleagues may question the intent of the physician prescribing the treatment or the nurse administering the treatment. This was the situation in the case of Dr Weitzel, a physician in Utah who was prosecuted for his treatment of pain in 5 elderly patients with dementia. To enhance the discussion for the students, the instructor may want to show a segment from "60 minutes" about the case of Dr Weitzel, a physician who was charged with murder, prosecuted and jailed for prescribing pain medications at the end of life for dementia patients (http://www.youtube.com/watch?v=zJB11Ka4Ycs).

In the essay in favor of pain treatments that relieve suffering, even if they cause the death of the patient, Mularski discusses pain management for end of life care in the intensive care unit. She argues that pain management should be the primary focus of end of life care and that suffering should be addressed by the interdisciplinary team. She reinforces the need for good communication with family members of patients to assist them in understanding that the goal of pain medications and other management strategies are to relieve suffering at the end of life (Mularski et al., 2009).

Clinicians from the opposing point of view raise questions about the real intent of many of the physicians who initiate palliative sedation. The ETHICUS study group examined the use of medication for sedation and pain treatment for seriously ill patients who died in intensive care units (Sprung et al., 2008). This collection of intensive care physicians from several European countries identify that deliberately terminating the life of another person is illegal. However, it can be exceedingly difficult to distinguish between measures taken to provide relief of pain and suffering and those done with the intention of shortening the dying process (Sprung et al., 2008).

Testing on the Issue

3. **Web Questions**

1. Intractable pain is:

a. Pain that takes longer to respond to medications.

b. Pain that is relieved by higher doses of medications

c. Pain that affects the internal organs and psyche.

d. Pain that is unrelieved even with the highest doses of pain medication.

2. Mrs. S. has very severe cancer pain is being treated at home on hospice at the end of life. The family is reluctant to give pain medications because they are afraid they will "kill" the patient. Which of the following would be the best response to their concerns?

a. "If she dies after you give a pain medication, just don't tell anyone you gave it."

b. "Your intent with the pain medication is to relieve pain; it is the cancer that is "killing" her."

c. The rule of double effect means that you probably will kill her with a pain medication when you give it.

d. “Just try to have her avoid pain medications as much as possible”.

4\. **Multiple Choice Questions**

3\. The main difference between terminal sedation and euthanasia is:

a. The intent of euthanasia is to provide supportive comfort care at the end of life.
b. The intent of euthanasia is to relieve pain and suffering rapidly by killing someone.
c. The intent of terminal sedation is to relieve intractable pain.
d. The intent of terminal sedation is to rapidly end the patient’s life.

4\. The rule of “double effect” means that

a. The laws about pain treatment at the end of life can also allow for euthanasia.
b. By law, physicians must always give the most aggressive pain treatment to patients who are dying.
c. In some cases, treatment of severe pain can also lead to a hastened death.
d. The practice of euthanasia can be excused for patients with severe pain.

5\. Terminal sedation is:

a. The practice of giving pain treatment at the end of life via intravenous infusion.
b. The practice of giving antipsychotic medications to patients who are delirious when they are dying.
c. The practice of using high doses of sedatives, pain medications, and anxiety medications to the point of causing the dying patient to stay in a deep sleep prior to dying.
d. The practice of ending a patient’s life on an intensive care unit when they are terminally ill.

6\. Sprung raises one main concern about the differences between terminal sedation and euthanasia, it is

a. Terminal sedation does a better job than euthanasia of treating pain at the end of life
b. It can be difficult to distinguish between terminal sedation (providing relief of suffering) and euthanasia (intending to shorten the dying process).

c. Most states have laws against terminal sedation.
d. Euthanasia is more likely to be accepted than terminal sedation.

7. Mularski identifies that palliative sedation is appropriate in some circumstances. Which of the following is NOT one of the criteria that could be used to justify palliative sedation:

a. aggressive efforts have failed to provide relief,
b. additional invasive/noninvasive treatments are incapable of providing relief
c. additional therapies are will create more illness and is unlikely to provide relief in a reasonable time frame
d. current pain treatments are already managing pain well.

5) Essay questions:

8. Identify two of the arguments that Sprung, et al presented to defend their view that there is no clear-cut distinction between treatments administered to relieve pain and suffering and those intended to shorten the dying process.

9. Describe the four criteria for palliative sedation as presented by Mularski.

1. (D) 2. (B) 3. (C) 4. (C) 5. (B) 6. (D)

Instructor's Resource Guide:

ISSUE 7. Does Too Much Treatment Result in an Inhumane Dying?

YES: Brownlee, S. (2008). Afterward. In *Overtreated: Why too much medicine is making us sicker and poorer* (pp.305-312). New York, NY: Bloomsbury.

NO: Bennett, A. & Babcock, C. (2010, March 4). Lessons of a $618,616 death. *BusinessWeek, (4170)*, 32-40.

1) Synopsis

In the article for the yes position, Amanda Bennett, an executive editor with Bloomberg News, and Charles Babcock, editor-at-large for *InformationWeek*, relays the story of Amanda's husband's cancer treatment and argues that the treatments provided extra years of life that were priceless to her and her children. In the article for the No position, Medical Journalist Shannon Brownlee raises questions about cost and quality of care at the end of life. She provides an experience of Dr. Peter Kibbe's who observed the end of life care for an elderly patient with severe dementia. The patient's implanted cardiac defibrillator frequently discharged, shocking the patient and causing severe pain and anxiety. The family insistence on heroic measures led to overtreatment that caused more pain and suffering at the end of life.

2) Discussing the Issue

"When we are, death is not, when death comes, we are not"

Letter to Menoeceus, Epicurus (341-270 bce)

If no two people agree about a good death, why do so many agree about what constitutes a bad dying?

NAMING ISSUES: Key terms rely on assumptions worth discussing; Is over or under-treatment the only or main item that makes dying inhumane? Does such a view "medicalize" dying? Does "overtreatment" suggest consensus about "appropriate treatment"? Does it imply similar fears about inappropriate over-treatment or undertreatment at the end of life among patients, family and caregivers? In what different ways can treatments become inhumane—how do they dehumanize, depersonalize, individualize, and consumerize end of life experiences? In the most expensive health care system in the world, why is extravagant care for body at the end of life experienced as such poor care for the soul and inadequate "care for person" (Risse, 1999)? In the absence of "cure" why is "more care" (e.g. increased ICU usage) not experienced as "better care" by patients and families? Who is responsible and according to what measure of accountability (ethical, professional, legal-criminal; legal-civil)? What access or coverage of effective care is available for whom?

Common incorrect forms of reasoning called fallacies include assuming meanings and responses to "over-treatment" or "inhumane dying" are simple or uniform for everyone. That is, assuming all treatment is the same or self-evident to caregivers and patients—or that everyone's experience of dying (e.g. even with a particular cancer) doesn't change over time or vary by individuals as diseases evolve. Some assume treatments are managed according to universally administered medicines everywhere about which there is undisputed agreement. Consensus is not unanimity. Others presume that clear responsibility rests with health care professionals rather than shared with informal caregivers or patients about how dying becomes "humane". Discuss: how is responsibility for humane dying shared among health care professionals and patients-caregiving families? Some presume that cultural agreement exists about ethical justifications for appropriate treatment or good dying among professional and legal categories (utilitiarianism, duties, rights, duties, justice).

BENEFITS AND RISKS IN TREATMENT DECISIONS AT THE END OF LIFE: There is more to making dying humane than appropriate treatment. In fact, most dying in hospitals happens by withholding and withdrawing inappropriate treatments (8/10). Who decides and how? Cultural consensus has focused on patient informed consent and decisional capacity—or by a valid surrogate—as well as team-based processes. Emerging USA cultural consensus about relinquishing futile treatments that provide no benefit, are medically ineffective, are non-beneficial, or are disproportionately burdensome at the end of life are counterposed by widespread cultural confidence that technology can always rescue one who is dying (Presidential Bioethics Commission, 2008; Callahan, 2008). What collaboration among patients, family and caregivers can avoid incorrect blame or poor conflict resolution? To blame dying persons or caregivers for a medicalized culture incorrectly identifies only part of the entire cause of the effect—hence is a fallacy of "complex cause" ("Everyone is dying! Everyone suffers! All pain has been medicalized!").

Good pain diagnoses and management works best with continuity of care and clear commuication. Multiple, specialized caregivers, exhausted families and complex causes of dying present challenges for treatment decisions.

Brownlee argues that the pain and anxiety experienced by the frequent discharge of an implanted cardiac device on a demented elderly patient—coupled with his family's insistence on heroic measures—provokes questions; "How can we best care for patients who are in the final stages of life? How do we stop thinking that failing to 'do everything possible' for elderly, dying loved ones is tantamount to killing them?....You can help yourself by asking for palliative care early. . . ." Amanda Bennett wonders about all the expense and effort spent to keep her husband Terrence alive—for what amounted to an extra fourteen to seventeen months that she valued as personal and family experience "Only I know that those months included an afternoon looking down at the Mediterranean with Georgia from a sunny balcony in southern Spain. Moving Terry into his college dorm. Celebrating our 20th anniversary with a carriage ride through Philadelphia's cobbled streets…[yet…]Taking it all into account, the data showed we had made a bargain that hardly any economist looking solely at the numbers would say made sense….Would earlier hospice care been kinder? I hadn't believed Terence was going to die so I had never confronted any of those dilemmas. And I never let us have the chance to say goodbye….But when I ask myself whether I would do it all again, the answer is— absolutely. I couldn't not do it again."

Different considerations help readers frame issues: are these matters of personal coping, social choices, public resources, of regulatory administration and oversite?

IDENTIFYING PRACTICAL RESOURCES: Various national and international organizations listed in our online web resources list continuing education regard end of life decision-making. Ask readers to cite specific categories and examples from essays, cases from the newspaper or personal stories that identify positive and negative accounts. Popular stores and fears can be helped with working definitions. What are practical ways of recognizing and coping with god, bad or inadequate treatments among patients, family and professionals? For example, what might family members giving hospice care learn from professionals? Different tools that measure and manage good treatment decisions continue to be debated.

Invite readers to consider how terms are understood by different audiences. Both essays and the Introduction and Conclusion describe different key terms that are helpful to discuss these examples, cases, and stories. Treatment decisions change and no instrument is perfect; all tools are interpretated by different audiences. Which advice has stood the time of "best pactices" regard treatment decisions (see websites). These offer many resources for families and colleagues.

Testing on the Issue

3) Web Questions

1. Bloomberg News Executive Editor Amanda Bennett argues

a. most end stage cancer treatments cause needless pain for patients and their families
b. she and her husband Terrence agreed that extra costs for his care were worth the extra months of life with his family
c. her corporate health coverage in several jobs completely covered all expenses, which were themselves only a fraction of bills charged
d. highly-motivated patients and families who seek aggressive and experimental treatments should be able to use resources of insurance coverage to prolong life, or dying

2. According to Medical Journalist Shannon Brownlee, by correcting irregular heartbeats, implanted cardiac defibrillators

a. have given extra years to frail elderly at risk of death from cardiac conditions.
b. have not led to improved education for patients and families about appropriate end of life goals
c. are expensive but improve blood flow to the brain that improves cognitive ability and cures dementia
d. should only be given after screening—and not be given to patients with dementia.

4) Multiple-Choice Questions

3. Bennet and Brownlee would agree that the *costs* for end of life treatments

a. where unnecessary could instead be used to improve the quality of our health by providing health insurance for every American
b. can instead help people say goodbye in earlier hospice decisions
c. shows sellers don't set the prices and the buyers don't know what they are because bills don't reflect true costs due to discounts in which actual payments don't reflect actual values; prices bear little relation to demand or how well goods and services work
d. demonstrates that specialists over-prescibe futile and experimental treatments for dying patients

4. Bennet and Browlee *agree* "Over-treatment" of end stage diseases is best defined as

a. what brings about *iotrogenic* events which cause complications or death
b. what ties up resources that have been proven could be better spent on health needs of a *future generation*
c. what are *futile* that offer no benefit, are medically ineffective, or are disproportionately burdensome at

the end-of-life'
d. what *overutilizes* health services, such as more visits, higher use of costly specialists, more hospitalizations, tests, procedures, and prescriptions than are otherwise appropriate for that disease

5. Bennet and Brownlee agree that "overtreatment" is *not* usually demanded by

a. *patients* in a hospital who want to go home and die
b. *families* who seek aggressive care that won't change the outcome of a dying person's disease
c. those which *tie up* scarce resources, drive up unnecesary costs and focus on cure rather than adequate pain and comfort care for dying
d. providers, hospitals and fragmented healthcare *specialists* who are re-imbursed for more tests and treatments

6. Bennet and Brownlee *agree*

a. despite trust in prolonged *survival*, neither patients nor famillies are well-advised about the frequently debilitating *costs* of using different technologies
b. a decision to *withhold* a treatment requires a stronger reason than a decision to *withdraw* a treatment that has clearly failed (Junkerman, Derse, Schiedermayer, Practical Ethics, 11)
c. technologies that are *possible become necessary* (a technological imperative)
d. technologies that were once *experimental soon become routine* (constant innovation)

7. Bennett and Brownlee agree that end-of-life treatment should be limited when

a. a patient decides (autonomy)
b. it is in a patient's best interest (beneficence)
c. treatment is futile (*medically ineffective, nonbeneficial or disproportionately burdensome)*
d. care is contrary to health-care standards of care (consciences of providers)
e. all of the above

8. Increased ICU usage among frail elderly and over-referrals for ICU do *not* reflect

a. physician "enthusiasm" and "*supplier-induced demand*" (where there is increased availability of ICU's)
b. a better experience of dying for patients and families
c. allocation models requiring professionals to be patient advocates yet stewards of limited social resources for in rationing (macroallocation) and triage (microallocation)
d. shifted professional-patient roles from fiduciary-beneficience to buyers and sellers of competent services (caveat emptor/vendor)

9. Bennett and Brownlee probably agree that inhumane treatment cannot be completely reduced to economic terms. Which category might each explore?

a. cost as used up money
b. price as compensation payment based on supply and demand

c. expense based on outflow for service or costs
d. value as exchanged goods and services based on worth in relation to a being

10. Bennett and Brownlee probably agree that treatment is most inhumane which

a. *dehumanizes* dying persons when it disconnects them from caregivers
b. *depersonalizes* care by treating the person as a body and death as a medical failure
c. *consumerizes* patients as dying "clients" whose dying processes are "billable events" and "coverable benefits"
d. *individualizes* dying by prizing autonomous treatment decisions that ignore resource limits or realistic outcomes.

5) Essay Questions

1. DISCUSS: Examine stories of people who died fighting cancer. Discuss whether it was "worth it" and on whose terms. Is an individual health care professional or palliative care team the best guide among different treatments called therapies? Among ancient Greeks, therapies were not merely external interventions, but also guidance about how to use personal, family or social resources wisely (Rieff, 1987). Is cancer, death, advice or technology the "enemy"? (Jonas, 1984; Werko, 2000; Hoffman, 2002; Rubenstein, 2010; Clow, 2001). Stories abound in oncology journals (some 75 in English, such as "Cancer Nursing Practice"), drama (the 1995 play "Wit"), film (some 28), books (Brooke and Keithe Desserich's 2009 *Notes Left Behind*; oncologist Siddhartha Mukherjee's pulitzer-prize winning, *The Emperor of All Maladies: A Biography of Cancer;* Walter Isaacson's 2010 *Steve Jobs* (Ch.35, 37, 41); *Illness as Metaphor* (1978), and *AIDS and it Metaphors* (1988) by Susan Sontag; *Swimming in a Sea of Death* (2008)about Susan Sontag by son David Rieff and religious coping in Leonard Hummel's *Clothed in Nothingness* (2003). Barbara Clow's 2001, "Who's Afraid of Susan Sontag? or, the Myths and Metaphors of Cancer Reconsidered". *Social History of Medicine* 14 (2): 293–312

2. **DISCUSS**: In a world where media drives expectations about medicine, your sister with cancer thinks her health care professional owes her a miracle. What do you say to her? What challenges are faced by patient-centered options such as "patient goals," "prolonging life," "physiological impact on the body," "therapeutic benefit"? When a patient does not or cannot experience anything, is it appropriate to describe a treatment as a therapy (a beneficial treatment) or merely as an effect (a typical outcome) (Schneiderman and Jecker, 2011: 156)? Are there limits to what society can afford when treatments address caregiver concerns more than patient needs?

