VCU Palliative Care ECHO*

November 14, 2019

Existential and Spiritual Assessment

*ECHO: Extension of Community Healthcare Outcomes

Continuing Medical Education

November 14, 2019| 12:00 PM | teleECHO Conference

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The following Planning Committee and Presenting Faculty Members report having no relevant financial relationships:

Jason Callahan, M.Div.
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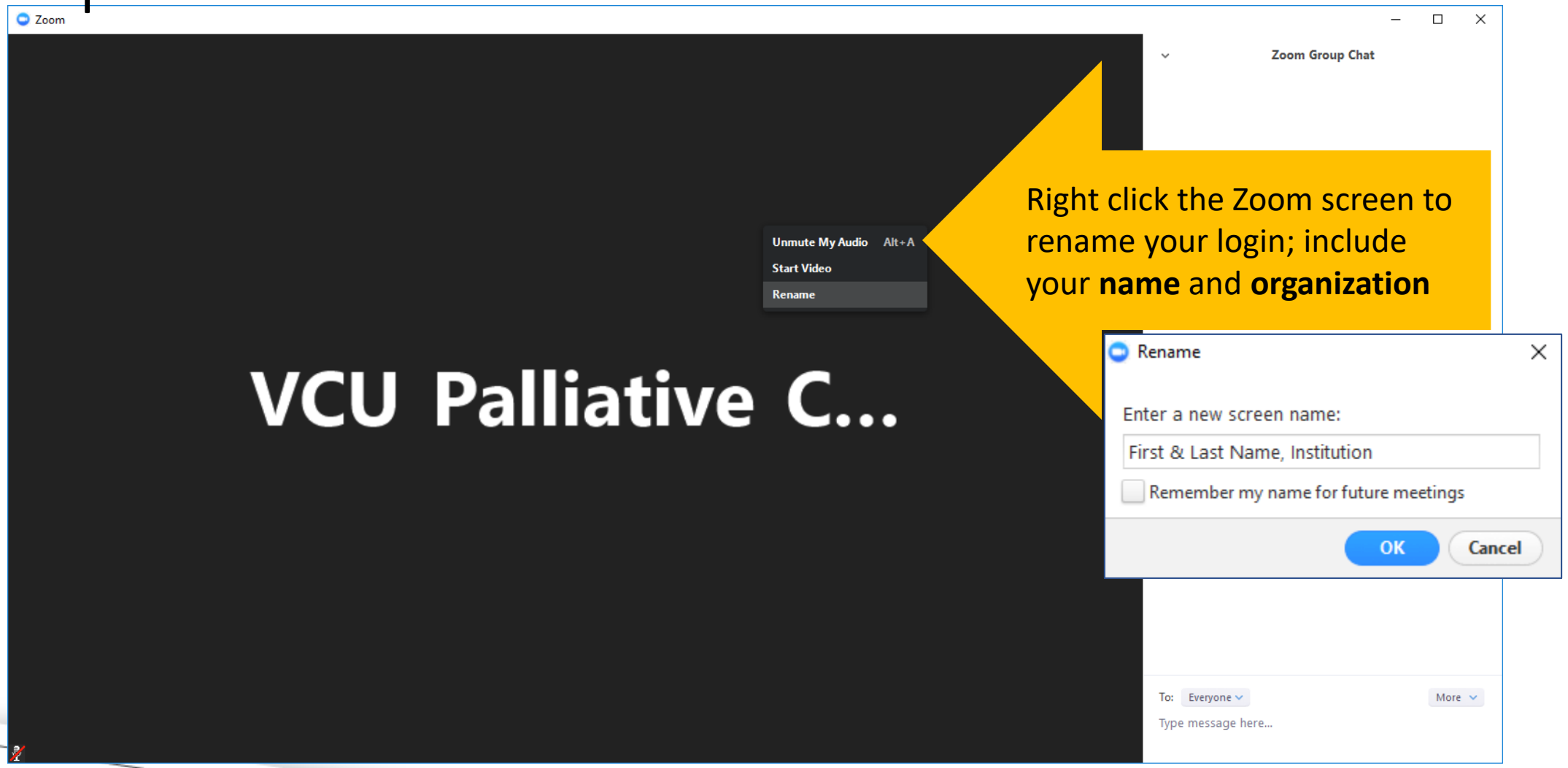
Helpful Reminders



