PainWeek

ADVANCED EDUCATION

CERTIFICATION SERIES

Psychosocial, Cultural, and Spiritual Aspects of Care

Jaime Goldberg, MSW, LCSW

Titles and Affiliations

Jaime Goldberg, MSW, LCSW
PhD Candidate, University of Wisconsin-Madison, Sandra Rosenbaum School of Social Work
Instructor, Online Master of Science and Graduate Certificate Program in Palliative Care
University of Maryland School of Pharmacy

Disclosures

- Nothing to disclose

Pretest

1. Spiritual distress can influence the experience of physical pain.
   A. True
   B. False

   The correct answer is TRUE. Psychosocial, emotional, and spiritual pain can all present as physical pain. We will talk about this concept of “total pain” in later in the course.

2. Practitioners should not share serious news with patients and families to avoid taking away their hope.
   A. True
   B. False

   The correct answer is FALSE. As we will discuss later in the course, hope belongs to the person who is experiencing it and cannot be taken away by others. Sharing information with patients and families in a person centered, culturally appropriate manner can help with decision-making that is aligned with a patient’s goals, values, and preferences.

Pretest (continued)

3. Grief is only experienced after a person has died.
   A. True
   B. False

   The correct answer is FALSE. Grief is the emotional response to any loss. Grief is experienced by both patients and families along the trajectory of illness and after death. Examples of grief include loss of health, functional status, and roles/identity (eg, no longer able to work because of illness).

4. Psychosocial, cultural, and spiritual aspects of care are only the concern of social workers and chaplains.
   A. True
   B. False

   The correct answer is FALSE. Social workers and chaplains may be the psychosocial and spiritual "experts" on a palliative care team, but these domains are important for all palliative care practitioners to be familiar with as a generalist.

Learning Objectives

1. Define psychosocial, spiritual, and cultural domains of care
2. Recognize how psychological, emotional, cultural, spiritual/existential, historical, and social factors impact a patient and family's illness/dying experience
3. Review the concept of total pain and the individual differences in the experience of pain and suffering
4. Discuss concepts of hope, grief, and meaning related to illness and end of life
5. Summarize common psychosocial interventions in serious illness and at the end of life
6. Recognize the importance of caring for the caregiver

"Professionally, I understand in a deeper way that death is not a medical event. It is a central life cycle event that we will all successfully complete, no matter how much medical care we get or don't get, or how healthfully we live or don't live our lives.

Death is a process to be lived not a problem to be solved."
Stu Farber, MD

Farber S. Living Every Minute. *J Pain Symp Manag*. 2015;49(4):796-800. doi:10.1016/j.jpainsymman.2015.02.002.

Domains of Palliative Care

- Structure and process of care
- Physical aspects of care
- Psychological aspects of care
- Social aspects of care
- Spiritual aspects of care
- Cultural aspects of care
- Care of the imminently dying
- Ethical and legal aspects of care

From: National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*, 4th Edition. www.nationalcoalitionhpc.org/ncp/.

Psychological Aspects of Care

- Thoughts and feelings about illness, treatment, care
- Affect – outward expression of emotions
- Coping with
  - Emotions – sadness, fear, anger, regret
  - Functional status changes
  - Changes in identity/roles
  - Symptoms

How Do I Respond?

Active listening

Empathy

Humility & curiosity

Self-awareness

Silence

“Tell me more…”

Refer patients and families to available programs and resources based on assessed need for services

Anxiety & Depression

- Unrelieved symptoms such as pain or dyspnea may create or worsen anxiety and depression
- Psychological, social, and spiritual distress are equally important contributing factors
- Depression is often difficult to diagnose given the changes of the disease process which may mimic signs and symptoms of depression (eg, loss of appetite, energy)
- Synergy of pharmacologic + nonpharmacologic interventions

- Screening tools
  - Edmonton Symptom Assessment Scale
  - Memorial Symptom Assessment Scale
  - Hospital Anxiety and Depression Scale

Test Yourself!

1. According to the National Consensus Project for Quality Palliative Care, which one of the following is NOT a domain of palliative care?
   A. Social aspects of care
   B. Physical aspects of care
   C. Familial aspects of care
   D. Cultural aspects of care

   The correct answer is C. While the National Consensus Project for Quality Palliative Care embraces a “patient and family as unit of care” approach, caring for the family/caregivers is not a distinct domain.

Test Yourself!