4. IDENTIFY: Can specialized professionals be conflicted about whether to benefit the patient and protect her from harm or maintain professional relationships (among staff, nurses, nurses and physicians, physicians and administration)? How should conflicts regarding overtreatment (or undertreatment) that do not meet a required standard of care be handled? (Frey, Veatch and Taylor, 2010: 23)

5. IDENTIFY: What are different ethical justifications and obstacles to patient and caregiver literacy about end of life technologies? How many of these are time-dependent—i.e. require urgent decisions? How many require different kinds of treatment advice? How does overtreatment look different in three different end of life scenarios—cancer, chronic heart failure and dementia? Modest knowledge is known about effective pain management with opiods for cancer and interventions for caregiver burdens (Lorenz and Lynne, 2004). "Cancer patients experience a somewhat predictable decline and are often served by hospice in their final weeks. In contrast, patients with organ system failure (e.g., congestive heart failure [CHF], chronic obstructive pulmonary disease [COPD]) may experience stable but impaired function punctuated by unpredictable, severe illness and rather sudden death and are rarely served by hospice. In further contrast, patients with dementia have prolonged declines and often reside in nursing homes."(Lorenz and Lynne, 2004).

1 (D), 2 (B), 3 (A), 4 (C), 5 (A), 6 (A), 7 (E), 8 (B), 9 (D) 10 (D)

Instructor's Resource Guide:

ISSUE 8: Are feeding tubes obligatory?

YES: Sandler, A. G. (2009). A right to nutrition and hydration: A need for vigilance. *Intellectual and Developmental Disabilities, 47(3)*, 234-238. doi:10.1352/1934-9556-47.3.234

NO: Orentlicher, D. & Callahan, C. M. (2004). Feeding tubes, slippery slopes and physician assisted suicide. *Journal of Legal Medicine, 25(4)*, 389-409. doi:10.1080/01947640490887544

1. *Synopsis*

Allen Sandler, an associate professor for special education, offers a case that demonstrates that nutrition and hydration were inappropriately viewed as futile treatment in a person with disabilities who was not truly terminal. He argues that persons with disabilities must have access to the same life-sustaining treatment as provided to those without a disability, including feeding tubes and that decisions about futility must be carefully considered. David Orentlicher, professor of law and Christopher Callahan, a physician present the historical underpinnings of feeding tubes and how laws have allowed withholding or withdrawing feeding tubes in persons with serious or terminal illnesses. They provide evidence that allowing refusals of tube feedings has **not** led to the slippery slope of requiring tube feeding removals as once feared. Rather, there continues to be an overuse of feeding tubes in persons with terminal diseases.

2. Discussing the Issue

This issue discusses the common practice of placing a feeding tube in persons with diseases that limit their ability to swallow. Although not all patients who require feeding tubes are terminally ill or dying, there are many feeding tubes placed as a temporary measure for the provision of nutrition and medications when a patient has been hospitalized for a serious illness and the outlook for recovery is uncertain. If the patient's condition worsens and there is no hope for recovery, families are often confronted with decisions to withdraw a feeding tube that has been put in place. In other cases, perhaps the majority of cases, feeding tubes are placed in patients with degenerative neurological diseases (like Alzheimer's disease). Placing a feeding tube near the end of life does nothing to change the deteriorating course of the disease (Sampson, Candy & Jones, 2009). Supporters of feeding tubes argue for the sanctity of life; feeding is essential to sustaining life and must be provided as a basic standard. From this point of view, any removal of feeding is considered morally wrong and is considered tantamount to killing the patients (Penner, 2005; Wick & Zanni, 2009). Naysayers identify that feeding tubes are not obligatory; patients who are in the process of dying are additionally burdened by food and fluids. Most medical professionals and the legal system have sided with those who believe that it is acceptable and ethical to withhold or withdraw feeding tubes (Sulmasy, 2005; Sulmasy 2006). It is normal for patients to stop eating a few days prior to death, because the resulting dehydration makes their breathing less labored and congested and provides for a more comfortable death (Lynn & Harrold, 1999; Sulmasy, 2006).

Readers of this chapter may be familiar with legal cases of Karen Quinlan, Nancy Cruzan, and Terri Schiavo, which highlighted the difficulty that families experience regarding the withdrawal of a feeding tube in a person in a persistent vegetative state (Ball, 2006; Sulmasy, 2005). Arguments can be made that persons in persistent vegetative state are not truly terminal. Penner (2005) argues that Mrs Schiavo was not truly terminally ill, she was simply severely disabled, and removal of the feeding tube threatens the others in the disabled community. However, in the Schiavo case the legal focus was on the previously expressed wishes of the patient. Essentially, the courts sought an indication from the patient's family members as to what the patient's wishes would be in this case. The case highlights the gray areas in ethical decisions, including "when is someone terminally ill or dying?"

Just as patients with persistent vegetative state could be thought of as "slowly terminal", someone with severe Alzheimer's disease or Parkinson's disease can have a long terminal phase to the disease. The readings highlight that enteral tube nutrition was not effective in prolonging survival for those with severe dementia, did not improve quality of life, and did not lead to better nourishment or prevent development of pressure sores. Some evidence indicated that for persons with severe dementia, feeding tubes may actually increase the risk of developing pneumonia (due to inhaling small quantities of the feed). Despite the research on feeding tube outcomes, physicians and families continue to place feeding tubes in patients with advance dementia because they want to show caring or concern (Gillick & Volandes, 2008). A better approach for family members may be to acknowledge the symbolic value of nutrition and to seek an alternative means of satisfying the need to feed the dying patient.

Sulmasy (2005) clarified the Catholic church position has never required people do everything possible to medically sustain life. *Catechism of the Catholic Church* states: "Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of 'overzealous' treatment. Here one does not will to cause death; one's inability to impede it is merely accepted. The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected" (U.S. Catholic Church, 2003). *Ethical and Religious Directives for Catholic Health Care Services* (2001) also states: "There should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, ***as long as*** this is of sufficient benefit to outweigh the burdens involved to the patient". The determination of benefit versus burden of tube feeding is challenging at the end of life.

In the article for the **yes** position, Allen Sandler, an associate professor for special education, offers a case of a guardian of a disabled person making a decision about nutrition and hydration as futile treatment, even though the disabled patient was not truly terminal. He argues that persons with disabilities have access to the same life-sustaining treatment as provided to those without a disability, including feeding tubes. Etc. In the article for the **no** position, David Orentlicher, professor of law and Christopher Callahan, a physician present the historical underpinnings of feeding tubes and how laws have allowed withholding or withdrawing feeding tubes in persons with serious or terminal illnesses. They provide evidence that allowing refusals of tube feedings has **not** led to the slippery slope of fewer and fewer patients receiving tube feedings. Concerns that physicians would require tube feeding removals or would not allow feeding tubes in impaired patients (the slippery slope) has not happened as previously feared. Rather, there continues to be an overuse of feeding tubes in persons with terminal disease.

Testing on the Issue

3. **Web Questions**

1. According to Orentlicher & Callahan (2004), what did decision-makers report as the primary goal of initiating PEG tube feeding in patients with dementia?
   a. Improve nutrition (pg 395)
   b. Help overcome acute illness
   c. Prevent aspiration pneumonia
   d. Control fluid intake

2. According to Orentlicher & Callahan (2004), which of the following is true about PEG tube insertion in patients with dementia?
    a. PEG tube placement has been shown to significantly improve nutrition and prevent aspiration pneumonia.
    b. PEG tube placement does not significantly improve nutrition or length of life and may increase the risk of aspiration pneumonia (pg 396).
    c. PEG tube placement improves quality of life but has no effect on nutrition or prevention of aspiration pneumonia
    d. PEG tube placement significantly decreases the risk of aspiration pneumonia and significantly improves quality of life, but does not significantly affect nutrition
4. **Multiple Choice Questions**
3. The primary reason that placement of a PEG tube in a patient with dementia may be considered controversial is because:
    a. It is an artificial means of providing nutrition
    b. It can prevent persons from aspiration pneumonia (accidently swallowing food into the lungs instead of the stomach).
    c. It could be perceived that health care providers or family members are trying to starve a patient if the feeding tube is not placed
    d. It is another cost absorbed by Medicare

4. According to Sandler (2009), what can health care professionals do to help families make decisions about PEG tube placement?
    a. Be aware of their own biases as well as social biases
    b. Provide accurate data regarding the risks and benefits of PEG tube placement for particular populations
    c. Be aware that PEG tube insertion is ineffective only in some populations
    d. All of the above (pg 236)

5. It is recommended to have a PEG tube placed in the last few days of life to improve comfort.
    a. True
    b. False

6. Which of the following best describes family expectations of PEG tube placement in patients with neurological disease or cancer:
    a. Consistent with real life results- families believed that PEG tube use would extend longevity and research has shown this to be accurate
    b. Consistent with real life results- families believed that PEG tube use would improve patient function and research has shown this to be accurate
    c. Inconsistent with real life - Families tend to have higher expectations of PEG tube outcomes than research has demonstrated.
    d. Inconsistent with real life results – Families tend to have lower expectations of PEG tube outcomes than research has demonstrated.

5) ESSAY QUESTIONS:

7. Explain Sandler's view regarding the right to nutrition and hydration. Do you agree or disagree with his assertions? Do his arguments contradict those of Orentlicher & Callahan? Why or why not?

8. Sandler argues that negative attitudes regarding persons with severe disabilities may cause health care professions to make incorrect judgments regarding the futility of treatment including PEG tubes for this population. Discuss the difference in expected outcomes between persons with a disability as compared with a terminal disease such as dementia.

1. (A) 2. (B) 3. (C) 4. (D) 5. (B) (6. (C)

Instructor's Resource Guide:

ISSUE 9: Does Withholding or Withdrawing Futile Treatment Kill People?

YES: N. E. Goldstein et al., from "It's Like Crossing a Bridge" Complexities Preventing Physicians from Discussing Deactivation of Implantable Defibrillators at the End of Life *(2007)*

NO: D. Sulmasy, from Within you/Without You: Biotechnology, Ontology, and Ethics *(2007)*

1. Synopsis

According to Nathan Goldstein, Associate Professor of Geriatrics and Palliative Medicine at Mount Sinai Hospital in New York and colleagues, physicians viewed deactivating implanted cardiac defibrillators (ICD) differently than withdrawal of other life sustaining treatments; physicians also expressed discomfort in approaching this discussion with patients or family members. Daniel Sulmasy, a Franciscan friar, ethicist and physician at the University of Chicago Medical Center, discusses the ethics of withdrawing futile treatments, and establishes the difference between foregoing a life sustaining treatment (such as deactivating an ICD) and the intent implied in the word "killing".

2. Discussing the Issue

Few would argue that patients have a right to refuse treatments that they do not want. At the end of life, however, it is usually family members making decisions about treatments. Even though the patient may be clearly dying, family members may feel conflicted about withdrawing treatments, especially if the patient dies immediately after treatments are withdrawn. The key issues in this chapter is to help students understand and discuss this conflict. Students should consider the difference between an intent to "kill" versus an intent to allow for a natural death. Generally when treatments are withheld (not offered) it is because they offer no real benefit for a different outcome; the patient is dying regardless of whether the treatment is started. More difficult for patients, family members, and physicians are the decisions to withdraw treatments after they have been started. Decisions to continue treatments in a dying patient do not necessarily prolong life. A good example of the burdens of the implanted defibrillator treatment is given in Chapter 9 in the Yes article by Brownlee. Students should consider the burdens of other treatments that are given to patients at the end of life. Asking them about other real life experiences of burdensome treatment at the end of life can allow a fuller discussion of these decisions that are not always clear to families. Such discussions could include chemotherapy in a person with severe Alzheimer's disease, or ongoing cancer treatment in a young person with stage 4 cancer that is known to be incurable. Students should be encouraged to explore concerns by family members making the decision. The instructor can discuss how one perceives the withdrawal of treatment can affect their experience of this. For example, contrast concerns by family members that withdrawing treatment is "giving up" or "killing" with that of families who view withdrawing treatment as letting go, offering comfort, or staying true to the patient's wishes.

In the articles provided Goldstein and his colleagues interviewed physicians to determine whether conversations with family members included the possibility of deactivating the implanted cardiac defibrillator device. Although most physicians recognized that these conversations should occur, the reality was that they rarely occurred. Some physicians expressed concerns about permanence of turning off the ICD device. Others identified the advantage to turning off an ICD device was that it does not immediately cause the patient's death (Goldstein, et al 2007). Since there is a delay, family members may not link the discontinuation of the ICD to death as much as they might when a respirator is discontinued (Kapa, Mueller, Hayes, & Asirvatham, 2010). Similar to family members, physicians in this study did not want their action to be linked to the patients death.

In the article in the no category, Daniel Sulmasy reminds physicians that a treatment inside a patient does not make it exempt from discontinuing the treatment. He clarifies that killing is an intentional act that is nontherapeutic that specifically causes a human being's death (Sulmasy, 2007). By contrast, he argues, removing a treatment or refraining from initiating a treatment such that allows a patient to die of their preexisting fatal disease does not carry the same intent. "Those actions that allow a patient to die are morally permissible when the physician's intentions are not to purposefully cause the death, but rather simply stopping the treatment" (Sulmasy, 2007).

Testing on the Issue

3. **Web Questions**

1. According to Goldstein et al. (2008), reasons physicians cited for not engaging in conversations about deactivating ICDs in patients with advanced illness included:

a. such conversations are regarded as futile
b. such conversations are uncomfortable for family members and therefore avoided
c. deactivation of ICDs is already known based on patient's POLST form
d. it is challenging for physicians to think of ICDs in the same context as end-of-life management. (Goldstein, pg. 2)

2. The "bridge" that Goldstein et al. (2008) refers to is:

a. the bridge between life and death
b. the bridge as an metaphor for the life cycle
c. the bridge towards accepting end-of-life care
d. the finality and no return implications of a decision like deactivating an ICD (Goldstein, pg. 4)

4) Multiple Choice Questions

3. The right to refuse medical treatment:

a. is acceptable only if the treatment offered is considered futile
b. is acceptable only if the patient is dying
c. is a right of all patients at all times of life
d. can only occur if previously expressed in an advanced directive

4. According to Sulmasy (2008), it can be argued ethically that an ICD (implanted cardiac device) is different from other therapies because:

a. an ICD is required intermittently rather than continuously
b. an ICD is a constitutive therapy rather than a regulative one
c. an ICD in placed internally rather than externally
d. under ethical examination, an ICD raises no new ethical questions

5. According to Sulmasy (2008), how is deactivating an ICD different from "killing"?

a. there is no difference- an ICD should not be discontinued under any circumstances
b. deactivating an ICD indicates a patient wishes to die and may indicate depression
c. deactivating an ICD is choosing to forego a life-sustaining treatment which is morally acceptable
d. deactivating an ICD does not immediately cause death

6. Challenges associated with ICDs at the end-of-life that were discussed in the chapter include:

a. cardiac shocks that can frighten the patient
b. there are no challenges with ICDs at the end-of-life
c. ICDs require frequent weekly monitoring
d. ICDs require close cardiology supervision which is not always available

7. According to Sulmasy (2008), why is it controversial to deactivate a patient's ICD near the end of life?

a. Family members must have written evidence that this is what the patient would choose
b. Physicians do not like to discontinue treatments that may be beneficial
c. Family members and physicians may view this as contributing to the death of the patient
d. Families and patients are often not familiar with ethics and ontology

8. Goldstein et al. (2008) concludes that in order to improve communication regarding ICDs in patients with advanced illness:

a. Providers should attend seminars to learn more about ICD deactivation
b. Providers should be given ample time to have such discussions
c. Providers should delegate this conversation to a patient's primary care provider
d. Research should further explore why ICD deactivation is such a complex topic and what tools providers need to better communicate with patients and families.