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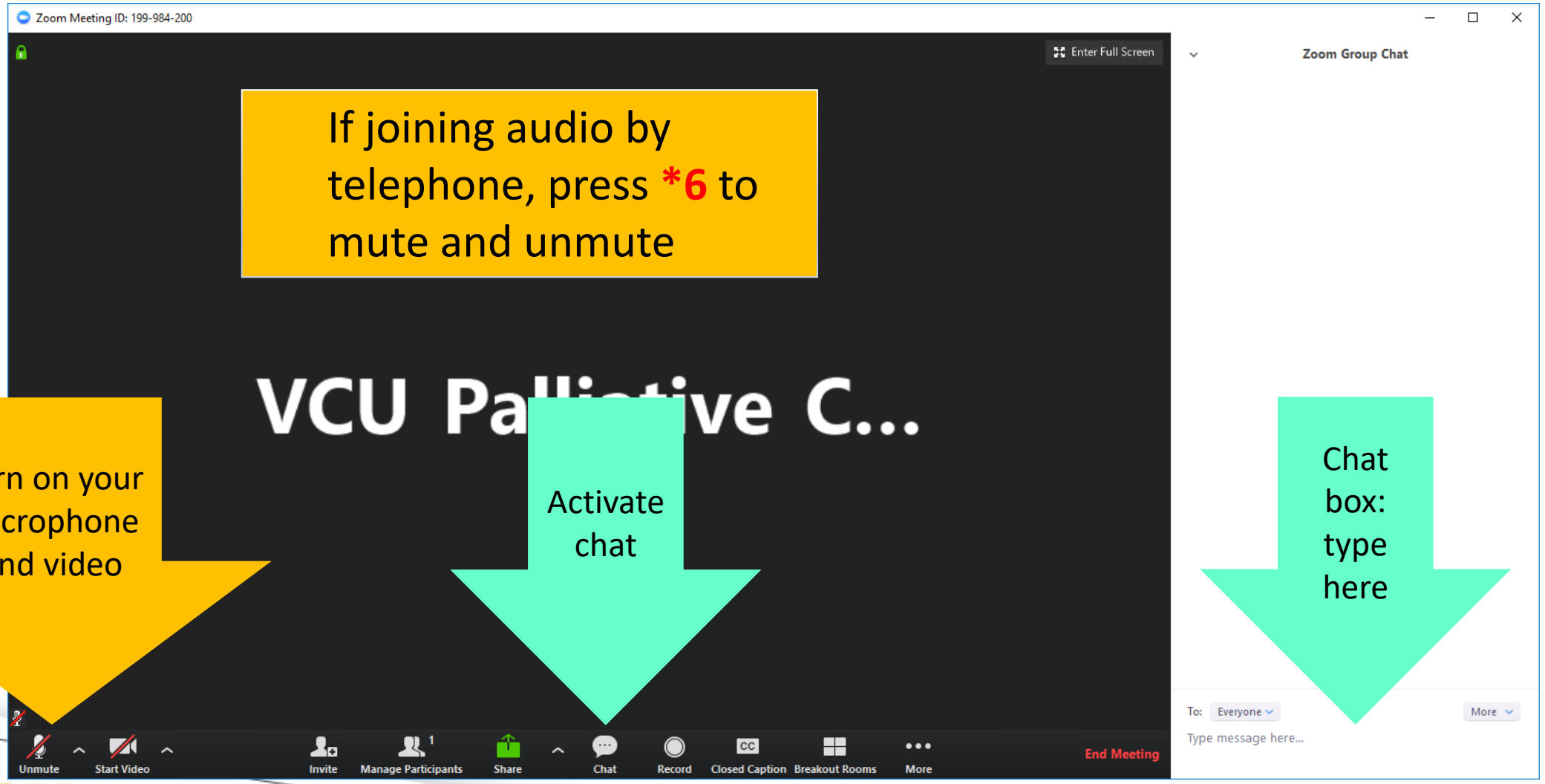


What to Expect

I. Didactic Presentation
   20 minutes + Q&A

II. Case Discussions
   - Case Presentation
     5 min.
   - Clarifying questions from spokes, then hub
     2 min. each
   - Recommendations from spokes, then hub
     2 min. each
   - Summary (hub)
     5 min.