2. Which of the following is TRUE regarding management of anxiety at end of life?
   A. Anxiety is rarely a medication side effect
   B. Pain should not be considered as a contributing factor for anxiety
   C. Pharmacologic management of anxiety is sufficient
   D. Spiritual distress can cause or exacerbate anxiety

   The correct answer is D. In fact, psychological, social, emotional, spiritual/existential distress can cause or exacerbate anxiety at the end of life

   A. This answer is incorrect. Anxiety is often a side effect of medication
   B. This answer is incorrect. Pain and other symptoms such as dyspnea should be considered when screening/assessing for anxiety at the end of life
   C. This answer is incorrect. Pharmacologic and non-pharmacologic interventions, such as mindfulness, cognitive behavioral therapy, integrative techniques can be effective interventions. It is important for teams to work together to implement complementary interventions

Social Aspects of Care

- Personal history
- Illness experience
- Social support network
- Caregiver needs
- Financial barriers
- Access to care
  (eg, transportation, medications)

- Referral to specialists for further assessment and intervention

Social Determinants of Health

Education

Economic stability

Neighborhood/ environment

Healthcare

Social/community context

Source: Healthy People 2030, U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. health.gov/healthypeople/objectives-and-data/social-determinants-health.

Patient Dignity Question

What do I need to know about you as a person to give you the best care possible?

www.dignityincare.ca/en/toolkit.html

Test Yourself!

1. All of the following are examples of social determinants of health EXCEPT
   A. Access to quality education
   B. Food security
   C. Genetic health conditions
   D. Financial stability

   The correct answer is C. A, B, and D are all examples of *social* aspects of life that can influence health. Genetic health conditions are a *biological* factor.

Test Yourself!

2. While meeting with a patient, she begins to cry as she tells you how difficult it is to cope with her serious illness. Which of the following would be NOT be a supportive response?
   A. Leaning in to the patient to show that you are listening attentively
   B. Providing reassurance by telling the patient that everything will be ok
   C. Saying “I can only imagine how difficult this is for you…”
   D. Remaining silent to give the patient time/space to continue to express their feelings

   The correct answer is B. Conveying empathy through our words and actions and giving the patient the time and space to share their feelings uninterrupted are our goals in this scenario. Platitudes may help us to “feel better” but they are not particularly helpful for the patient in that moment.

Spiritual Aspects of Care

"Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices."

Puchalski et al. *J Palliat Med*. 2014;17(6): 1-15.

Spirituality and Religion

Spirituality	Religion
Where do I find meaning/purpose?	Can give form to spirituality
How do I make sense of the world?	Belief systems
Connection – self, others, nature, transcendent	Community, rituals, practices, sacred texts

FICA Spiritual Screening Tool©

Faith, Belief, Meaning

- Is there any particular faith tradition or belief system in which you were raised?

Importance/Influence

- Which of your current beliefs/ideologies are most valuable to you right now?

Community

- Who is important to you?

Address/Action

- How can we (members of the healthcare team) best address these issues in our care?

Puchalski, Romer. *J Palliat Med*. 2000;3:129-137.

Test Yourself!

1. Which of the following is FALSE?
   A. Spirituality encompasses meaning-making and connection
   B. Spirituality and religion are synonymous
   C. Spirituality is a vital component of palliative care
   D. Spirituality is expressed through beliefs and values

The correct answer is B. Choices A, C, and D are all true. As noted in the earlier slide, "Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices." Religion can give form to spirituality, but the words/concepts are not the same.

Test Yourself!