5)Essay Questions

9. What is the difference between foregoing a life sustaining treatment (such as deactivating an ICD) and the intent implied in the word "killing"? Outline some of the arguments made by Sulmasy (2008) to explain the difference.

10. Explain some of the characteristics described by Sulmasy (2008) that make ICD deactivation different from discontinuing other therapies. Is there an ethical or ontological difference and if so, what is it?

Answers:

1.d 2.d 3.c 4.d 5.c 6.a 7.c 8.d

Instructor's Resource Guide:

ISSUE 10: May A Dying Person Hasten her Death?

YES: Hedberg, Katrina, David Hopkins, Richard Leman, and Melvin Kohn (2009). The 10-Year Experience of Oregon's Death with Dignity Act: 1998-2007. *The Journal of Clinical Ethics* V. 20, N 2: 124-132
NO: *Wolf*, Susan M. (2008) "*Confronting* Physician *Assisted Suicide* And Euthanasia: My Father's Death." *Hastings Center Report 38*.5, 23-26.

1) Synopsis

In the article for the yes position, Katrina Hedberg, the Oregon State Epidemiologist, Public Health Division and colleagues, discuss the characteristics of persons who have taken action under the Oregon Death with Dignity Act. These authors found that most of the dying patients who requested medications to end their lives felt a strong need for autonomy and control. She examines the ten year experience of the Oregon Death With Dignity Act, including patient characteristics, trends, medications prescribed, physicians' characteristics, as well as worrisome trends in pain control and psychiatric evaluations and issues not addressed such as physician follow-up, regulation in the context of unique circumstances in Oregon (Caucasian residents, high Hospice coverage and advanced care planning).In the article for the NO position, Susan Wolf, the McKnight Presidential Professor of Law, Medicine & Public Policy at the University of Minnesota, discusses her long standing opposition to physician assisted suicide and reflects on how her father's death challenged that view. She discusses the treatments, their relationship and the processes they went through to arrive at their decisions.

2) Discussing the Issue

NAMING ISSUES: Key assumptions rely on widely debated terms; viz., *When* is a person dying (imminently dying, those in end stage illnesses, terminally ill, expecting to die, those for whom treatments are ineffective, too burdensome or too costly called futile, issue 9)? What does *hasten* mean (to withhold/withdraw treatment, to voluntarily stop eating, palliative sedation)? Do four types of "hastened" death assume that death is *medicalized*; foregoing treatment and nutrition-hydration, using painkillers, sedation, and legal self-administration of lethal medication--or reflect the (variable) fact that death does not often occur at home?

Is death the *worst outcome* of dying? Can a *good dying* be a good clinical outcome? As in Issue 4 (Compassion Fatigue), what might family members giving hospice care learn from professionals about risks of empathetic care for the different stages of dying persons?

Ask readers to identify common incorrect forms of reasoning called fallacies which assume all dying is the same (*hasty generalizations*)or every death is so completely unique there are no bases for comparisons (explanations have *limited scope* at http://onegoodmove.org/fallacy/toc.htm). Discuss: what roles can a person have in her experiences of dying or foreseen death? What happens if the lens is shifted from "desisting overtreatment" to "a good dying"? Clinical situations of complex, evolving care find it hard to measure "bright lines" of ethical categories demarcating direct and indirect "active" killing versus "passive" death from "proportionate or disproportionate" withholding/withdrawing of treatment. Difficult applications are not therefore useless; however, what is the most apt *unit of analysis* (death events, dying processes)?

BENEFITS AND RISKS IN TREATMENT DECISIONS AT THE END OF LIFE: There is more to dying than death. Discuss the controversial shift to “patient-centered” categories. For example, note the shift from “informed consent” to “decisional capacity”; from “physician assisted suicide” to “assisted death” or “assisted dying”; from “suicide” to “hastened death”. Does this indicate a welcome turn to patient decision-making or simply obscure objectionable practices by a few physicians?

Experiences of dying are complex; they challenge end of life treatment decisions. Hedberg and colleagues argue that the Oregon Department of Human Services collects data but "remains neutral about the law itself." Wolf (among others) asks about "unreported cases." How is part of the debate about accurate information and part about public agencies that monitor practices that are regulated? Are so-called differences between merely reporting (*description*) and advocating (*prescription*) clear—especially when disagreements exist about what public agencies whould be accountable for what kinds of public goods (*ascription*)? Do Hedberg and colleagues simply report practices or does their legal regulation commend them as worthwhile? Does Wolf simply tell a story or "exhort" dying persons not to self terminate? Are these matters of personal coping, social choices, public resources, of regulatory administration and oversight?

IDENTIFYING PRACTICAL RESOURCES: Our online sources list web resources for end of life decisions. Ask readers to cite specific categories and examples from essays, cases from the newspaper or personal stories that identify positive and negative accounts. Popular stories and fears can be helped with working definitions. What are practical ways of recognizing and coping with good, bad or inadequate treatments among patients, family and professionals? For example, what might family members giving hospice care learn from professionals?

Invite readers to consider how terms are understood by different audiences. Both essays and the Introduction and Conclusion describe different key terms that are helpful to discuss these examples, cases, and stories. Which advice has stood the time of “best practices” regarding treatment decisions (see websites). These offer many resources for families and colleagues.

Testing on the Issue

3) Web Questions

1. Oregon State Epidemiologist Katrina Hedberg and colleagues argue that legal self-administration of lethal medication is

A. a good way to die
B. used by only a small number of terminally ill Oregonians
C. part of decreasing usage trends in DWDA participation in Oregon
D. the best way to die in Oregon

2. According to McKnight Presidential Professor of Law, Medicine & Public Policy at the University of Minnesota Susan M. Wolf, the hardest yet most memorable aspect of her time with her dying father was

A. withholding and withdrawing futile treatment
B. refusing his request for accelerating death that he thought necessary for humane dying

C. helping him transfer among hospitals for specialized care
D. keeping vigil in an ICU for his comfortable death

4) Multiple-Choice Questions

3. Wolf's experience with her father suggests she would *disagree* with Hedberg and colleagues that

A. patients with end stage cancers seek to end their lives
B. patients experience adequate end of life continuity of care (guidance by physician or health care team)
C. "accelerating" or "causing" one's death burdens caregivers
D. end of life depression is adequately diagnosed

4. Hedberg and Wolf *disagree* about which methods of hastening death

A. foregoing treatment--withholding and withdrawing treatment
B. voluntarily stopping eating and drinking and refusal of nutrition and hydration
C. lethally risky pain relief
D. legal self-administration of lethal medication

5. Which of the following aspects of DWDA participation in Oregon was not true of Wolf's experience with her father's dying?

A. most are already in hospice
B. most are white, educated and from 55-84 years
C. reasons for requests include loss of autonomy and decreasing ability to engage in enjoyable activities
D. most are dying from cancer

6. Wolf argues that hastened death by safeguarded lethal self-administration for terminally ill

A. is incorrect due to the wrongness of killing
B. poses threats to professional integrity and is open to slippery slope abuses
C. can be an autonomous choice that is merciful and compassionate
D. None of the above

7. Hedberg and colleagues argue that persons choose safeguarded lethal self-administration for terminally ill as

A. pathologically self-inflicted harm
B exceptionally loving sacrifice
C. lessening overwhelming burdens on family caregivers and wanting control over the circumstances surrounding death
D. opposing responsibilities for self-preservation, to others or the divine

8. Which of the following is NOT one of the concerns shared by Wolf, Hedberg and colleagues about trends in DWDA participants?

A. inadequate pain control
B. one third of patients who get prescriptions do not use them
C. inadequate psycho-social referrals (e.g. for co-morbid depression)
D. fears of being a burden on others

9. What issues are *not* addressed in the data of the DWDA that are unique to Oregon and might make comparisons with other jurisdictions difficult?

A. physician follow-up after prescriptions are written
B. high usage by persons with Cancer
C. the high number of Caucasian residents, Hospice coverage and advanced care planning
D. the small numbers but high comparatively rate of usage by persons with ALS (Amyotrophic lateral sclerosis), known in Europe as motor neuron disease

10. With which of the following statements concerning hastening death would both authors disagree?

A. The idea and practice of a painless death ought to be available to all ("democratized").
B. Self-caused death can be reduced by effective diagnosis of personality disorders, social stressors, effective pain management and reducing fears of caregiver burdensomeness.
C. A legal right is adequate moral justification for terminally ill to use safeguarded lethal self-administration.
D. A good dying requires adequate symptom management.

5) Essay Questions

1. DISCUSS: Examine stories of dying patients who requested medications to end their lives. Review stories of dying patients who chose not to end their lives. What roles do family members and health care professionals play? Why is the place and time of death a factor?

2. DISCUSS: In a world of media, how are "patient-centered" choices, languages and options influencing literacy, understandings and decisions about end of life personal goals and social policies?

3.IDENTIFY: How are conflicts identified and constructively resolved among, dying, families and caregivers for goals at the end of life when cure is at an end but healing is still possible (in the wider sense of reconciliation)? Should we expect pharmacology to solve problems best mediated?

4.IDENTIFY: Whether or not hastened, what practical obstacles to good dying are overcome with which basic information from outcomes based clinical sciences such as quantitative and qualitative data (I [depression], II [advance directives], IV [compassion fatigue], XIV [hospice vs. hospital]), ethnography (XVII [cultural competencies])? How do different theories of justice practically improve dying? In other words, how do particular experiences of dying and death have empirically better outcomes based on specific kinds of justice? These include interpretations of justice in dying as equality (informed consent and decisional capacity in Chapter I), need (depression, I, pain managment , V, VI), merit (futility, IX, brain death XIII), productivity-contribution (EOL costs, XV), justly sharing burdens of dysfunctions and justice as fairness (cultural competencies, XVII)?

5. CLASS EXERCISE: Using Online Postings, Compare Washington State Law and Oregon Law
FAQ: http://www.doh.wa.gov/dwda/faq.htm
http://www.secstate.wa.gov/elections/initiatives/text/i1000.pdf

I. POST EIGHT SENTENCE ANSWER ONLINE:

1. READ, POST and ASSESS Best/worst Safeguards Stated at http://www.doh.wa.gov/dwda/ at (Washington Death with Dignity Act, Initiative 1000)

2. READ, POST and ASSESS best TWO most Frequently asked questions described at http://www.doh.wa.gov/dwda/faq.htm

3. FIND AND POST ONE SIMILARITY with Oregon's Death with Dignity Act, under "Requirements, at http://www.oregon.gov/DHS/ph/pas/ar-index.shtml

4. FIND AND NAME at least one SUPPORTING and one OPPOSING ORGANIZATION. State which ETHICAL justification is used (e.g. duty, rights, consequences, principles, virtues)? Points for most creative answer/website (Nurses, Social workers, etc.)

1 (B), 2 (D), 3 (C), 4 (D), 5 (A), 6 (D), 7 (C), 8 (B), 9 (C) 10 (C)

Instructor's Resource Guide:

Issue 11. Can Legal Suicide Really Safeguard Against Abuse?

YES: Ronald A. Lindsay, from "Oregon's Experience: Evaluating the Record," *The American Journal of Bioethics* (vol. 9, no. 3, pp. 19–27, 2009)
NO: Daniel Callahan, from "Organized Obfuscation: Advo
cacy for Physician-Assisted Suicide," *Hastings Center Report* (vol. 38, no. 5, pp. 30–32, 2008)

1) Synopsis: In the article for the yes position, Ronald Lindsay, a lawyer and CEO of the Center for Inquiry, reviews the first decade of the Oregon Death with Dignity Act. He identifies data from Oregon's decade-long experience that refute predictions that the quality and availability of palliative care declined, and suggest risks of abuse are outweighed by benefits of legalization. Senior Research Scholar, President Emeritus, and Cofounder of the Hastings Research Center, Daniel Callahan argues that advocates for physician assisted suicide do two things. First, they *describe* what they are doing in unclear, evasive, or confusing terms ("obfuscate"). Second, they recommend or *prescribe* such practices as good in principles, regulatory policies, and law. Historically, Dutch reports in the 1980's—later confirmed in 1990, 1995, and 2005—contained undocumented euthanasia without informed consent of patients (nonvoluntary euthanasia), then reasoned that unreported euthanasia was based on appropriate caregiver paternalism (judging "quality of life") not abuse. American advocates shifted from "suicide" to "physician aid in dying" to please voters with term "death with dignity" that claims dignity depends upon control. As evident in the support for Washington State's measure by former Governor Booth who had Parkinson's, what began as a quest for control of pain, really medicalizes autonomy by controlling death events. State regulations in Washington and Oregon do not collect or disclose needed data from public scrutiny and debate.

2) Discussing the Issue

Are discussions shaped by historical experiences of legal regulations, stories of disputed practices or normative claims about what ought to happen? Lindsay describes the importance of physician assistance and answers several main objections that are utilitarian-consequentialist. These include negative effects on palliative care, the alleged disparate impact on the vulnerable, the initiation of the slide down the slippery slope, and the problem of abuse, understood to mean the problem of persons receiving assistance improperly. Callahan recounts how disputed practices in the Netherlands caused many to re-describe assistance—which, he argues, eventually led to "death with dignity" shifting from controlling pain to being portrayed as having control over "death events."

NAMING ISSUES: Like general public discussions--patients, family caregivers, doctors, nurses, lawyers and policy-makers all use language of "suicide," "safeguard" and "abuse" with different meanings. But different assumptions rely on key terms and categories widely debated; viz., Do current *safeguards* really protect "caregivers" from legal liability more than insure patients have a good dying (adequate palliation)? Does *abuse* incorrectly imply cultural consensus about what are in fact contested ideas about appropriate *uses* ("legal, lethal self-administration") or disproportionate *mis-uses* ("over-utilization")?

Does abuse refer to *actual cases* (influence or pressure), *patterns* (Kevorkian's "back alley suicides"), *policies* (encouraging overutilization) or *laws* (self-administration versus assistance) (Tucker, 2008)? How wide is the category of those *who are at risk*; those with terminal diagnoses, imminently dying, in end stage illnesses, facing futile treatments, expected to die, vulnerable populations, disabled, nonprivileged without healthcare access, competent, incompetent, unduly influenced, or abused by others (Clark, 1996:n71). Should *Safeguards* eliminate or effectively *reduce* risks? Are legal safeguards adequate of *eligibility* (residency, decisional capacity, terminal status) and *procedures* (physician consults, waiting periods)?

Ask readers to identify common incorrect forms of reasoning called fallacies which assume all abuse is the same (*hasty generalizations*)or every misuse is so completely unique that there are no bases for comparisons (explanations have *limited scope* at http://onegoodmove.org/fallacy/toc.htm). Discuss: what roles can a person have in her dying or foreseen death?