III. Closing and Questions

- Bi-weekly tele-ECHO sessions (1.5 hours)
- Didactic presentations developed by inter-professional experts in palliative care
- Website: www.vcuhealth.org/pcecho
- Email: pcecho@vcuhealth.org

Let's get started!

Introductions

VCU Team	
Clinical Directors	Egidio Del Fabbro, MD VCU Palliative Care Chair and Program Director Danielle Noreika, MD, FACP, FAAHPM Medical Director/Fellowship Director VCU Palliative Care
Clinical Experts	Candace Blades, JD, RN – Advance Care Planning Coordinator Brian Cassel, PhD – Palliative Care Outcomes Researcher Jason Callahan, MDiv – Palliative Care Specialty Certified Felicia Hope Coley, RN Diane Kane, LCSW – Palliative Care Specialty Certified Tamara Orr, PhD, LCP – Clinical Psychologist
Support Staff Program Manager Telemedicine Practice Administrator IT Support	 Teri Dulong-Rae & Bhakti Dave, MPH David Collins, MHA Frank Green

Existential and Spiritual Assessments

Presented by Jason Callahan, MDiv, MS, BCC

Palliative Care Chaplain

VCU Health

Objectives

- Identify existential distress in patients, families and caregivers.
- Select appropriate interventions in addressing existential distress.
- Discuss grief and bereavement issues.

Common Sources of Spiritual Distress

- Guilt, shame or forgiveness issues 54%
- Broken or damaged relationship with faith tradition or community 53%
- Lack of a sense of meaning 45%
- Loss of usual source of religious or spiritual coping or well-being 44%
- One or more life events that are unresolved 44%
- Close relationship is broken or damaged or disappointing 43%
- Anxiety about afterlife 42%
- Loss of hope or the ability to reframe hope 37%
- Loss of a sense of dignity 33%
- Broken relationship with divine 26%
- Loss of confidence in a religious belief: questioning 25%
- Shaken world view or concept of the divine 15%
- Need for sense of legacy 14%
- Other 13%
- Addiction-related issues 9%
- Abuse-related issues 4%

***Source**: The National Hospice and Palliative Care Organization's Hospice Care in America Report (2013)*

Existential, Spiritual, and Religious needs

- A key element of working with issues of spirituality or existential awareness is to address how people find meaning in their lives. This may be especially true when facing illness, suffering, or death. Palliative care providers continually encounter patients and their loved ones in their times of greatest pain, vulnerability, and confusion as well as at times of ineffable joy and connection to something greater than themselves.
- As practitioners of whole-person care, it is incumbent upon practitioners to attend to patients' needs in body, mind, and spirit. Whole-person palliative care includes care for the spiritual and existential distress of patients and those who love them.
- The Clinical Practice Guidelines for Quality Palliative Care (National Consensus Project, 2013) include standards for spiritual screening as part of the whole person assessment of patients' needs and resources. The guidelines also affirm the role of board certified chaplains in the provision of a quality palliative care service.

Chaplains as Facilitators of Spiritual Care for the Palliative Care Team

- Chaplains do not own spirituality in the practice of palliative care. Each health care discipline has its own rich history of incorporating spirituality into professional practice. As spiritual care experts, chaplains support the spiritual care provided by the other members of the team and address higher level spiritual care needs with expertise gained through graduate level education and chaplaincy training.
- As spiritual care experts, in addition to the spiritual care provided to patients and loved ones, chaplains provide spiritual care to the interdisciplinary care team in order to support their personal and professional well-being and to encourage compassion, sensitivity, and awareness of the spiritual dimension of palliative care.

Assessing and Responding to Spiritual Distress

- As specialists on the palliative care team, palliative care chaplains guide and facilitate the spiritual care provided to patients, their loved ones and the other members of the interdisciplinary team. In coordinating spiritual care for patients and their loved ones, chaplains may encourage the team to utilize a tool to identify spiritual distress. Such tools can be used by all members of the palliative care team to identify the spiritual needs and resources of patients and their loved ones. Numerous tools are available to assist providers in screening for possible spiritual distress.