2. With regard to the spiritual screening tool, what does the acronym FICA© stand for?

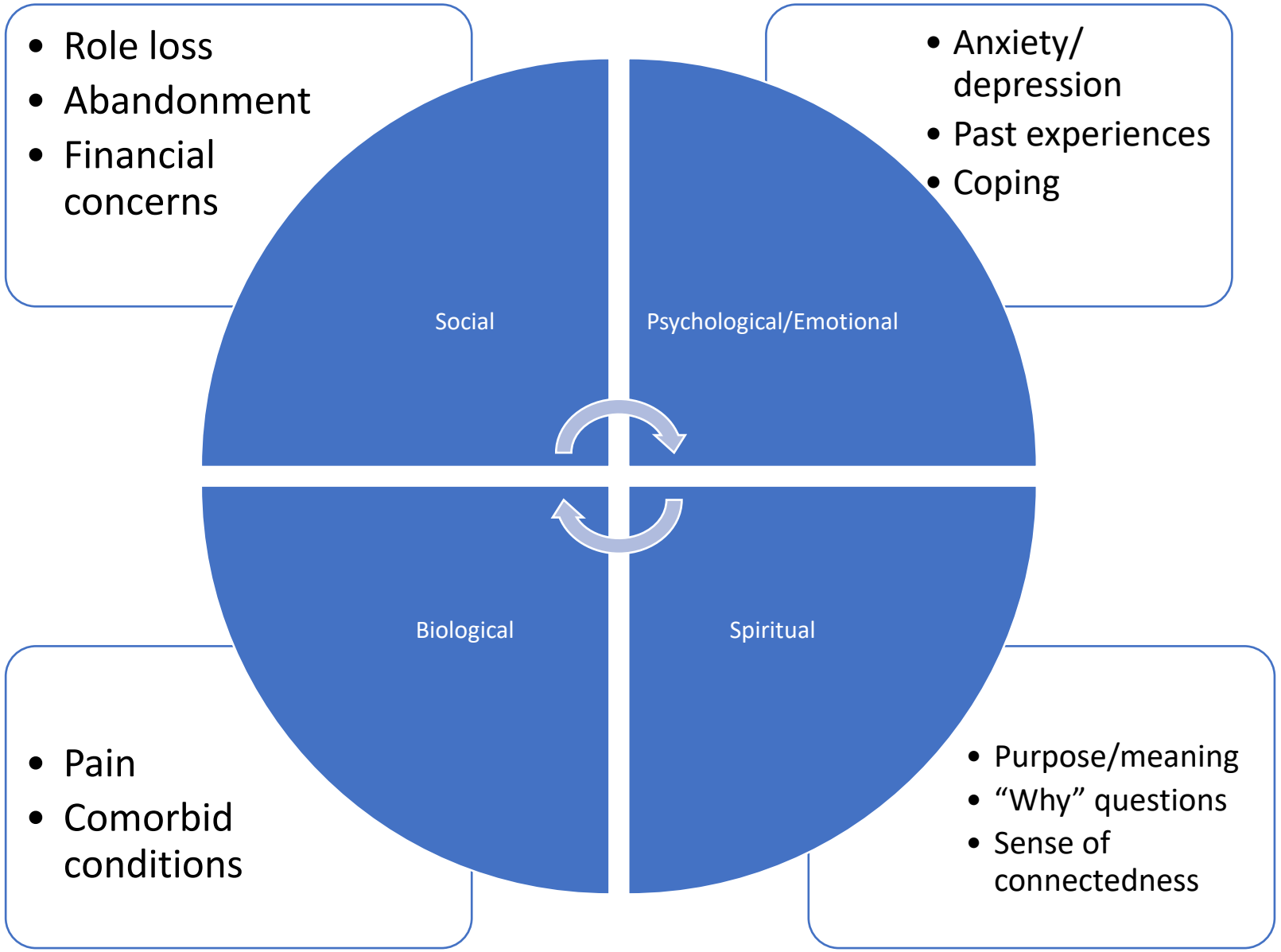
A. Family, Importance, Care, Ask questions
B. Faith, Importance, Comfort, Affirm
C. Family, Influence, Cancer, Ask questions
D. Faith, Importance, Community, Address

The correct answer is D. FICA stands for faith/beliefs/meaning; importance/influence; community; address/action

Cultural Aspects of Care

- Cultural humility
  - Approach others with humility and curiosity
  - Patients/families are experts in themselves
  - We don’t have all the answers
- Every encounter is a cross-cultural encounter
- Heightened self-awareness
  - Countertransference
- Health literacy and language barriers

Total Pain


• Role loss
• Abandonment
• Financial concerns
• Anxiety/ depression
• Past experiences
• Coping
Social
Psychological/Emotional
Biological
Spiritual
• Pain
• Comorbid conditions
• Purpose/meaning
• “Why” questions
• Sense of connectedness

Total Pain (continued)

Influenced by…

- Culture
- Spiritual beliefs
- Substance use history
- Trauma history

Suffering

Test Yourself!