How does the shift from *legalization* to *regulation* influence claims about abuse? Does "regulation" bring "regularizing"? Are professional advocates for assisted death normalizing what everyone agrees should be exceptional—or simply removing social stigma from what can be legally kept a rare but humane option? In Oregon, Washington and Montana, the issue is not "legalization" but "regulation". Public policy is embodied in this legislative act; emerging questions of its impact on, for example a "health care system " (organization and payment of "health" and "care"). Most persons are in hospice. Questions have shifted from "legitimation" (Should X be permitted on Y grounds of theory) to "administration"; viz., what constrains whose rights and holds whom accountable for what responsibilities? Charges of abuse and rebuttals include claims about "legitimation" (should X be permitted) and "administration"; viz., X practice is (in)adequate on grounds that are legal, self-regulated or socially regulated. Knowingly or not-are state regulatory agencies that report a practice neglecting or advancing certain interests in a demand based system of health care ("regulatory capture")?

BENEFITS AND RISKS IN TREATMENT DECISIONS AT THE END OF LIFE: Who decides and how? The debate over data is ongoing. Ask readers to list merits and liabilities of safeguards and state what data is important. Different considerations help readers frame issues: are these matters of personal coping, social choices, public resources, of regulatory administration and oversite?

IDENTIFYING PRACTICAL RESOURCES: Our online web resources list many tools. Ask readers to cite specific categories and examples from essays, cases from the newspaper or personal stories that identify positive and negative accounts. Invite readers to consider how terms are understood by different audiences. Both essays and the Introduction and Conclusion describe different key terms that are helpful to discuss these examples, cases, and stories. These offer many resources for families and colleagues.

Testing on the Issue

3) Web Questions

1. Based on evidence from Oregon's Death with Dignity Act (DWDA), Ronald Lindsay, a lawyer and CEO of the Center for Inquiry argues that

A. Oregon has become a suicide mill
B. DWDA has no abuses

C. participants in DWDA have a better death than those who die from natural causes in Oregon
D. Risks are outweighed by benefits and palliative care has improved

2. President Emeritus, and Cofounder of the Hastings Research Center, Daniel Callahan argues that

A. state regulations in Oregon don't collect or disclose needed data
B. the shift from suicide to "physician aid in dying" correctly puts patients in control
C. control of pain helpfully medicalizes autonomy by controlling death events
D. advocates of physician assisted suicide have proven it can be safely regulated

4) Multiple-Choice Questions

3. How are we to evaluate the evidence from Oregon? What do Lindsay and Callahan agree is *NOT* one of the criteria that should be used as criteria to measure information?

A. the impact on palliative care for dying
B. slippery slopes (wider abuses)
C. that most use comes from those in hospice
D. impacts on vulnerable (e.g. coercion of incompetent dying)

4. Which *substantive constraint* that restricts eligibility is cause for the most concern among Oregon's DWDA (is open to "abuse")—according to critics, but *not* Lindsay?

A. Residency
B. Competency-decisional-capacity
C. Co-morbid depression
D. Terminal status

5. According to critics—but not Lindsay, which *procedural restriction* of eligibility is cause for the most concern among Oregon's DWDA (is open to "abuse")?

A. Two physician consultations and waiting periods
B. Third party co-signors and voluntary family notification
C. Options to rescind
D. Counselling Referrals

6. According to Lindsay, we should change the category from "physician assisted suicide" to "physician-assisted dying/death". Which is NOT one of the reasons?

A. The patient must be terminally ill and maintains control of the process throughout, and decides, when, if at all, the patient will ingest the medication
B. The rate of legal physician-assisted dying in Oregon may be significantly less that the rate of *illegal* physician-assisted dying in other states.
C. More than one-third of patients who obtain a prescription under the ODWDA never take the drug.
D. Some patients ingest the drug months after it is prescribed.

7. Do those who favor assistance in dying have less respect for life? What does Lindsay rather than Callahan argue?

A. *Conceptually*, a New York State Task Force argues that legalization for terminally ill will expand to nonterminal patients.
B. Legalizing self-termination for terminally ill *causes* less respect for life among dying patients, caregivers, physicians and/or citizens.
C. *Logically* one cannot meaningfully lack respect for one's own life when one is not—or only barely aware(e.g. dying unconsciously, or imminently)?
D. Oregonians who respect rights of a terminally ill don't show *less respect* for lives of dying patients, caregivers, physicians and/or citizens.

8. Lindsay and Callahan *agree* the *most widely reported* of the recurrent charges of abuse in legally safeguarded, lethal self-administration for terminally ill with decisional capacity is:

A. inadequate safeguards in compliance and reporting
B. false autonomy and misplaced compassion;
C. wrongful killing and bad medicine,
D. slippery slopes and risks to vulnerable populations

9. Different judgments are made about benefits and risks of DWDA, because, in contrast to Callahan, Lindsay thinks data shows

A. specific laws are bad
B. reporting systems and documented patterns of practices are inadequate
C. analyses and reports about usage of laws have design flaws
D. data is sufficient because "population based"

10. With respect to specific examples of individual cases of abuse, Lindsay and Callahan *agree*

A. whether and how data is gathered and analyzed shapes perceptions of public good
B. skepticism about the statute's safeguards and data is appropriate
C. there is a clear metric to balance benefits of legalization from risks due to possible abuse
D. there is no baseline for evauating risks of abuse from patients who forego life-sustaining treatment

5) Essay Questions

1. DISCUSS: Examine stories of people who died us Oregon or Washington's laws. Compare stories of dying patients who chose not to end their lives. What were key differences in ; causes of death; key reasons for choosing death mentioned by Lindsay and Hedberg (X)? Among those who choose to self-terminate, why do so many have cancer and remain cognitively intact? Is there a difference between "concluding" and "ending" life?

2. DISCUSS: In a world where media drives expectations about medicine, what do we hear about end of life causes of death that shape our expectations? "News reports about cancer frequently discuss aggressive treatment and survival but rarely discuss treatment failure, adverse events, end-of-life care, or death. These portrayals of cancer care in the news media may give patients an inappropriately optimistic view of cancer treatment, outcomes, and prognosis." "Cancer and the media: how does the news report on treatment and outcomes?" Fishman J, Ten Have T, Casarett D., *Arch Intern Med*. 2010 Mar 22;170(6):515-8. Epub 2010 Mar 16.

4. IDENTIFY: Can patients, family members and specialized professionals be conflicted end of life decisions? How should conflicts be resolved?

5. CLASS EXERCISE: List and debate merits and liabilities of different safeguards in Washington State's Initiative: List choices as alternatives:

Washington State Inititiave 1000 (Death With Dignity Act)
http://www.doh.wa.gov/dwda/
http://apps.leg.wa.gov/RCW/default.aspx?cite=70.245

"This measure would permit terminally ill, competent, adult Washington residents medically predicted to die within six months to request and self-administer lethal medication prescribed by a physician. The measure requires two oral and one written request, two physicians to diagnose the patient and determine the patient is competent, a waiting period, and physician verification of an informed patient decision. Physicians, patients and others acting in good faith compliance would have criminal and civil immunity."

SAFEGUARDS	**+ Merits**	**-Liabilities**
Adult (18 or over) resident	No temporaries	Relocations?
Mentally competent, verified by two physicians (or referred to a mental health evaluation)	Screens incompetent self-referrals	Competency flexible for pro-assisted death Health Care Professionals
Two physicians verify terminal illness with less than six months to live	Screens nonterminal	"Terminal, medically predicted" assessments routinely inaccurate
Two physicians verify voluntary noncoercive requests	Screens coercion	Physicians and HCP's tacitly recom AD
Patient informed of palliative/hospice option	Warranties "Informed" consent	"informed" inadequately given palliative/hospice care
15 day waiting period btwn oral/written request	Warranties no rush to decide ("durability")	Is interim palliative/hospice care intensified? ("endurance")
48 hour waiting period btwn wrttn reqst and wrtng prscrptn	Warranties no rush to decide ("durability")	Is interim palliative/hospice care intensified? ("endurance")
Nonrelative/nonemployed co-signer of written request	Warranties noncoercive decision	How are uninvolved relevant?
Family discussion encouraged not	Encourages without requiring	Neglects family basis of end of life

required due to confidentiality	kinship communication	decision making
Patient option to rescind at any time	Protect patient change of mind	Thrust of process discourages change

1 (D), 2 (A), 3 (C), 4 (C), 5 (D), 6 (B), 7 (D), 8 (A), 9 (D) 10 (A)

Instructor's Resource Guide:

ISSUE 12. Is Palliative Sedation Actually Euthanasia in Disguise?

YES

Battin, M.P. (2008). Terminal sedation: Pulling the sheet over our eyes, *Hastings Center Report* 38, no. 5: 27-30

NO

National Ethics Committee, Veterans Health Administration (2007). Ethics of Palliative Sedation as a Therapy of Last Resort, *Am J Hosp Palliat Care,* 23 (6), 483-491

1) Synopsis: YES: University of Utah philosopher and ethicist Margaret Battin argues that clinical practices of palliative sedation and euthanasia are conceptually alike yet permit one to distinguish clinical mistreatment (misuses) from ethical maltreatment (abuses) in palliative sedation. The implausible effort to draw a completely bright line (based on physician intentions) between continuous terminal sedation and euthanasia makes the practice of terminal sedation both more dangerous and more dishonest than it should be and makes what can be a decent and humane practice morally problematic. But there are many last resort options, including patient-elected cessation of eating and drinking and direct physician-assisted dying. Terminal sedation is not an acceptable "compromise" if it overshadows these alternatives. There is no reason that terminal sedation should not be recognized as an option, but there are excellent reasons why it should not be seen as the only option or even the best option for easing a bad death. NO: The National Ethics Committee of the Veteran's Health Administration outlines guidelines for palliative sedation as an approach of last resort for dying patients with intolerable symptoms. Palliative sedation is defined in terms of patient symptoms, final stages and informed consent. Safeguards are detailed that include expert consultation, spiritual care, patient and surrogate participation, palliative expertise, monitoring the patient and sedation, documentation and procedures for resolving stakeholder conflicts. Based on the physician's intention to relieve suffering and a proportion between sedation for unremitting suffering and the harm of rendering the patient unconscious, palliative sedation is not sedation toward death, physician assisted suicide or euthansia.

2) Discussing the Issue

Does palliative sedation conceal euthanasia—or is it an acceptable alternative to contested legal regulation of self-termination for terminally ill?

Ask readers to discuss several quotes:

> …*a night in which all cows are black* (Hegel, [1807], 94)
>
> ...*the fact of dusk does not mean there's no difference between night and day.* (attributed to Samuel Johnson)
>
> *"For patients suffering from severe pain, dyspnea [breathlessness], vomiting, or other intrusive symptoms that prove refractory [resistant] to treatment, there is a consensus that palliative sedation is an appropriate intervention of last resort." (National Ethics Committee, 2007).*

NAMING ISSUES*: Why explore palliative sedation? Why do some equate palliative sedation with "terminal sedation" and judge it to be such a* plausible solution*—whereas others reject the equation—as such an* unconvincing alternative resolution *to contested legal regulation of self-termination for terminally ill?*

Four different reasons *recur:* first world dying; new clinical practices of palliative sedation; "double effect" reasoning and common fallacies equating "palliation" with "sedation". Questions emerge: Can better pain management—if not "relief" improve dying? Can a "better" dying be an object of just societies? That is, can "palliated pain" make dying "good enough "—rather than simply be reasons for desisting overtreatment? This book and chapter explores "death as if dying mattered" as a "sustainable cultural performance" of memory and anticipation (Ricoeur)—instead of merely "procedurally relinquishing inappropriate interventions."

CULTURAL CONTEXTS*:* A lot of first world dying occurs in medicalized contexts that require decisions to manage end stage pain and desist overtreatment. Half of the world's population now lives in cities; some eighty percent of Americans live near an urban area. North America contains 4.5 percent of the world's population yet thirty percent of the world's hospitals—together with nursing and medical schools that educate many from around the world. Most persons want to die at home, yet eighty percent of deaths in hospitals occur from withheld or withdrawn treatment and under-treated pain. Why have "hospitals" become "hostile" to effective pain relief instead of hospices for good dying (Risse, 1999)? The story is complex (Dartmouth Atlas of Health Care).

PALLIATION-SEDATION*: The general public, patients, family caregivers, doctors, nurses, lawyers and policy-makers all use categories "palliation," "sedation," and "termination." Emerging clinical practices show "more ICU usage" is not "better dying" (Dartmouth Atlas). Actual experiences of end stage dying in the first world differ among four leading causes; heart disease, stroke, cancers and COPD (CDC). These give rise to different experiences of pain—and evolving treatment practices (Ch VI). Hence different types of relief or "palliation" have emerged with clinical practice guidelines (Olsen, Swetz and Mueller, 2010). Among four traditions of Jews, Christians, Muslims and Common Law, some consensus about palliative sedation is real (who decides, how and why, Sulmasy, Mackler, Sachedina and Buckley in Buckley, 2012).*

COMMON FALLACIES: Ask readers to identify common incorrect forms of reasoning about palliation, sedation (and termination) called fallacies which assume they are synonomous (fallacies of definition that are too broad or too narrow) or simple causes and effects (i.e.causal fallacies of complex cause, at http://onegoodmove.org/fallacy/toc.htm).

DOUBLE EFFECT: For example, according to Battin and VHA, what are legitimate uses of lethally risk pain relief for my dying mother? Older traditions of "double-effect" reasoning are revised and disclose a surprising consensus between Battin and VHA about important elements. Palliation is not *intrinsically wrong* (e.g. morphine used for pain) and may *foresee a bad effect* while intending a good effect; (morphine relieves pain, depresses respiratory drive and potentially hastens death). A *bad effect doesn't cause a good effect* (that is, respiratory depression and death don't cause—or *substitute* for adequate pain relief). Palliative sedation is *a means proportionate to an end* in which an expected good outweighs a particular bad. (Morphine is proportionate and suitable to pain, pain is significant and death is imminent). *Disagreements emerge* over whether/how unconsciousness harms—and what patients/physicians may (not) intend or use (Battin).

With respect to my dying mother, do double-effect conditions “justify” actions in principle, or serve as exceptionless axioms for avoiding what is blameworthy or simply give general maxims for prudent action (Beauchamp, 2001; Jonsen and Toulmin, 1988; Keenan, 1993)? In fact, “double effect” is useful not because it identifies idealized, atemporal, geometric axioms (“Only intend to palliate!” “Never sedate in a way that terminates…”). Rather “double effect” guides comparative (“taxonomic”) work among concrete, temporal and presumptive reasoning (“What balance of palliation and sedation best comforts my mother?” Sulmasy in Buckley, 2012).

Why use “double effect” for my mother’s dying? Merits have liabilities: its short-hand formula (“foreseen but unintended outcomes”) conceals categories contested in utilitarian and more than utilitarian formulations (Keenan, 1993). Half a millenia of historical meanings now arc across a dozen cultural traditions not limited to western or “Christian” in practical as well as theoretical disciplines. No “essential” meaning is historically supportable (Stanford Encyclopedia of Philosophy). Disreputable uses, misuses and abuses of different formulations co-exist with revisions, qualifications and re-negotiated meanings (Jonsen and Toulmin, 1988; Catechism, #2263, #2279, 5th edition, Catholic Ethical and Religious Directives #61). Some clinicians argue double effect usage must be very nuanced at the bedside (Sulmasy, 1999; 2002); other clinicians find usage with pain relief very rare (Rob George and Claud Regnard, “Commentary: Lethal Opiods or Dangerous Prescribers?” Palliative Medicine 2007 21: 77-80).