Generalist and Specialist Assessments

- As the clinical professional who is primarily responsible for spiritual assessment and intervention, a board-certified professional chaplain is a highly valued member of the palliative care team. In addition to their role with patients and families, chaplains serve to help educate their teams regarding the spiritual, religious and existential issues that affect their patients' lives, and help to facilitate discussions that engage other team members in understanding and exploring these areas. This opportunity for self-exploration and insight is extremely important for teams who work with suffering and existential distress.
- While physicians and nurses on the palliative care team may hesitate to address issues of religiosity, or the spiritual and existential distress of their patients, they can become competent providers of "generalist" level care, identifying when patients are experiencing these higher order needs and effectively responding to basic requests.
- Social workers are trained to assess and provide interventions for spiritual and existential distress, but often lack the specialized skills and training of the chaplain, especially as it relates to specific issues of spirituality, religion or existential concerns. Referrals to the palliative care team chaplain, when available, for more specialized, in-depth assessment and intervention is a critical part of the whole-person care provided by a palliative care team

SDAT

- One tool that has been validated through research studies is the **Spiritual Distress Assessment Tool (SDAT)**.
- The SDAT can be utilized by all members of the interdisciplinary team to identify sources of spiritual distress. If a patient is assessed to have spiritual distress, a referral to the palliative care team chaplain is an appropriate next step.
- When practitioners are listening at deeper levels for the meaning and coping strategies that patients and loved ones have developed, they may find kernels of information that shed light on spirituality and existential coping. This information provides an opening for deeper assessment, either in the moment or in referral to a chaplain as the clinician specialized in spiritual care. Practitioners of all disciplines need to be prepared and have a level of comfort with moving into these conversations. This requires being proactive and self-aware in their limitations and opportunities for growth. Palliative care chaplains support the team in developing the capacity to assess patients and their loved ones for spiritual distress and spiritual resource.

Models of Spiritual Care Assessment

- Spiritual assessment is required as part of an overall patient assessment by the Joint Commission and an ability to formulate and utilize spiritual assessments is one of the common standards of professional chaplaincy certified bodies.
- “Spiritual assessment” is a broad term that refers to many types of assessments that are conducted by chaplains as well as other members of the interdisciplinary team.
- **Spiritual assessment can refer to:**
  - Spiritual screening
  - Spiritual history
  - Spiritual distress
- In-depth spiritual assessment conducted by a professional chaplain. Spiritual assessment is an in-depth process of connecting with the patient’s care team, conducting an in-depth review of the patient’s medical record and engaging the patient and their loved ones to determine spiritual care needs and resources in order to develop a care plan.

Spiritual Screening

- A spiritual screen is a brief tool that includes just one or two questions often asked of a patient and their loved ones upon admission. Spiritual screens determine a patient's religious affiliation and whether the patient has special religious and/or cultural needs, such as dietary restrictions, blood products or gender preferences in regard to their providers.
- A spiritual screen obtains demographic information that rarely changes in the course of a patient's admission. Spiritual screens may not always represent the patient's preferences accurately and will need to be confirmed by a member of the palliative care team – ideally the palliative care chaplain.

Spiritual History

- A spiritual history is a more in-depth tool used by interdisciplinary clinicians to assess the ways in which a patient's spiritual and/or religious history impacts their medical care. Spiritual histories, in contrast to spiritual screens, are dynamic and may change during the course of a patient's hospitalization. A spiritual history assesses the ways in which one's beliefs, values, and participation in a spiritual or religious community impacts medical decision-making.
- Spiritual histories are used by physicians, nurses, social workers and chaplains to engage beliefs and values that contribute to positive and negative religious coping in relationship to illness. Spiritual history tools tend to be brief with easy to memorize acronyms. Many of the tools were developed by physicians or other clinicians interested in developing the spiritual dimension of their clinical work. The authors of these tools developed these methods to encourage their colleagues to address the spiritual dimension of care