1. Total pain often responds best to medication alone.
    1. True
    2. False

    The correct answer is FALSE. Total pain often does not respond to medication, even with dose escalation. Psychosocial and spiritual interventions are often the most effective when addressing total pain

2. Cultural humility means all of the following EXCEPT
    1. Recognizing that we cannot “fix” every situation
    2. Memorizing all belief systems and rituals of many cultures
    3. Approaching patients with curiosity about their lived experience
    4. Being familiar with our own bias and triggers

    The correct answer is B. A, C, and D are all part of practicing with cultural humility. These principles underscore the importance of approaching patients (and families) as whole people who are experts in their own lives and valuing what they have to share. While it can be helpful to be familiar with belief systems and rituals of many cultures, we need to be careful not to assume that a particular patient practices in a certain way. Instead, we need to explore with each individual. This is where the Patient Dignity Question can be helpful.

Hope and Meaning in Serious Illness

"[Hope is] an essential experience of the human condition. It functions as a way of **feeling**, a way of **behaving**, and a way of **relating to oneself and one's world**."

Farran, Herth, Popovich. *Hope and Hopelessness: Critical Clinical Constructs*. Thousand Oaks, CA: Sage Publications; 1995.

Hope and Meaning in Serious Illness

Fluid and dynamic

Present even in absence of desired outcome

“But I don’t want to take away their hope…”

Hoping for a miracle

Consider responding to “unrealistic hope” with emotional responses rather than information

Trauma-Informed Care

- History of traumatic experiences
- Trauma during or from healthcare
- Assess trauma narrative
  - Early development – attachment, personality
  - Adverse experiences
  - Understanding illness trajectory and interactions with healthcare system

Trauma-Informed Care (continued)

- May manifest as/result in
  - Reduced social supports
  - Challenges in communication with and trust of healthcare providers
  - Complications in the process of life review
  - Increased emotional distress
  - Exacerbation of pain symptoms
  - Decreased overall well-being

For more information on Trauma-Informed Care Guidelines:
Substance Abuse and Mental Health Services Administration. SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. HHS Publication No. (SMA) 14-4884. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014. ncsacw.samhsa.gov/userfiles/files/SAMHSA_Trauma.pdf.

Psychosocial Interventions

Brief Interventions

- Crisis management
- More frequent, shorter visits

Narrative Therapies

- Dignity-based therapy (Chochinov)
- Legacy building
- Life review
- Story telling
- Journal writing
- Hope-based counseling

Grief and Bereavement Counseling

Psychosocial Interventions (continued)

Cognitive Behavioral Therapy

- Education
- Pain/symptom journal
- Cognitive techniques
  - Reframing
  - Thought stopping
  - Problem solving
  - Coping skills training
- Mindfulness techniques
- Relaxation
- Guided imagery

Integrative Therapy

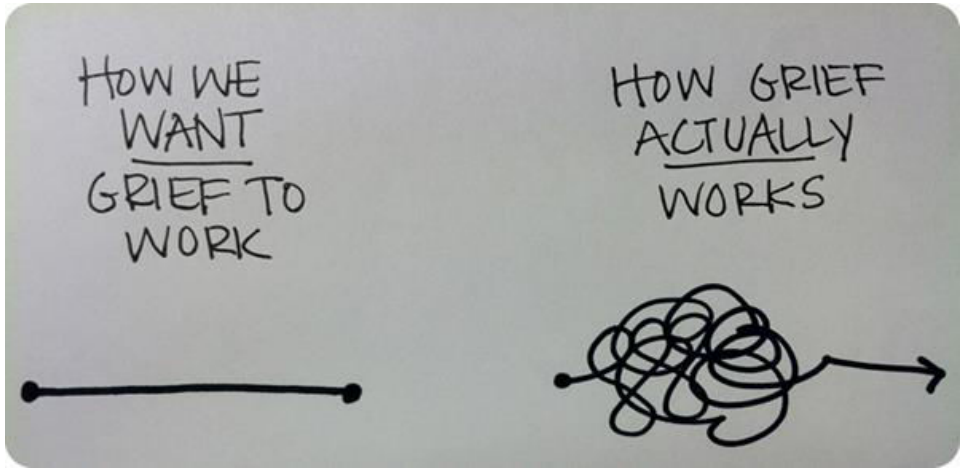
- Calming environment
- Art and music therapy
- Pet therapy
- Aroma therapy
- Touch-based techniques

Being Present at the End of Life

- Work as a team
- Create the best setting possible
- Be present
- Listen
- Observe for signs of distress in patient/family
- Try to meet family needs
- Encourage self-care
- Gently educate as needed
- Frequent, short visits

Grief and Bereavement

- Common grief reactions
  - Physical
  - Cognitive
  - Emotional
  - Social
  - Behavioral
  - Spiritual/existential
- Each person grieves differently
- Cultural and religious norms vary
- Individual and group support options



Caring for the Caregivers

“You can’t wash the tears from someone’s face without getting your hands wet.”