BENEFITS AND RISKS IN TREATMENT DECISIONS AT THE END OF LIFE:

Who decides and how? Debates concern key categories and assume medical literacy (palliative sedation, terminal sedation, guidelines called algorithms). Ask readers to list merits and liabilities of each. Online web resources offer many tools. Ask readers to cite specific categories and examples from essays, cases from the newspaper or personal stories that identify positive and negative accounts. What are practical ways of recognizing and coping with good, bad or inadequate stories, treatments among patients, family and professionals? Both essays and the Introduction and Conclusion describe different key terms that are helpful.

Testing on the Issue

3) Web Questions

1. What distinguishes palliative sedation from euthanasia? In 2007, the National Ethic Committee of the Veterans Health Administration (VHA) stated palliative sedation is *distinct* from euthanasia because palliative sedation

A. is a therapy of last resort
B. aims to relieve the patient’s suffering and not cause death by using a risky procedure that carries a proportionate benefit
C. can only be used by those willing to forgo life-sustaining treatment
D. appropriately treats those with existential suffering (affliction without physical symptoms)

2. University of Utah philosopher and ethicist Margaret Battin argues sedation unto death called *terminal sedation*

A. already has legal safeguards similar to assisted death
B. includes patient-elected cessation of eating and drinking

C. allows competent administration of correct dosages for physician assisted death
D. should be one but not the only nor perhaps the best among many last resort options

4) Multiple-Choice Questions

3. VHA and Battin agree that palliative sedation

A. is the best option for most who are dying
B. is simply another name for terminal sedation
C. relieves unrelievable symptoms called intractable, by sedating a person to unconsciousness until she dies
D. sedates a terminal patient towards death

4. Which question do Battin and VHA disagree about?

A. Is palliative sedation different from physician assisted suicide and euthanasia?
B. Is palliative sedation ever ethically appropriate for patients who are not imminently dying?
C. Should a willingness to forgo life-sustaining treatment be a condition for administering/receiving alliative sedation?
D. Is palliative sedation an ethically appropriate response to existential suffering?
E. May palliative Sedation be provided to patients who lack decision-making capacity?

5. *When* should palliative sedation be considered? Battin probably agrees with the VHA that a "Yes" to certain questions serves as a guideline (algorithm) to determine when a symptom is truly "refractory" or resistant to relief. Which is *not* one of them?

A. Are further interventions capable of providing relief?
B. Does the patient request terminal sedation?
C. Is the anticipated chronic or acute morbidity of the intervention tolerable to the patient?
D. Are the interventions likely to provide relief within a tolerable time frame?

6. As I am dying, is palliative sedation an appropriate response to my *existential suffering?* According to the VHA which question is NOT relevant?

A. Can we define and distinguish a psychiatric condition like depression from my existential suffering (affliction without a physical symptom)?
B. Despite my suffering, do I still have decisional capacity?
C. What kind of relief is appropriate to which kind of goal for the end of my life (perceived wellnness, disease)?
D. Is my existential "distress/anxiety" best "medicated"?

7. VHA and Battin agree, w*ho should decide* whether palliative sedation be provided to a dying person?

A. physicians, nurses and a health care team most competently judge a patient's true condition
B. spouse, partner and family-next of kin use a "best interests" standard
C. the patient based on informed consent or decisional capacity, or her valid proxy-surrogate
D. a court uses a substituted judgment standard of "what the patient wanted"

8. Does palliative sedation conceal euthanasia? VHA and Battin agree that "terminal sedation"

A. happens where life is intentionally taken against the sanctity of life
B. is *"disguised" in some practices* that are in fact euthanasia that risk being back-alley, un(der)regulated and under-reported.
C. should be *granted limited limited permissions* based on informed consent and be given limited permission based on rights-based voluntary autonomy or caregiver paternalism with due care.
D. *cannot and should not* be regulated practices.

9. VHA disagrees with Battin and argues that palliative sedation is not sedation toward death, physician assisted suicide or euthansia. Which is *not* one of their criteria?

A. Outcomes data shows benefits outweigh burdens.
B. Using palliative sedation is not intrinsically wrong.
C. A physician's intention to relieve suffering intends good but foresees bad.
D. A proportion exists between sedation for unremitting suffering and the harm of rendering the patient unconscious.

10. The VHA Ethics Committee recommend as policy that palliative sedation be available. Which is *not* one of the criteria?

A. as a therapy of last resort when pain and other symptoms are not lessened by interventions that are tolerable to the patient
B. for patients in the final stages of dying, with a DNR order and signed informed consent or valid surrogate permission
C. with safeguards such as ongoing consultations and monitored comfort care
D. in states where physician assisted death is legal

5) Essay Questions

1.DISCUSS: Examine stories of people who died from "palliative sedation" and "terminal sedation". What were key differences in how patients, family and health care professionals remember and described such deaths? Are such deaths described differently in advance and afterwards?

2.DISCUSS: In a world where media drives expectations about medicine, what do we hear about end of life sedation and palliation (Ch VI)? Public debate requires informed discussions—yet news sources can be unevenly informed. Mass media influence the interpretations of statistical findings. C. Seale, "How the mass media report social statistics: a case study concerning research on end-of-life decisions." Soc Sci Med 71 5 (2010) :861-868.

3. IDENTIFY: Based on debates about "Palliative Sedation," why is it important to distinguish *treatment* that is futile from *symptoms* that resist relief? Pick a specific case and use the following chart to distinguish three types of what a Presidential Commission calls "Futile Treatment".

FUTILITY ALGORITHM

TYPE	WHO DECIDES?	CRITERIA	MEANING
OBJECTIVE	Doctor-Health Care Team	Medical Effectiveness	Capacity of the procedure to alter the natural history of the disease
SUBJECTIVE	Patient (Valid Surrogate-proxies)	Benefit	Patient's assessment of the treatment's desired result
INTERSUBJECTIVE	Doctor (team) and Patient (family)	Cost	Costs, discomfort, pain, inconvenience "Quality of Life"

SOURCES: The President's Council on Bioethics, A Summary Of The Council's Debate On The Neurological Standard For Determining Death. Chapter Seven. Controversies in the Determination of Death: A White Paper by the President's Council on Bioethics. The President's Council on Bioethics. Washington, D.C., December 2008, page 91; Edmund Pellegrino, Decisions to withdraw life-sustaining treatment: A moral algorithm. Journal of the American Medical Association, 283(8), 1065-1067; Pellegrino, E. D. & Sulmasy, D. P. (2003). Medical ethics. In D. A. Warrell, T. M. Cox & J. D. Firth (Eds.), Oxford textbook of medicine. USA: Oxford University Press; Pellegrino, E. D. (2005). Futility in medical decisions: The word and the concept. HEC Forum, 17(4),308-318.

4. CLASS EXERCISE: When is a symptom truly refractory that palliative sedation can be used? Debate the guidelines (algorithm) offered (VHA).Pick a specific case and use the following chart to discuss it.

REFRACTORY TREATMENT ALGORITHM:

1. Are further interventions capable of providing further relief?
2. Is the anticipated acute or chronic morbidity of the intervention tolerable to the patient?
3. Are the interventions likely to provide relief within a tolerable time frame?

REFRACTORY TREATMENT ALGORITHM

TYPE	WHO DECIDES?	CRITERIA	MEANING
OBJECTIVE	Doctor-Health Care Team	Palliative Effectiveness	Capacity to provide further relief
SUBJECTIVE	Patient (Valid Surrogate-proxies)	Benefit/risk (anticipated acute/chronic morbidity)	Patient’s assessment of the intervention’s desired result as “tolerable”
INTERSUBJECTIVE	Doctor (team) and Patient (proxies, family)	Benefit/burden of relief measured over time	Costs, discomfort, pain, inconvenience thresh-holds of relief “over time”

SOURCE: National Ethics Committee, Veterans Health Administration (2007). Ethics of Palliative Sedation as a Therapy of Last Resort, *Am J Hosp Palliat Care,* 23 (6), 483-491

1 (B), 2 (D), 3 (C), 4 (A), 5 (B), 6 (B), 7 (C), 8 (B), 9 (A) 10 (D)

Instructor's Resource Guide:

ISSUE 13: Is Brain Death Dead Enough?

YES: Choi, EJ, Fredland,V., Zachodni,C., Lammers,J.E., Bledsoe, P. & Helft, P.R.(2008). Brain death revisited: the case for a national standard, *Journal of Law, Medicine & Ethics*, *36* (4), 824–836.

NO: Zeiler, K. (2009). Deadly pluralism? Why death-concept, death-definition, death-criterion and death-test pluralism should be allowed, even though it creates some problems. *Bioethics, 23 (8),* 450–459. doi:10.1111/j.1467-8519.2008.00669.x

1. Synopsis

Eun-Kyoung Choi and colleagues at the Charles Warren Fairbanks Center for Medical Ethics in Indianapolis review the current definitions and call for national standard for brain death that would eliminate uncertainty across hospitals, states, and jurisdictions.

Kristin Zeiler, a medical ethicist argues that the definitions of whole brain death as the irreversible cessation of "all" functions of the brain is limiting, because it doesn't embrace other biological possibilities of death. She discusses the need to link death definitions with operational criteria and the specific tests that can measure those criteria when someone has died.

2. Discussing the Issue

Defining when someone is truly dead is not as straightforward as it might seem. Many argue that persons could be considered dead if they no longer have capacity to think, reason, talk, manage daily activities and experience relationships (such as in a serious traumatic brain injury. Discussions with students should include the benefits and drawbacks of defining death in multiple different ways as proposed by Zeiler. Some of the discussion of definitions of death might include what it is to be a person. Is "personhood" defined only by thinking capacity? As a supplement to this class, the instructor should consider viewing the *Moment of Death*, a documentary produced by M. Manucci for the National Geographic Society. This video, discusses historical attempts at determining death, describes "near death" events and the complexity of issues for persons who met criteria for cardiac death that survived. The video actually demonstrates the examination criteria in determining death as discussed in the Shaner article. In addition, it provides support to Zeiler's commentary on death pluralism, that is, allowing for multiple definitions and views on defining death. It is an ideal supplement help students visualize the issues in the essays in this chapter. The video is especially good at helping students to understand that there are many gray areas in our understanding of the moment of death.

The Uniform Determination of Death Act is a landmark document that helped to shape how death is determined in this country. Instructors should consider retrieving this document (the reference is listed in the chapter) and posting it as supplemental material to the chapter. In addition, instructors may also want to retrieve the 1995 American Academy of Neurology (AAN) criteria, clinical examination requirements, and testing to be conducted to determine brain death. These criteria are demonstrated in the Moment of Death video, and include specific criteria for physical and neurological examination findings to determine brain death. (Quality Standards Subcommittee of AAN, 1995).

In the article for the yes position, David Shaner, a neurologist and Director of the Bioethics program of Kaiser Permanente of Southern California, reviews the policies and procedures of identifying brain death. He reviews the Council on Ethical Affairs of the California Medical Association (CEA) set of policies and procedures for determining neurological death. He emphasizes the need for consistency in using these procedures so that family members understand the certainty that brain death has occurred.
Others argue that careful and clear criteria must be met in order to define death.
In the article for the no position, Kristen Zeiler, a medical ethicist argues that the definitions of whole brain death as the irreversible cessation of "all" functions of the brain is limiting, because it doesn't embrace other biological possibilities of death. She argues for death definition, criteria and testing "pluralism". She discusses the need to consider more than one death definitions, operational criteria and specific testings to accommodate the religious and cultural beliefs that also define death.

Testing on the Issue

3. **Web Questions**

1. What is pluralism as discussed in this chapter?

a. Having numerous points of view on a single topic
b. Having more than one definition or criteria for death
c. Refers to the numerous different manners in which one can die
d. Refers to the numerous ways different states determine death

2. The determination of death has changed since the 1950's because:

a. We have access to more technology
b. Physicians are now required to attend seminars regarding appropriate death determination
c. The practice of organ transplantation has provided an incentive to determine death while organs are still viable
d. We have access to increased ICU availability

4) Multiple Choice Questions

3. An example *criteria* used to establish death might include:

a. unreceptivity, unresponsiveness, no movement or breathing, no brainstem reflexes
b. once death has been diagnosed, the provider shall discontinue support unless organ donation is planned
c. more liberally minded persons can have themselves declared dead if only brainstem function remains, centrists can adhere to the whole-brain death concept, and conservatives can opt for a cardiopulmonary definition
d. paging the on-call physician to do a general assessment of the patient

4. According to the chapter, death determination can be controversial because:

a. A patient's religious values always dictate death determination

b. Physicians feel like a failure when death is an outcome
c. There are numerous definitions, criteria, and tests to determine death
d. Families tend to express unreasonable hostility, loss of trust, and demands on the provider after a family member dies

5. The purpose of the Uniform Determination of Death Act of 1980 was:

a. to provide a comprehensive and detailed operational criteria for how to determine death
b. to provide general clinical guidelines for providers to determine death
c. to change the definition of death so that more organ transplants could be performed
d. to clearly define death

6. One of the first documents to define brain death was created by:

a. The Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death
b. The Uniform Determination of Death Act
c. The state of New Jersey
d. The state of California

7. According to “Really, most sincerely dead” what is the ideal way for a provider to communicate with a family whose loved one has died?

a. Encourage the social worker to visit the family first and break the news
b. Comprehensively explain the difference between death and brain dead to the family when discussing their loved one
c. Clearly state that the patient has died with directness, clarity, and veracity
d. Improvisation by the provider is required to individualize the experience for families

8. A patient diagnosed with “brain death” (total brain failure) may still be able to:

a. maintain some degree of blood pressure
b. recover completely from their illness
c. speak in short sentences
d. eat some foods and liquids

5)Essay Questions

9. Clearly identify which populations would be most likely to be affected by a broader definition of brain death. Specifically identify how a change in brain death definition might affect them and provide examples.

10. Zeiler (2009) supports death test pluralism. Using everyday language, explain what death test pluralism is and the pros and cons of pluralism as it pertains to a topic such as death.

Answers:

1.b 2.c 3.a 4.c 5.d 6.a 7.c 8.a

Instructor’s Resource Guide:

ISSUE 14. Is It Better to Die in Hospice than Hospitals?

YES
Prince-Paul, M. (2009). When hospice is the best option, *Oncology Nurse, 23* (4), 13-17.
NO
Crippen, D., Burrows, D. et al. (2010). Ethics roundtable: ‘Open-ended ICU care: Can we afford it?’ *Critical Care* 2010, **14**:222

1. Synopsis

Mary Jo Prince-Paul of the Francis Payne Bolton School of Nursing at Case Western discusses the hospice model of care and the criteria that need to be met to enroll in hospice. David Crippen a physician in the Department of Critical Care at the University of Pittsburgh Medical Center, presents a roundtable discussion with physicians around the world who have very different views about how to approach the care of a dying patient who is using a expensive intensive care resources at the end of life.

2. Discussing the issue

In this chapter we discuss the advantages and disadvantages of deaths at home with hospice and deaths in hospitals or ICUs. Readers should be aware that most Americans (60%) actually die in the hospital and 20% of these die in intensive care units (ICUs). This chapter also defines and discusses hospice care and the criteria required to qualify for hospice care. Readers should understand the goal of hospice (the provision of comfort care for dying patients in the last 6 months of life). Although originally designed as a care approach for cancer patients, patients can meet criteria for hospice if they have a 6 month life expectancy with other end stage diseases (congestive heart failure, COPD, Parkinson’s disease, dementia) (Rogers, 2009; Prince-Paul, 2009). Hospice care can occur in many different places, in the patient’s home (if they have a caregiver), in an assisted living or nursing home, or in a hospice facility.

The challenge for health care professionals is that it is difficult to predict when someone is close to dying or meets criteria for hospice if that patient has been in a sudden accident. Victims of sudden auto accidents can spend weeks in critical care units and sometimes unexpectedly recover. One of the essays gives an example of a young man with an infection of his brain who is critically ill and physicians are reluctant to make hospice referrals.