In-Depth Spiritual Assessment

- Unlike spiritual screening, history and distress tools, full spiritual assessments are completed by a qualified chaplain and are more in-depth approaches to addressing the patient and loved ones' spiritual needs and concerns. Unlike spiritual histories and spiritual screenings, spiritual assessment is not a scripted or standard set of questions asked in the same way each time.
- Assessing the spiritual needs and resources of patients and loved ones is an evolving relational dialogue that should be engaged by a professional chaplain (Handzo et al., 2012) or a closely supervised chaplaincy student. Competent palliative care chaplains use spiritual assessment tools to create consistency across the spiritual care service and to ensure an approach to care that holds the chaplain accountable to a thoughtful methodology.
- Spiritual assessment is complex and requires specialized understanding of spiritual needs and resources, positive and negative coping, and particular knowledge of spiritual and religious traditions. Spiritual assessment is important to the overall palliative care plan because it guides the care plan and interventions, allows for quality communication with colleagues, and provides an opportunity to identify and evaluate outcomes.
- While spiritual assessments are essential to competent palliative care chaplaincy, as George Fitchett, a leader in the field of professional chaplaincy, has noted, spiritual assessments are not well tested through empirical study, leaving opportunity for chaplain researchers to strengthen the evidence base for the assessment tools they draw from (Fitchett, 2014).
- The spiritual assessment tools that follow represent prominent models in the field of spiritual care.

The 7 x 7 Spiritual Needs Assessment Model (Fitchett, 2002)

- The 7 x 7 model takes a “functional” approach to assessment, meaning that it is concerned with:
- How a person finds meaning and purpose in life and,
- The behavior, emotions, relationships and practices associated with that meaning and purpose.
- Fitchett contrasts his functional approach to spiritual assessment with what he calls a “substantive” approach. While a functional approach is pragmatic in considering how beliefs, values, and practices function in the life of the patient, a substantive approach asks whether or not a person holds a particular substantial belief such as a belief in reincarnation or a belief in God. Fitchett argues that, in a spiritually pluralistic context such as a public hospital, the functional approach to spiritual assessment is more inclusive of diverse beliefs and practices than a substantive model of spiritual assessment.
- The 7 x 7 model is based on an interdisciplinary approach to spiritual assessment. Fitchett views spiritual assessment as one of seven primary dimensions of the holistic assessment of a patient’s overall needs and resources.

The 7 x 7 Spiritual Needs Assessment Model (Fitchett, 2002)

7 Dimensions of a Holistic Assessment

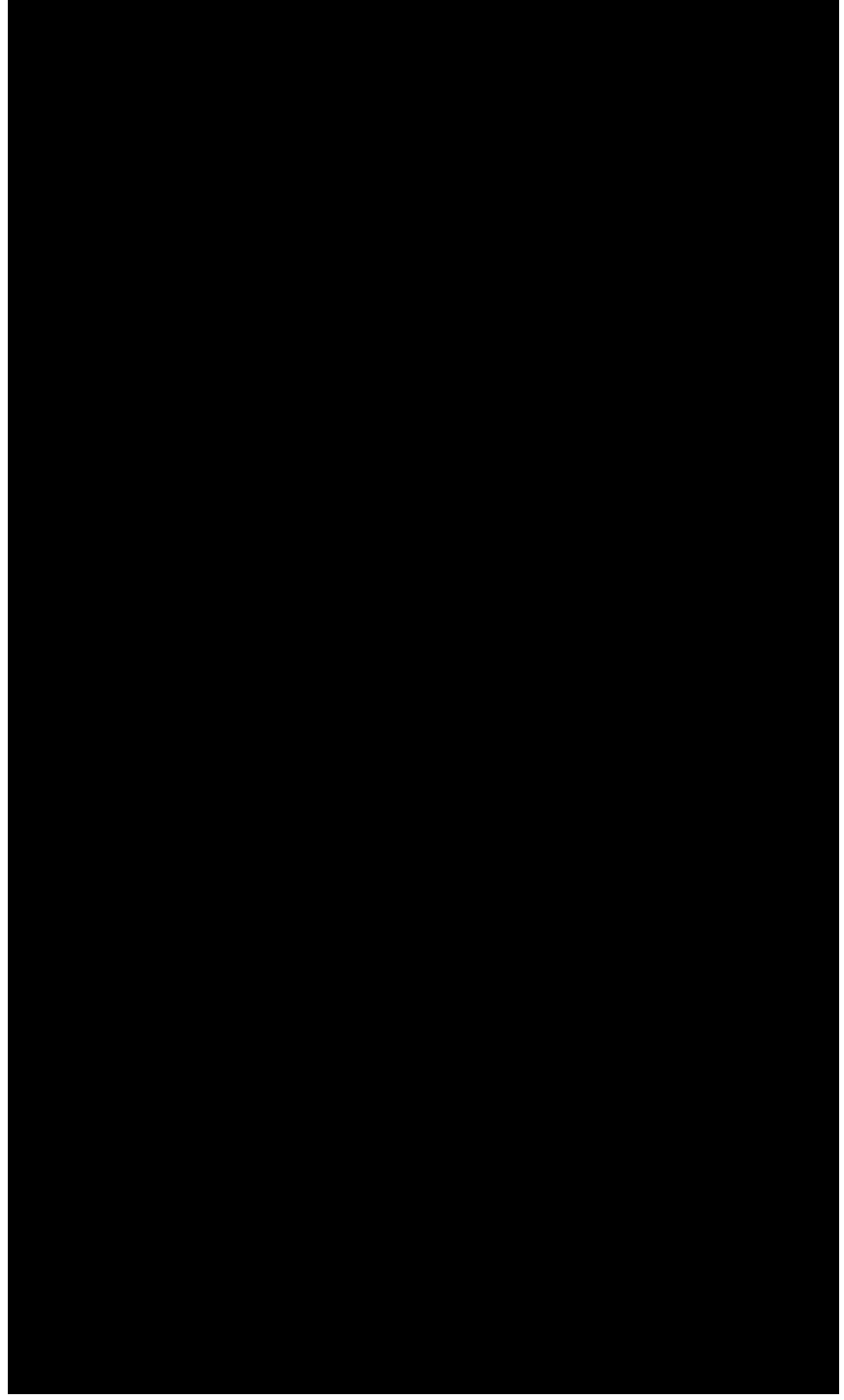
- Medical (Biological)
- Psychological
- Family Systems
- Psycho-Social
- Ethnic, Racial, Cultural
- Social Issues
- Spiritual