Menu of Misconceptions

- I will “fix” this.
- I am responsible for outcomes.
- If I care enough, everything will be alright.
- The sufferer will appreciate everything I do.
- I will have enough resources (time, money, material, skills, training) to make this better.
- Significant people in my life will support and approve my absence from our relationship while I invest in this.
- I know what I’m getting into.
- I can do this alone.
- If I’m [spiritual, grounded, enthusiastic, dedicated…] enough, I can deal with the stress of working with people who are suffering.

Adapted from Rev. Samuel Wood’s presentation
Compassion Fatigue: Caring for the Caregiver

Caring for the Caregivers

- Compassion fatigue/ empathic strain
- Compassion satisfaction
- Systemic challenges
- ProQoL
  - www.proqol.org/

Personalized Self-Care Plan

- What is my plan for self-care in each of the following areas (some activities may overlap in areas)?
  - Emotional
  - Cognitive
  - Physical
  - Social
  - Spiritual/meaning/purpose

Test Yourself!

1. A person's experience of illness can be influenced by
   A. Past trauma
   B. Interactions with the healthcare system
   C. How much support they have from family and friends
   D. All of the above

   The correct answer is all of the above. A person's illness experience can be influenced by many factors, including past trauma, which could be triggered/exacerbated because of an illness. Navigating the healthcare system can be complex; interactions with practitioners and staff can impact feelings of trust and coping ability. Practical and emotional support from family and friends can also influence how a patient experiences their illness.

Test Yourself!

2. A patient has received factual information from the medical team about a new cancer diagnosis. When you visit with them the next day, they say, “Are you sure I have cancer?” Which of the following would be the **most empathic** first response?
   A. “Yes, let’s review the scans again.”
   B. “I think you are in denial.”
   C. “It sounds like this information is overwhelming.”
   D. “Let me ask the team that spoke to you yesterday to come back.”

The correct answer is C. The patient and family may need information repeated and/or may need to meet with the team that shared this serious news with them again. But, **first** we need to address the **emotions** behind the patient’s with an empathic response. The patient is experiencing a typical and expected reaction to hearing difficult news. Labeling them as “in denial” does not build rapport/trust with them and could shut down the conversation.

Key Takeaways

- We need to pay attention to the whole person, including their psychosocial, cultural, and spiritual needs
- Patients and families have so much rich information to share about their own lived experience
- We need to ask, listen, and respond empathically
- We can’t have all the answers. We can’t “fix” every situation
- We need to work on recognizing our own biases, triggers, and tendencies and put them to the side to create space for the patient’s needs
- With the intensity of this work, we need to remember to care for ourselves and each other

Resources

Textbooks

- Katz RS, Johnson TA, eds. *When Professionals Weep: Emotional and Countertransference Responses in Palliative and End of Life Care*. 2nd ed. New York, NY: Routledge; 2016.
- Puchalski C, Ferrell B. *Making Healthcare Whole*. West Conshocken, PA: Templeton Press; 2010.
- Breitbart WS, Alici Y. *Psychosocial palliative care.* New York, NY: Oxford University Press; 2014.

Articles

- National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th Edition. Available from: https://www.nationalcoalitionhpc.org/ncp/ [free pdf download]
- Silk, S., and Goldman. How not to say the wrong thing. Los Angeles Times April 7, 2013.
- Back, A.L., Bauer-Wu, S.M., Rushton, C.H., & Halifax, J. (2009). Compassionate Silence in the Patient–Clinician Encounter: A Contemplative Approach. *Journal of Palliative Medicine, 12*(12), 1113-1117.

Videos

- Mass General Hospital. (2010). Early Palliative Care: Improving Quality of Life.
- Palliative Care Research Institute. (2014). Dignity Therapy: Michele.
- DeLong, L. (May 7, 2014). Changing the face of death. TED Talk, College of the Canyons.
- Kalanithi, L. (November 2016). What makes life worth living in the face of death. TEDMED.
- Life Before Death. (2012). Total Pain and Mental Health. (4:18 minutes)

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