Readers should be aware of the marked regional differences in referrals to hospice. The Dartmouth Atlas of Health (2010) compared deaths in hospitals versus hospice in different regions of the country for Medicare recipients. More than half of Medicare recipients getting cancer treatment at Westchester Medical Center in Valhalla, N.Y. (57.3 percent) ended up dying in the hospital. This compares with only 18.7 percent of cancer patients who died in the hospital at Evanston Northwestern Healthcare in Evanston, Ill (Dartmouth Atlas of Health Care, 2010; Rau, 2010). The Dartmouth study implies that the difference in where a patient may die is linked to the physician prognosis and willingness to refer to hospice. One survey of oncologists reported that one in five oncology physician would wait to have a conversation about do-not-resuscitate (DNR) orders until a few days or few hours before the patient’s death. (Baile, Lentzi, Parker, et al, 2002, p 2189). Both families and physicians may be reluctant to give up on aggressive treatments. In either case, these families are more likely to have patients die in the hospital, surrounded by technology. It would be helpful to better understand why families and physicians in other areas of the country appear to be more amenable to hospice.

Critical care physicians are aware that the highly technical world of the ICU is not an ideal place to die. In 2008, the American Academy of Critical Care Medicine issued a consensus statement of recommendations for end of life care in the ICU (Truog, Campbell, Curtis, Haas, Luce, Rubenfeld, Rushton, & Kaufman, 2008). Their recommendations include: provide training on communication skills for physicians; initiate a family conference early in the ICU stay to discuss and establish goals, values and directives; conduct interdisciplinary team rounds so that families are not faced with different specialists giving different messages; refer dying patients to a palliative care team or provide an ethics consult when families are demanding futile care; and develop a supportive culture for staff and families of patients dying in the ICU (Truog, Campbell, Curtis, Haas, Luce, Rubenfeld, Rushton, & Kaufman, 2008).

Testing on the Issue

3)Web Questions

1. Which of the following statements is most accurate?

a. Persons are eligible for hospice at any time after being diagnosed with cancer.
b. Only persons with cancer can be eligible for hospice
c. Persons with any terminal disease, with a 6 month life expectancy are eligible for hospice.
d. Two physicians have to declare a person terminal before they can be referred to hospice.

2. Complete this statement with the most accurate ending. Hospice care:

a. is the provision of comfort care at the end of life for anyone who meets criteria of being terminally ill.
b. is an indication that the patient is giving up.
c. is only for elderly patients who need 24 hour around the clock care.
d. does not include care or support for the family members or caregivers.

4. **Multiple Choice Questions**

3. Which of the following is NOT a barrier for referrals to hospice end of life?

a. the patient's concern that hospice care will destroy their hope
b. the physician's sense that the patient still might respond to another therapy
c. the physician's clear understanding of the limited prognosis of the patient.
d. the health care teams' lack of understanding that hospice criteria can be met even if the patient does not have cancer

4. The key differences between the European intensive care doctors and the U.S doctors in the Crippen article were:

a. The European doctors were more likely than American doctors to provide very aggressive care
b. The European doctors were more likely than the American doctors to plan for referrals to palliative care for the patient.
c. The American doctors were more likely than the European doctors to refer to palliative care.

d. The American doctors were more likely than the European doctors to curtail expensive testing.

5. When a dying patient needs to have decisional capacity assessed, which health care provider can do this?

a. Only a psychiatrist
b. Any mental health provider
c. Social workers
d. Any primary care provider who knows the patient well.

6. The Dartmouth Study mentioned in the chapter introduction identifies that

a. Physicians in some areas of the country are more likely to refer to hospice
b. Areas of the country where there are more hospitals and specialists are less likely to keep patients in the hospital when they die.
c. Regional differences in the use of hospice are related to differences in patient conditions
d. There are no regional differences in the use of hospice.
Answers:

1.b 2.a 3.c 4.b 5.d 6. a.

5. ***Essay Questions***

7. If you were in a motor vehicle accident and had sustained injuries that were life threatening, would you want family members to take you out of the ICU home to die? Why or why not? What would be the barriers for doing this?
8. Consider the difficulties physicians face as they try to determine whether someone has 6 months to live or not (the criteria for hospice). What are the risks of them declaring a patient fit for hospice too soon?

Instructor's Resource Guide:

ISSUE 15. Should Eldercare at the End of Life Be Subsidized?

YES

National Bureau of Economic Research. Out-of-Pocket Health Care Expenditures at the End of Life, Retreived from http://www.nber.org/aginghealth/2010no2/w16170.html

NO

Chao,L. Pagan,J.A., Soldo, B.J.(2008)- End of Life medical treatment: Do survival chances and out-of-pocket costs matter? *Med Decis Making*. *28*(4): 511–523. doi:10.1177/0272989X07312713.

1)Synopsis

Samuel Marshall and Jonathan Skinner of the Department of Economics at Dartmouth College, and Kathleen McGarry of the Department of Economics at UCLA, discuss a study on the out of pocket costs for hospital and nursing home care at the end of life and how these can be a drain on households even though elders have some subsidized medical care through Medicare. Liao Chao, José Pagan of the University of Pennsylvania and Beth Soldo of the University of Texas Pan Am, identify that older adults were more likely to want expensive end of life treatments if they were subsidized by Medicare, but less likely to want treatments if survival chances were poor or their spouse would be impoverished by their care.

2)Discussing the issue:

Prior to the 1960s, 34% of the older adult population lived in poverty because of health care costs which were privately paid. It was difficult for persons over age 65 to get private health insurance coverage at that time (National Academy of Social Insurance, 2011). In 1965, Medicare was created as a national health insurance policy under the Social Security Act. While this insurance has helped to improve the health and longevity of older Americans, it has also created some problems. Since virtually everyone over the age of 65 has health insurance, tests and procedures that might not otherwise have been done in the past, are done today because these procedures produce revenue for doctors and hospitals. This chapter will discuss the advantages and disadvantages to providing subsidized health care for older adults at the end of life and examine the out of pocket costs that are still incurred by older Americans.

The cost of health care at the end of life accounts for a high proportion of total health care costs in the United States. The percentage of Medicare payments attributable to patients in their last year of life was 28.3% in 1978 and has remained about the same at 25.1% in 2006 (Donley & Danis, 2011). In order to really address the question of whether end of life care for older adults should be subsized, one might imagine what care for older adults would be like without any Medicare entitlement program. The thousands of Americans without health insurance can attest to the problems this would create. If there was no Medicare entitlement program, older adults or their family members would have to cover their own health related costs after retirement and at the end of life. Our society could easily slip back into the pre-Medicare situation of more than one third of older adults living below poverty because all of life savings are spent on health related costs.

Perhaps a better question is how can we reduce the costs of the existing subsidized care for older adults at the end of life? Several efforts have been made to reduce the costs of end of life care that are incurred by society. One study found that Medicare beneficiaries enrolled in a Medicare healthcare management organization (HMO) used 51% fewer hospital days in the last two years of life when compared with fee for service enrollees (Fonkych, O'Leary, Melnick, Keeler, 2008). Because HMOs have financial incentives to manage care, they make coordinated efforts to better communicate patient goals and eliminate unnecessary or undesired care. Patients who are seen as approaching the end of life are referred to skilled nursing facilities and hospice rather than continuing to incur higher hospital costs (Fonkych, O'Leary, Melnick, Keeler, 2008). Fee for service Medicare (that is Medicare that simply pays for each bill submitted) lacks incentives to manage these dollars. Sixteen different specialists can order multiple kinds of the same types of testing for end of life patients, and each of these are simply paid under fee for service Medicare. Since there are no incentives to manage or monitor spending at the end of life for these patients, costs increase as physicians and hospitals bill for each treatment.

Another approach to reducing costs to society is to reduce the aggressive and unnecessary treatments and tests at the end of life by having physicians include discussions of personal out of pocket costs with discussions of proposed treatment approaches (Donly & Denis, 2011; Bailey, 2011). Although discussing costs of care prior to making clinical decisions has been controversial, some argue that leaving costs out of the discussion, does not fully respect the patient's autonomy either (Bailey, 2011; Epstein, 2007). If a patient or their family must pay for a treatment they can't afford, then it seems unethical for a physician to leave costs out of the conversation. Although older adults have insurance, one study reported that terminally ill patients with moderate or high care needs are more likely to rate costs of their terminal illness and medical care as a moderate or great economic hardship on their family (Emanuel, Fairclough, 2000). In a study of patients with cancer, 19% had used up all or most of their personal savings, 21% were unable to pay for their basic necessities, and 9% had declared bankruptcy (Blendon, et al. 2006). Clinicians argue that if studies on intensive care for older patients could predict and determine which subsets of elderly patients have good outcomes from ICU, costs could be reduced. If groups of older adults least likely to benefit from aggressive care could be referred more appropriately to palliative care or hospice, federal funds used on intensive care units could be curtailed.

Currently one of the few successful approaches to reducing end of life costs is to ensure that patients have a clear sense of their prognosis and that patients have established advance directives for their care (see issue 2) (Pope, Arnold & Barnato, 2011). End of life care is less costly and more likely to reflect patient wishes when advance directives are in place (Silveira, Kim & Langa, 2010). Outcome based studies could help clinicians identify the appropriateness of admission to or continuation of ICU support for older adults. All intensive treatments for frail older adults should be revisited periodically and discussions should clearly include prognoses and cost implications. Older patients who do not respond well to treatments could be redirected to palliative care options. Changing eldercare to this focus could save money and suffering, while allocating resources towards those who would most benefit (Lantos & Meadow, 2011).

In the argument for the yes position, Marshall, Skinner and McGarry (2010) provide evidence that the out of pocket costs for hospital and nursing home care at the end of life can be a drain on households even though elders have some subsidized medical care through Medicare. Their argument supports subsidized care because elders are still incurring substantial costs that are not covered.

In the argument for the no position, Chao, Pagan and Soldo (2008) identify that older adults were more likely to want expensive end of life treatments if they were subsidized by Medicare, but less likely to want treatments if survival chances were poor or their spouse would be impoverished by their care. This data supports the need to discuss costs as part of the decision making process for end of life care choices. As the number of Medicare enrollees grows from 46 million in 2010 to 76 million in 2030, demographers warn that the amount of money spent on prolonging lives of old people may become unsustainable. Efforts could be made to change the fee for service model of health care, so that the financial incentives to hospitals and physician groups require them to step back and ask “what are we doing here?” and “are we being good stewards of the federal/societal dollars to provide appropriate care at the end of life?”. Clinicians need to have clear, honest and understandable discussions with patients about the prognosis of their condition. These discussions should include whether the treatments available will actually make any difference in the course of the patient’s end of life care. Patients make very different decisions about aggressiveness of health care when costs or impoverishment are added to the equation (Chao, Pagan and Soldo, 2008).

Testing on the Issue

3)Web Questions

1. According to Marshall, Skinner and McGarry (2010), out of pocket costs for elderly are
    e. Significant for end of life care even with Medicare as insurance
    f. Completely covered by Medicare
    g. Not a problem for the majority of older adults because of their wealth
    h. Only a problem if Medicare patients aren’t referred for hospice
2. Marshal Skinner and McGarry indicate that older patients incur the greatest costs at the end of life because
    e. Home health care and nursing home care don’t participate in hospice.
    f. Home health care and nursing home care for basic health changes must be paid out of pocket.
    g. Older persons tend to request expensive hospital treatments that are not covered by insurance.
    h. Hospice care is not covered by Medicare.

4)MULTIPLE CHOICE QUESTIONS

3. The National Bureau of Economic Research identified that largest category of out of pocket costs for older adults at the end of life costs was for:
    e. Hospice care
    f. Hospital care
    g. Nursing home care
    h. Home caregivers

4. Which of the following is most accurate according to the National Bureau of Economic Research:
    e. The weathiest households of older adults spent the lowest amount on end of life care
    f. The middle class households of older adults spent the highest amount on end of life care
    g. The lower class households spent the highest amount on end of life care
    h. The weathiest households of older adults spent the highest amount on end of life care

5. When patients are given information about survival chances and the costs of care at the end of life they are more likely to choose aggressive treatments if they are covered by insurance.
    c. True
    d. False

6. Which of the following best describes the key finding of the study by Li-Wei Chao on patient choices and end of life out of pocket costs
    e. Males were more likely to opt for expensive treatments if they had to be paid out of pocket
    f. Blacks were less likely to opt for treatments regardless of payor source and survival chances

g. White respondents were more likely to recommend opting out of treatment if it meant depleting savings.

h. Elderly married women were more likely to opt for treatment even if it meant depleting savings.

7. The authors of the two essays would be most likely to agree on which of the following statements:

a) Discussions of out of pocket costs should not influence choices for care at the end of life.

b) Out of pocket costs for older adults can significantly influence choices for care at the end of life

c). Older adults rarely incur significant out of pocket costs for end of life care.

d). Older adults are not given enough information on out of pocket expenses for end of life care.

5) ESSAY QUESTIONS:

8. Physicians are often taught that expenses should not be the deciding factor when recommending the proper treatment for a patient. If physicians are unaware of the costs of the treatments they recommend, it may be unlikely that they discuss costs with the patients they care for at the end of life. Discuss the pros and cons of fully disclosing costs of end of life care with older adults as they make decisions.

9. The study by Chao indicates that subjects were more likely to opt out of the end of life treatment if it meant impoverishing the subject's spouse. Should physicians of dying patients ask family members of the costs of care are depleting savings before proceeding with care choices? Why or why not?

1.(A) 2. (B) 3. (C) 4. (D) 5. (A) 6. (C) 7. (B)

ISSUE 16. Is Dying Improved By Belonging to a Religious Community Rather Than Simply Being a Spiritual Person?

YES

Pevey, C.F., Jones, T.J., Yarber, A. (2008) How religion comforts dying, *OMEGA*, 58(1) 41-59.

NO

Satterly, J. (2001) Guilt, Shame, and Religious and Spiritual Pain *Holist Nurs Pract* 15(2):30-39

1) Synopsis

In the article for the yes position, Carolyn Pevey, and her colleagues at Auburn University Montgomery, report findings of a qualitative study which identified several ways in which some Christian religions were linked to better coping with dying. Religion, when it comforted these dying people, did so by offering a relationship to the dying, by giving the hope of life after death, through identifications, and through the assurance of cosmic order. In the article for the No position, Lamont Satterly, Master of Divinity and Founder of the SEARCH foundation, raises the issue of religious pain in dying patients. Patients have unresolved issues of pain rooted in religious guilt and spiritual shame because of breaking moral codes. Religious pain is rooted in guilt leading toward punishment and experienced as fear. It is resourced through the positive teachings of the patient's religious legacy. Spiritual pain is rooted in shame leading a patient to abandon hope in God's love. It is resourced through bringing unconditional love to the patient's sense of self-hatred and inner criticism.

2) Discussing the Issue

NAMING ISSUES: Pevey examines how religion comforts and Satterly asks how religion discomforts spiritual well-being. Ask readers: what spiritual quests or religious practices improve or worsen dying? Is it prayer; trust in cosmic order where God is in control; accompanied friendship; guilt and shame; anger with God; hope in afterlife; belief in miraculous cure? Ask readers to use the following questions and reflect why *no* contemporary claims about religion(s) and dying are uncontested. Key assumptions rely on widely debated terms; viz., *When* is a person dying (imminently dying, those in end stage illnesses, terminally ill, expecting to die, those for whom treatments are ineffective, too burdensome or too costly called futile, issue 9)? What does *improvement* mean (religious belonging, spiritual well-being—as perceived by dying person or their intimates)? What is the best *metric* for *religious belonging* or *spiritual well-being* (self-described identity, prescribed beliefs, practices and rituals; ascribed traits)? Does a western category *religion* (or cosmic order) inaccurately bias answers by focusing upon beliefs (divine) or practices (rituals) that presuppose western *theistic models* for increasingly, geographically *diverse diaspora cultural* populations (Orthodox, Muslim, Latino/a, Asian)? In addition, do plural traditions that are global and frankly *nontheist or* atheist reframe many questions of theistic socialization into belief in an empathic relational partner as a Eurocentric cultural bias (Hinduism; Buddhism, Daoism, Bell, 1992, 1997; Killen, 2004; Keown, 2005; Pui Lon, 2007)?