7 Dimensions of a Person's Spiritual Life

- **Beliefs and Meaning**: What beliefs does the person have which give meaning and purpose to their life? What major symbols reflect or express meaning for this person? What is the person's story? Do any current problems have a specific meaning or alter established meaning? Is the person presently or have they in the past been affiliated with a formal system of belief?
- **Vocation and Obligations**: Do the persons' beliefs and sense of meaning in life create a sense of duty, vocation, calling or moral obligation? Will any current problems cause conflict or compromise in their perception of their ability to fulfill these duties? Are any current problems viewed as a sacrifice or atonement or otherwise essential to this person's sense of duty?
- **Experience and Emotions**: What direct contacts with the sacred, divine, or demonic has the person had? What emotions or moods are predominantly associated with these contacts and with the person's beliefs, meaning in life and associated sense of vocation?
- **Courage and Growth**: Must the meaning of new experiences, including any current problems, be fit into existing beliefs and symbols? Can the person let go of existing beliefs and symbols in order to allow new ones to emerge?
- **Ritual and Practice**: What are the rituals and practices associated with the person's beliefs and meaning in life? Will current problems, if any, cause a change in the rituals or practices they feel they require or in their ability to perform or participate in those which are important to them?
- **Community**: Is the person part of one or more, formal or informal, communities of shared belief, meaning in life, ritual or practice? What is the style of the person's participation in these communities?
- **Authority and Guidance**: Where does the person find the authority for their beliefs, meaning in life, for their vocation, their rituals, and practices? When faced with doubt, confusion, tragedy or conflict where do they look for guidance? To what extent does the person look within or without for guidance? (Fitchett, 2002).

Emerging Models of Spiritual Assessment

- **Palliative Care Spiritual Assessment (Fitchett et al., 2017)**
  - The palliative care spiritual assessment tool is based on the SDAT spiritual distress tool and informed by Pargament's spiritual and religious struggles research (R/s Struggles), and Steinhauser and colleagues' work on the QUAL-E quality of life scale (Steinhauser, et al., 2004).
  - The Palliative Care Spiritual Assessment tool has not yet been published and continues to evolve. The authors encourage chaplains in the field of palliative care to utilize and adapt the tool. The template is a work in progress and the authors believe that the basic format can serve as a format for other specialties within the field of chaplaincy. Next steps for the research team include testing the validity, reliability, and clinical usefulness of this palliative care assessment and the forming of teams to develop similar assessment templates for other clinical contexts (Fitchett, APC Conference 2017).