Common incorrect forms of reasoning called fallacies assume all religions are essentially the same (*hasty generalizations*)or every religious tradition and spiritual belief is so absolutely unique to each person that there are no bases for comparisons (explanations have *limited scope* at http://onegoodmove.org/fallacy/toc.htm). In death and dying, what are different ways that religious belonging and spiritual well-being connect us to one another?

THREE DIFFERENT KINDS OF QUESTIONS: From Pevey and Satterly, ask readers to identify and name: At the end of life, how is spiritual well-being measured differently in stories, social functions and symbolic connections? Over decades, hundreds of scholarly research articles have interpreted and applied "spirituality" according to dozens of "assessment" criteria. These connect with longer traditions of religious and spiritual writings.

Three questions recur: existential meanings, social functions and symbolic interconnections. Ask readers to discuss each; viz., (1) Why is pancreatic cancer ending my life? For some the chief religious challenge of dying is *personal existential meaning*. Narrative interpretations of experience (phenomenology) yield coping attitudes and behaviors (e.g. avoiding punishment images or anger-blame to God). (With what stories do Pevey's patients identify? What does Satterly's elderly woman feel guilty?). For some, the main challenge of dying is a *surrounding culture* perceived as foreign (secular); viz., (2) Will heart surgery cure my doubts about God's love? Social practices of confessional belonging influence a willingness to seek support, use prayer and aggressive end of life treatments. (Why do Pevey's patient's feel supported? Why does Bill in Satterly's story feel unloved?). For some the chief religious challenge of dying in plural cultures is diversity—hence challenges become how our *dying connects us socially and naturally*. (3) How can my incurable cancer make a more just, sustainable and humane world? Different cultural and professional competencies re-interpret our embodied identities within larger social and natural frameworks with different kinds of structuralisms. (How is God in control for Pevey? Why does love reconcile all for Satterly?)

BENEFITS AND RISKS IN TREATMENT DECISIONS AT THE END OF LIFE: Diverse cultural and plural traditions challenge *general* claims about religion. Nor is religious belonging a rival to spiritual quests. Experiences of dying are also complex; they challenge end of life treatment decisions. Are these matters of personal coping, social choices, public resources, of regulatory administration and oversight?

IDENTIFYING PRACTICAL RESOURCES: Our online sources list web resources for end of life decisions. Ask readers to cite specific categories and examples from essays, cases from the newspaper or personal stories that identify positive and negative accounts. For example, what might family members giving hospice care learn from professionals? Invite readers to consider how terms are understood by different audiences. Both essays and the Introduction and Conclusion describe different key terms that are helpful to discuss these examples, cases, and stories. Which advice has stood the time of "best practices" regarding treatment decisions (see websites). These offer many resources for families and colleagues.

Testing on the Issue

3) Web Questions

1. Carolyn Pevey, and her colleagues at Auburn University Montgomery argues that religion comforts the dying. Which is NOT one of their reasons?

A. prayer is the best medicine
B. relationships with dying
C. hope in an afterlife
D. trust in cosmic order(control by a perceived other)

2. Lamont Satterly, Master of Divinity and Founder of the SEARCH foundation argues that

religious pain afflicts the spiritual well-being of dying persons because

A. even believers in heaven don't want to die to get there
B. religions teaching love for others cause people to hate themselves
C. unresolved issues of pain rooted in religious guilt and spirituality cause shame because of breaking moral codes
D. actual suffering creates anxiety that a good God neither rewards virtuous nor punishes wicked

4) Multiple-Choice Questions

3. Is religion medicine?

A. No data demonstrates religious believers die better
B. Some research shows some who practice religion experience more comfortable deaths
C. Most religious practitioners seek more aggressive end of life care yet experience worse deaths
D. Evidence demonstrates prayer improves a chance of miracles

4. For those who are dying, how would Pevey and Satterly measure "religion" differently than "spirituality"

A. shared texts, practices and beliefs ("belonging")
B. well-being told in stories
C. social functions of behavior and rituals
D. symbolic connections to one another and nature

5. Among dying who find comfort in religion, what do Pevey and Satterly *agree is not* one of the most comforting aspects?

A. trust that end of life wishes will be honored
B. social support while dying
C. trust that one will be well-remembered
D. hope in an afterlife

6. Why would Pevey and Satterly *agree* it is important to determine which religious figures in real life or stories are those with whom a dying person most identifies?

A. Examples explain *how* a dying person understands her relationship to a divine other.
B. Examples show *why* some suffer unnecessarily ("my cross")
C. Examples demonstrate *how* particular beliefs (resurrection) socially re-inforce personal confidence ("optimism of the redeemed")
D. Examples explain to caregiving intimates *why* end of life choices seem unreasonable

7. According to Pevey, why do some who are dying find that relinquishing control to a higher power is comforting?

A. Worrying won't help
B. Increased religiosity reduces depression
C. God is in control and will take care of one

D. A belief in an afterlife comforts dying

8. According to Satterly, when a dying person experiences guilt and religious pain rooted in a memory of breaking moral codes from her own religious tradition, it is best to

A. unmask all religious fears as mere projected fantasies of infantile needs
B. convert the dying person to a more humane tradition
C. help the person forgive herself before she dies
D. enable a person to experience forgiveness by connecting with ("resourcing") someone from her own tradition

9.According to Satterly, when a dying person experiences spiritual pain grounded in the emotion of shame, it is best to

A.let the person be unmasked as unloveable so she will accept help
B. work with others to bring unconditional love to a person to believe she is lovable, despite harsh inner criticism
C. invite her to consider a different tradition of self-love to shift from self-hate
D. help the person learn to love herself before she dies

10. Pevey and Satterly both *agree* that

A. positive images of God improve comfort for dying
B. end of life conversions are effective
C. guilt from pain and shame of a "disappointed" God are a greater burden than having no faith (atheism)
D. only trained professionals can help dying

5) Essay Questions

1. DISCUSS: Examine stories of dying patients whose religious images while dying were influential. Some retrieve how positive symbols help good dying by trust in divine mercy and friendship (Fitzgerald, 2006; Reinis, 2007). Others deliberately choose not to use (traditional) religious images (Steve Jobs, Christopher Hitchens).

2. DISCUSS: In a world of media, how is dying and death as an event and process interpeted in religious categories (images of the divine, prayer; trust in cosmic order where God is in control; prayer; accompanied friendship; guilt and shame; anger with God; hope in afterlife; belief in miraculous cure). Which are important; stories, social functions, sumbolic interconnections? Discuss what difference it might make if religious symbols for dying change from judgment (cross) to redemption (resurrection)?

3.IDENTIFY: How is reconciliation described in religious terms when cure is at an end but healing is still possible?

4. CLASS EXERCISE: COMPARE: What does *your own* religious tradition claim about a good dying and death? Chaplaincy websites are listed in our internet resources. It is important to compare what *contemporary* religious and historic traditions claim with what is *historically* known about diverse cultures and plural traditions. For the range of contemporary statements, see our internet resources, especially the lists at the Duke Institute on Care at the End of Life (http://divinity.duke.edu/initiatives-centers/iceol). For more general accounts online see "Death and Dying in World Religions" at the Wabash Center, (www.wabashcenter.wabash.edu/resources/guide-headings.aspx). Five good cultural comparisons include the anthology by Lucy Bregman, *Death and Dying in World Religions* (Kendall Hunt, 2009), *Religion, Death, and Dying*: Volume 3: Bereavement and Death Rituals (Praeger, 2010); Lynne Ann DeSpelder and Albert Lee Strickland, *The Last Dance: Encountering Death and Dying* (McGraw-Hill, 2011); the brief short summary by Kenneth Kraemer, *The Sacred Art of Dying: How World Religions Understand Death* (Paulist Press, 1988), and Courtney S. Campbell, "Religious Ethics and Active Euthanasia in a Pluralistic Society." *Kennedy Institute of Ethics Journal* 2.3 (1992): 253–277. Campbell sets out a descriptive typology of religious perspectives on legalized euthanasia—political advocacy,individual conscience, silence, embedded opposition, and formal public opposition—and then examines the normative basis for these perspectives through the themes of sovereignty, stewardship, and the self.

5. CLASS EXERCISE: How do different religions transform dying? They do this by understanding dying as differently transformative. Ask readers to compare two stories of "religious dying" using the chart below:

How Is Dying Transformative? What Religions Culturally Say

CATEGORY	QUOTE	MEANING	USA%	WHO USA	MEASUREMENT PROBLEMS
Autogenesis	"I am Master of my fate"	Naturalistic-universal force	6-10 %	Buddhisms, Daoisms, Ethical Culture, Secular Humanism, Unitarian Universalism	What is "Fate"; "Destiny"?
Synergism	"I am in tune with the Infinite"	Holism about force-filled nature	28%	New Age Spiritualisms	What is "Health" "Holism," in relation to "Universe"?
Empathy	"God experiences with me"	Theisms	70% +	Judaisms, Islam, Christianities including Catholicisms, Othodoxies,	What is "empirical/ nonempirical"?

				Protestantisms	
Monergism	“God worked a miracle in me”	Divine/faith healing	1-7 %	Christianities/ nondenominational	Verification unattributable

Adapting Martin Marty "Religion and Healing: The Four Expectations" from Religion and Healing in America, edited by Linda L. Barnes and Susan S. Seredin, Oxford, 2005, 487-504.

1 (A), 2 (C), 3 (B), 4 (A), 5 (D), 6 (A), 7 (C), 8 (D), 9 (B) 10 (A)

Instructor's Resource Guide:

ISSUE 17. Is Dying Made Better by Culturally Competent End-of-Life Care?

YES

Searight, H,R, & Gafford J. (2005). Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians. *American Family Physician*; 71, (3), 515-22.

NO

Barnato, A., Anthony, D. L, Skinner,J. Gallagher, P.M, Fisher, E. (2010). Racial and ethnic preferences for end of life treatment. *J Gen Intern Med 24*(6):695–701.

1)Synopsis

Professor H. Russell Searight, of Lake Superior State University, and Jennifer Gafford, a psychologist write about the cultural differences of patients that must be considered when approaching end of life decision making and how these approaches can improve care. Amber Barnato, a physician at the Center for Health Research at the University of Pittsburgh, describes a study of end of life care preferences which found some cultural/racial groups prefer life sustaining treatments that make their care at the end of life more likely to be in the hospital with aggressive treatments.

2)Discussing the issue

Cultural beliefs, values and rituals influence choices throughout one's lifetime. Healthcare choices are also influenced by cultural beliefs and values. Readers should understand that the cultural background of dying patients strongly influences the choices that they make at the end of life (Johnson, Kuchibhatla, & Tulsky, 2008). Researchers have demonstrated that end-of-life preferences vary significantly between different races or ethnicities (Duffy, Jackson, Schim, Ronis, & Fowler, 2006). For example, researchers have found that blacks and Hispanics are reluctant to use hospice, are less likely to complete advance directives, and are less likely to want life-sustaining treatment withdrawn, even if it is futile (Duffy, Jackson, Schim, Ronis, & Fowler, 2006).

Race and ethnicity predict end-of-life decisions even when researchers adjusted data for socioeconomic and educational status. For example, given equal educational levels, black physicians remained more likely than their non-Hispanic white counterparts to choose aggressive treatment options (Curlin, Nwodim, Vance, Chin, & Lantos, 2008). Physicians' perspectives on end of life appear to be linked to ethnicity, geographic region, experience caring for the dying, and the religious characteristics. Physicians from minority ethnicities were more likely to be opposed to physician assisted suicide, terminal sedation and withdrawal of life support. Catholic physicians were more likely than Protestant physicians to be opposed to withdrawal of artificial life support. This research suggests that deep rooted cultural and religious beliefs and values influence physicians as well as patients in the choices that they make for end of life care (Curlin, Nwodim, Vance, Chin, & Lantos, 2008).

One researcher conducted a series of focus groups to examine cultural beliefs about end of life care. Research subjects included Arab Muslim, Arab Christian, Hispanic, and Black men and women, and compared interview findings from all ethnicities (Duffy, Jackson, Schim, Ronis, & Fowler, 2006). These researchers found that some end of life care wishes were important to all groups, including: wanting to be kept comfortable at the end of life; having good physician communication about diagnosis, prognosis and treatment; having responsibilities taken care of; being offered hope and optimism; and having spiritual beliefs honored. Her findings indicated that most subjects also identified having love and compassion, being cared for, expressing feelings, fixing relationships, being able to say good-bye, being given choices, making plans, not being in pain, and being "ready to go" as very important (Duffy, Jackson, Schim, Ronis, & Fowler, 2006).

Several studies have particularly noted racial disparities in aggressiveness of care at the end of life. This is thought to be linked to fact that African Americans have lower rates of advance directives and are less likely to choose hospice as compared with whites. However Hanchate and colleagues (2008) dispute this, suggesting choosing hospice would do little to reduce the costs of end of life care for minorities, especially if the choice was made after all other avenues for were exhausted. The 3 minority groups in their study died of similar causes when compared with white patients, but Black Medicare decedents (especially those living in high cost urban areas) were significantly more likely to receive resuscitation, mechanical ventilation, and gastrostomy for artificial feedings than are white decedents living in the same area. They also noted that Hispanics were even more likely than blacks to receive ICU care, mechanical ventilation, dialysis, and cardiac catheterization. These researchers speculated that if nonwhites received timely, effective care throughout their lives may find it easier to reject futile care at the end of life (Hanchate, et al, 2008).

Other researchers suggest preferences for life-sustaining therapies make be linked to African American spirituality or beliefs about death and dying, or could be linked to a general mistrust of the healthcare system which offered years of unequal care access (Johnson, et al, 2008; Hanchate, et al). For end of life care, this distrust unfortunately can result families of dying patients demanding everything possible for their loved one at the end of life. Dying in a high tech environment with numerous uncomfortable procedures may help the family to feel as though they have done "everything", but may not be the most comforting or comfortable environment for the patient.

Education on culturally competent approaches to care conversations are now required in the education of health care professionals. Efforts need to be made to ensure that cultural views are respected and that full disclosure of the patient's prognosis are discussed in a way that family members understand what the treatment options will provide. they are demanding for care. Not all cultures value autonomy (that is, patient self determination) in the way that the American culture values this ideal. Health care professionals must be able to listen to the concerns and issues of other cultures, seek understanding of other points of view and offer careful guidance as they approach end of life discussions. Involving community or spiritual leaders to participate in these conversations can be useful for many cultural groups.

Others suggest that choices for aggressive care at the end of life are linked to poor health literacy, not understanding the full implication of the outcome of care, or not completely understanding that the aggressive care will be futile (Volandes, et al, 2008). Physicians and researchers have raised concerns about the need to continue to offer aggressive care and give everything to the demanding families of minority patients who are dying, even when that care is known to be futile. In some states (Texas) the law now allows that if two physicians agree on the prognosis of a patient and agree a treatment is futile, they can withdraw the treatment, even against the family wishes. If our health care providers must provide very aggressive care to be "culturally competent", then health care costs at the end of life will remain high.

One way of supporting cultural preferences in end of life care is to understand the importance of including family members, community members or religious leaders to support patients and families in their decisions. In one study, white families who discussed placing a dying person on life support wanted to do so to sustain them temporarily until other family members could be assembled; African American families in the same study requested life support to sustain life at all costs and hope for a miracle (Shrank, et al, 2005). Understanding the need for respectful communication regarding the patient's condition and establishing trust with African American families may improve decision making at the end of life. Gerdner and colleagues (2007) provide a rich insight into the views on dying and rituals related to death and burial for the Hmong population. She notes that in the Hmong community, clan leaders play a large role in decisions that are made for community members who are at the end of life.

In the article for the yes position, Searight and Gafford (2005) identify the cultural differences of patients that must be considered when approaching end of life decision making. They offer guidance for working with translators, guides to cross cultural conversations, and ideas for how to present bad news to patient families who are facing critical end of life decisions.

Barnato and colleagues (2010) provide an opposing view. They describe a study of end of life care preferences which found some cultural/racial groups prefer life sustaining treatments that make their care at the end of life more likely to be in the hospital with very aggressive treatments. This study indicates that always following cultural views would mean that minority patients would be more likely to die uncomfortable deaths tethered to machines in an intensive care unit.

Testing on the Issue

3)Web Questions

1. Considering the essays in this chapter and identify which one of the following statements that both of the essay writers would likely agree to be accurate:

a. Persons of a minority cultures will always want aggressive care at the end of life

b. A better understanding of cultural experiences may improve end of life care.

c. There aren't very many differences in end of life preferences based on culture

d. Cultural experiences influence how families approach funerals but not end of life care requests.

2. According to research studies, which of the following was **NOT** given as a possible explanation for aggressive care requests at the end of life by Hispanic and black populations?

a. The lower health literacy of minority cultural groups limits understanding of the treatment benefits and burdens that physicians are describing to them.

b. Fear of dying in minority groups is more common.

c. Deep rooted cultural and religious background of the minority patients influence end of life decisions.

d. Longstanding discriminatory health care practices may influence the decision of patients to request more aggressive care at the end of life.

4) Multiple Choice questions

3. The State of Texas law allows physicians to restrict futile treatments even if patients demand them, as long as a second physician confirms that the patient is terminal and the treatment will not offer any benefit. For dying patients of minority cultures, this practice is ***unlikely*** to be viewed as

a. A way of gaining access to hospice care

b. A paternalistic and discriminatory approach to end of life care.

c. A refusal of the medical staff to believe in miracles

d. A reluctance by physicians to work toward consensus agreement for the requested aggressive care.

4. Cultural groups do have some common approaches to end of life care requests (Duffy, et al, 2006). Which of these is ***not*** one of the commonalities that she described?

a. Wanting to be kept comfortable at the end of life.

b. Wanting religious practices and rituals respected

c. Strong preference to die at home with no technology.

d. Wanting good physician communication about diagnosis, prognosis and treatment options.

5. When physicians need to use a translator to communicate the "bad news" that a patient is dying, the most acceptable approach is:

a. To have a family member do the translating.

b. To have the translator change or "soften" the language in the interpretation.

c. To have the physician look at the translator during the entire discussion.

d. To ask for a trained translator to provide a word for word translation.

6. According to the article by Searight (2005), which of the following is true:

a. Some cultures view discussions of serious illness and death as disrespectful and impolite

b.Some cultural groups believe a patient should never been told of a terminal illness because the simple telling of this will cause the patient to die sooner

c. All cultural groups prefer to be dealt with honestly and told their diagnosis and outlook when they are dying.

d. A and B

7. The reason that physicians in the American health care system want to give full information about a terminal illness to a patient is because

a. The U.S. system of medical ethics emphasizes autonomy, which requires the patient to be in charge of the decisions for their care regardless of their cultural background.

b. The U.S. system of medical ethics emphasizes paternalism, which requires the physician to make all the decisions for care

c. The U.S. system of medical ethics emphasizes beneficience, which requires the physician to do the best thing for the patient.

d. The U.S. system of medical ethics emphasizes filial piety, which requires the patient to discuss all end of life decisions with their family.

8. Based on the essays, which of the following statements is true:

a. The cultural and religious background of the physician does not influence the treatment options they offer patients at the end of life

b. White physicians of northern European descent are more likely to offer very aggressive end of life care

c. Black physicians are significantly more likely than white colleagues to recommend aggressive treatment when a patient is terminal

d. Care at the end of life is guided by specific protocols which require physicians to make the same recommendations for end of life care regardless of culture.

5) Essay questions:

9. Asa White is an 85 year old black male who marched in Civil Rights marches in Alabama in the 1950s and 1960s. He has refused to sign an advance directives form, and verbally indicates he wants to be fully resuscitated, even though he has late stage kidney disease. You know CPR efforts are likely to be futile in this case. Describe the social and cultural forces that might influence his end of life decisions.

10. Mrs Kagawa is a 75 year old Japanese woman who is suffering from terminal cancer. Her son does not want her to know the diagnosis or be told that she is dying. Discuss the approach that the physician might take in this case, based on the essay by Searight.

Instructor's Resource Guide:

ISSUE 18. Do Funeral Rituals Help Grief?

YES
Kastenbaum, R. (2004). Why funerals? *Generations;* Summer 2004; 28, 2; 5-10.
NO
Kohler, N. (2011). We've been misled about how to grieve, *MacLean's magazine*, February 21.

1. Synopsis:

Robert Kastenbaum, Professor Emeritus of Gerontology and Communications at University of Arizona at Tempe, discusses the historic and current reasons why the rituals of funerals are important to those who mourn. Nicholas Kohler, a writer/journalist with MacLean's, a national news magazine in Canada discusses inadequacies in Kübler-Ross's five stages of grieving as protective bereavement, and relates newer research by George Bonanno that indicates how individuals have unique grieving processes that include elements of constructive resilience.

2. Discussing the issue

Following death of a loved one, family members are faced with dozens of decisions: whether to have a funeral or memorial service, where to locate this service, what rituals or practices to follow related to cultural or religious background, how to manage the financial and legal aspects of closing out an estate of the person who died, and how to manage their own grieving for the loss of the deceased in the midst of all of these decisions (Quillam, 2008). These decisions can be overwhelming if the deceased person was a child, young adult, or young mother or father, and can be very difficult when a frail elderly spouse is handling the affairs. In this chapter we discuss funeral and mourning practices and whether funeral rituals help families with grieving or create additional problems for persons who are in mourning.

Instructors are encouraged to use the websites listed in the book to guide the readers about rituals of various cultural group, religious groups and regions of the world. American cultural rituals often include embalming of the body, allowing the body to be open for viewing at a funeral home or place of worship, a memorial or religious service, and a ceremony of lowering the casket to the gravesite for burial. These rituals allow bereaved individuals to celebrate the life of the person who died, mourn his or her death, as well as receive the support of others. The benefit of having a funeral is not only that it allows a public expression of grief but also allows others to provide support and comfort to survivors (Hayslip, Booher, Scoles, Guarnaccia, 2007). Some cultural approaches to grieving include loud wailing or sing-sing type wailing and weeping as a part of the early mourning and grieving practice. The Hmong population has a period of active mourning, viewing stroking the body of the dead person and wailing loudly (Gerdner, et al, 2007). This wailing practice as part of mourning is found in other cultures as well: Jewish Yemenite, for example (Juliana & Claassens, 2010), the Highlands of Papua, New Guinea (Glaskin, 2001), and in Iranian funeral customs, Serbian, and Bangledesh grieving practices (Wilce, 2009). Indigenous non-Muslim Africans can take up to 2 weeks to bury the body of the deceased, making expensive and elaborate arrangements for the burial while the family gathers (Muga, 2009).

One challenge facing survivors of disaster victims is that of not being able to claim a body, as in the 9-11 trade center towers collapse (Kastenbaum, 2004). This robs family members of parts of the ritual that are so important for closure. Other disasters have interrupted grieving rituals as well, such as the inability to provide the usual New Orleans jazz funeral rituals for those that died in Hurricane Katrina. The closure and flooding of the funeral homes and the scattering of survivors interrupted the usual approaches to the burial of the dead (Dass-Brailsford, 2010). Burial rituals that are interrupted by disaster prevent the living from moving ahead with their lives because they unable to conclude their role in allowing the deceased to find peace (Kastenbaum, 2004).

Although funerals may allow families and friends place closure on a person's life, families are particularly vulnerable to be taken advantage of as they grieve. Quillam (2008) writes that the death of a loved one can be disorienting to family members. They can be vulnerable to emotionally laden and expensive decisions when they might otherwise be careful about making costly funeral plans or settling an estate. She identifies that most family members will be left with bills to pay, taxes to file and estate settlement decisions for which they have no experience and are unlikely to ever do again. With grief clouding these decisions, it is easy for executors of estates to make poor decisions or less than optimal choices (Quillam, 2008). In his article on Kenyan funerals, Muga (2009) discusses the case of a man who came to take out a loan for his aunt's funeral whose expenses were high because they needed to make arrangements for her to be buried in her ancestral village. The man returned a few months later to take out another loan for the funeral of his own mother, again to transport her back to her ancestral home. These loans were likely to become a huge financial burden to this man, but he could not refuse the obligations of his tribal culture (Muga, 2009).

Some of the first work on grieving, was written in the 1960s when the hospice movement was beginning. In 1969, Dr Elizabeth Kübler-Ross' introduced five stages of grief. These include: Denial stage - trying to avoid the inevitable; Anger stage - frustrated outpouring of bottled-up emotion; Bargaining stage - seeking in vain for a way out; Depression stage - final realization of the inevitable; Acceptance stage - finally finding the way forward. She wrote that grieving had to be experience in a staged and systematic way. Many health care professionals were taught these stages and believed that these transitions must be met for persons to move forward, or they would get "stuck" in the grieving process (Kübler-Ross, 1969).

Instructors are encouraged to access the articles that discuss the research of George Bonanno (2010), who has examined many mourning rituals and experiences. He looked at what happens when people experience the death of a child or of a parent, and found that people experience many emotions, not just anger and denial, but also joy and relief, allow them to deal with losses. He argues that grieving goes beyond a feeling of deep sadness. Grieving may involve quietly, internally managing the loss of someone close, or can also involve positive experiences, discussions of good memories, humor and joy. His research finds that mourning is not a predictable set of stages, but rather a very individualized and sophisticated process (Bonanno, 2010).

In the article for the yes position, Kastenbaum (2004) discusses the historic and current reasons why the rituals of funerals are important to those who mourn. He examines the reasons that we have funerals today and how these rituals have changed over time for different groups of people. He reinforces the value of funerals, even for the religiously unaffiliated as an important ritual of passage. In the opposing view, Kohler (2010) discusses inadequacies in Kübler-Ross's five stages of grieving as protective bereavement, and relates newer research by George Bonanno that indicates how individuals have unique grieving processes that include elements of constructive resilience. He argues that people grieve in a variety of ways, with or without rituals.

Funeral rituals generally end with the funeral and burial of the dead. Hunter (2007-2008) acknowledges that these riturals are helpful in providing immediate structure for the bereaved following death. However, grieving extends well beyond the funeral time frame. Rituals that would be most helpful to families would consider the long-term emotional needs and the need for a construction of new meaning of life after loss, as the person experiences grief (Hunter (2007-2008). While many recognize the value of private, religious, or other public rituals for mourners, there is newer evidence that people are able to grieve successfully in a variety of different ways (Bonnano, 2010; Koningsberg, 2011).

The frequent discussions and rehashing of a traumatic death with bereavement counselors may not be healthy in moving people on toward a new future as once previously thought. Hunter (2007-2008) suggests that the funeral industry provide some guidance to help the bereaved construct a “ritual of remembrance and new meaning”. Also, the notion that grieving should be done within a few weeks or months of a loved one’s death is unrealistic (Moules, 2010-2011). Many researchers have found that family members or persons who have lost a spouse or a child generally require at least two years to work through a reconstruction processes of making sense of the loss. Bereaved persons need time to find reasons for the loss, and need to understand the benefits of the presence of the deceased in their lives. Bereaved persons need to create a new identity that no longer includes the presence of the person who died, while still embracing the memory of the life that was lost (Hunter, 2007-2008).

Learning Outcomes

After reading this issue, you should be able to:

- Gain an understanding of whether and how death rituals help survivors cope with death.
- Describe the difference between the five stages of grieving and the new views on how people grieve and mourn the loss of loved ones
- Understand the importance of grieving as an important emotional response to the loss of a loved one.
- Identify and debate the benefit or burden of religious affiliation for those coping with death of a loved one.

Testing on the Issue

3. Web Questions

1.Considering the essays in this chapter and identify which one of the following statements that both of the essay writers would likely agree to be accurate:

a. Death rituals are similar across all cultural groups

b. A better understanding of grieving and death rituals may help health care professionals better address the needs of grieving families.

c. Deep intensive counseling which reviews the dying process of the patient is very helpful to those who grieve

d. Cultural norms dictate grieving, so everyone from a specific culture grieves in the same way.

2. In the Kohler article, the author identifies the work of George Bonnano which suggests that grieving

a. Occurs in fixed stages.

b. Varies widely and is unique to each individual.

c. Follows a specific time pattern.

d. Occurs more rapidly if indepth psychotherapy occurs.

4. Multiple Choice questions

3. The research work by Bonnano (2010) shows that grief

a. Can include joyful and positive memories of the loved one

b. Creates depression in anyone suffering a loss.

c. Would rarely include humor or good memories

d. Provokes anger and disgust in most people.

4. Which of the following cultural groups does ***not*** including loud weeping and wailing as a part of the mourning ritual?

a. Hmong

b. Indigenous persons from the Highlands of Papua, New Guinea

c. Indigenous persons from Peru.

d. Jewish Yemenite.

5. Kastenbaum (2004) compares mourning rituals of ancient cultures with current day practices and finds three commonalities. These are:

a. Persons from both time frames would want to feel that the "loved one" is all right, even though dead.

b. Persons from both time frames do not want to sever ties completely with the loved one who has died.

c. Persons from both time frames would want to show love and respect of the one who has died.

d. Persons from both time frames have had the ritual of burying the body in the ground.

6. Kastenbaum (2004), suggest that the September 11, 2001 disaster in NYC demonstrated that funerals are both for the living and the dead. He explains that this was the case because

a. Family members required a great deal of counseling in order to hold a funeral.

b. Funerals for the victims of the disaster were overly publicized for the family members involved.

c. Family members felt they could not go on with their lives until a body was recovered and a funeral could occur, but many bodies were not recovered.

d. A and C

7. Kastenbaum's essay identifies three reasons why funerals might be devalued today. Which of the following is not one of those reasons:

a. Funerals have become too commercialized for most persons.

b. Rapid sociological and technological changes have reduced the intergenerational consensus on the value of funerals

c. More persons are unaffiliated with religious communities and wish to avoid the religious trappings of funerals.

d. Many people have outlived their support systems and lack affiliation with persons who would find benefit in a funeral.

8. Based on the essays, which of the following statements is true:

a. Funerals are an outdated custom that will likely be abolished in the future.

b. Funerals are the only time that most people mourn the loss of a loved one.

c. Funerals are a ritual for both the living to remember and mourn and the dead to achieve respect in the passage from this life.

d. Funerals have not changed much over the course of centuries.

5) Essay questions:

9. Your aunt complains that her sister "still talks very fondly about and gets teary-eyed" over their little sister who died 55 years ago. Is this a normal part of grieving? Why or why not?

10. A elderly friend of yours dies with specific instructions for "NO FUNERAL". Her husband

elects to have a funeral service anyway and seeks comfort in his choir singing at the funeral. Use the essays to support or refute this man's decision.

1. (B) 2. (B) 3. (A) 4. (C) 5. (D) 6. (C) 7. (A) 8. (C)