Pediatric Spiritual Care Assessment

- Pediatric patients in palliative care have unique needs that require thoughtful assessment and intervention. A central consideration for pediatric spiritual assessment is the developmental age of the patient and their understanding of illness and death. Other considerations that make palliative care chaplaincy unique include caring for very young patients who may not be able to speak and the potential ethical dilemmas that arise when developing a palliative care plan for minors under the legal age of consent. It is important for the team to allow a child to participate as much as possible in their decision-making in consideration of the child's level of understanding of the medical information and potential treatment outcomes. In some cases the process of determining when to withhold or withdraw treatment can become complex if a child’s wishes differ from those of their parents, guardians, or physicians.

Developing the Spiritual Care Plan

- The process of utilizing and documenting a spiritual care assessment is an important dimension of full circle spiritual care. For the palliative care chaplain, as an advanced spiritual care practitioner, assessment forms the foundation for the chaplain's contribution to the overall palliative care plan.
- Based on the assessment of needs, resources and distress, a simple and clearly stated spiritual care plan is then developed.
- **The palliative care chaplain's care plan will contribute to the patient's over-all palliative care plan of care and goals and should include the following:**
  - A plan for supporting the patient's spiritual needs, resources and distress as each impacts the patient's **medical decision-making** process.
  - A strategy for addressing spiritual needs, resources and distress in light of the patient's **quality of life** both now and as the patient looks ahead to the future.
  - A plan for supporting positive spiritual coping and addressing any **spiritual distress** that may negatively impact the patient's coping with chronic or serious illness.
  - Strategies for addressing the spiritual, religious and **existential needs** of patients and loved ones who are facing a terminal diagnosis.
  - A plan for supporting appropriate **spiritual practices** that may help the patient adjust to change and loss.
  - Specific strategies for addressing the spiritual dimension of **physical, emotional or psychological pain and suffering** as a result of serious or chronic illness.

Spiritual Care Interventions

- Spiritual care interventions are the heart of full circle palliative care chaplaincy. With thoughtful spiritual care interventions, chaplains mediate hope, cultivate compassion and bring healing and reconciliation to places of brokenness and fractured meaning in the lives of patients and their loved ones.
- With serious illness, previous assumptions about the world can begin to unravel as patients question the meaning of their illness. Spiritual care interventions in the context of palliative care and hospice address the deepest struggles of the human condition. Spiritual Care Interventions flow out of the spiritual care assessment and care plan. Well-constructed interventions are co-created in the relationship with the patient, her loved ones, and the other palliative care clinicians as a collaborative team. Interventions may be active, such as facilitating a spiritual care practice, or more receptive, as when a palliative care chaplain provides a silent and compassionate presence to a grieving patient
- Just as the other healthcare professionals rely on care plans, it is important for the chaplain to have a clear sense of how to proceed with a patient, based on a skilled assessment of needs and resources. Once a plan is constructed from the palliative care team’s interdisciplinary care plan and the specific spiritual care plan, the chaplain provides interventions based on evidence-based practice and the chaplain's own gained experience as a reflective practitioner. The palliative care chaplain then assesses interventions to observe whether or not a particular intervention is accomplishing a desired outcome.

Foundational Interventions

- Palliative care chaplains draw from foundational spiritual care interventions that include skills that beginning chaplains will learn to embody in their practice. Foundational chaplaincy interventions reflect the values of professional spiritual care and establish a basis for more complex care to take place.
- **Foundational interventions include:**
  - Reflective listening
  - A nonjudgmental regard for cultural and religious difference
  - Appropriate use of self-disclosure
  - Rapport building
  - Empathy
  - The ability to be present to silence without filling the space with words
- More **complex interventions** will build on these foundational skills.

Providing Interdisciplinary Spiritual and Existential Care

- **Listening for Religious, Spiritual, and Existential Distress**
  - Many providers assume that patients express spiritual and existential distress using specific religious or spiritual words such as God, faith, prayer, sin, karma or other similar terms.
  - While this may be true for some, many patients also express spiritual and existential distress through language that seems more commonplace and may be misunderstood. A patient may wonder aloud, “How in the world am I going to make it through this? They may speak about feeling “useless,” “hopeless,” or questioning what they did to “deserve this” illness.

Interdisciplinary Interventions for Suffering

Examples of Interventions to Address Suffering

- Pain and symptom management
- Life review
- Support for medical decision-making
- Integrative therapies
- Spiritual support
- Ethical decision-making
- Family counseling
- Addiction support
- Dignity therapy
- Mindfulness
- Guided imagery
- Art or music therapy

Spiritual Care as Meaning-Making

- The practice of chaplaincy is an art of meaning-making. When patients and their loved ones face serious illness, the fabric of meaning which brings life purpose and a sense of coherence may become fractured and frayed. Meaning-making interventions require that the chaplain maintains an openness to unforeseen possibilities in allowing the care seeker to explore their own world of meaning. What is meaningful to the chaplain may not have resonance with the care seeker. The palliative care chaplain provides a nonjudgmental transitional space for new meaning to emerge in often new and surprising ways in the context of loving support.

Meaning-Making Interventions

- **Deep listening**: Deep listening provides the foundation for the reweaving of meaning. Deep and reflective listening allows the patient to listen to the voice of inner intuition and insight that often holds the answers to the challenges of adjusting to profound change and loss. Simply allowing space and time for the patient to listen to herself is a profound act of caring.

- **Spiritual and emotional support and counseling**: Although chaplains are not licensed counselors, counseling skills such as empathy, unconditional positive regard, restating, cognitive reframing, narrative counseling, and motivational interviewing can help a patient clarify and engage their experience with a greater sense of empowerment.

- **Life review**: Life review invites the patient and their loved ones to reflect on the past in order to weave themes from the past into a new sense of meaning in the present. Life review is helpful for people at the end of their lives because it invites a reflection on the joys, losses, important relationships and accomplishments so that the patient can experience gratitude, forgiveness, and acceptance of the past. Life review also provides an opportunity for patients to share their legacy and wisdom with one willing to receive insights and life lessons learned through experience.

- **Dignity therapy**: Dignity therapy was developed by a psychiatrist named Harvey Chochinov. In his work with the dying, Chochinov recognized that many people suffer at the end of life from a sense that their lives did not matter and their existence will be forgotten. In response to this existential lack of meaning, Chochinov developed a tool for recording patients' legacy and life story to be passed on to relatives, loved ones and others the patient would like to be remembered by.

Prayer, Meditation, Ritual, & Other Mind/Body Interventions to Alleviate Spiritual and Existential Suffering

- Palliative care chaplains bring a holistic view of health to the palliative care interdisciplinary team through utilizing mind- body interventions for complex symptom management. While the field of chaplaincy has traditionally relied on psychological and theological sources of assessment and intervention, there is an increasing recognition of the importance of attending to the body as well as the mind and spirit as a source of care and support. Interventions that draw out the body's natural wisdom and healing can activate the parasympathetic nervous system and calm the patient's body, mind, and spirit.

More Complex Palliative Care Chaplaincy Interventions

- Identifying and addressing ethical dilemmas and conflicts.
- Assisting the interdisciplinary team in assessing for decisional capacity.
- Helping to establish surrogate decision-makers for non-decisional patients who are unbefriended or have complex family dynamics.
- Facilitating a family meeting
- Providing mind-body interventions to support pain management
- Utilizing Dignity Therapy
- Teaching the team about specific cultural beliefs and values as they influence medical decision-making
- Providing emotional and spiritual support for complex grief
- Working with addiction
- Collaborating with the patient's spiritual advisor or religious leader for complex medical decision-making

Ethical Wills

- Like dignity therapy, an ethical will is a way of capturing one's legacy and passing on one's values and one's legacy to future generations. One way of thinking of an ethical will is as a love letter to the patient's loved ones. Every ethical will is as unique as the person writing it. Ethical wills may contain blessings, personal and spiritual values, and end of life wishes.
- **Ethical wills may also contain:**
  - Important personal values and beliefs
  - Spiritual values
  - Hopes and blessings for future generations
  - Life's lessons
  - Love
  - Forgiving others and asking for forgiveness

Family Systems Interventions

- Family systems theory provides a helpful way for engaging family dynamics as they unfold for patients with a serious illness. Family systems interventions will often take place in initial or ongoing palliative care consultations with multiple family members and team members present. In engaging the family systems of patients, their loved ones and the interdisciplinary team, competent chaplains can cultivate self-awareness of the chaplain's own role(s) within the system as such roles are activated in patient care encounters and family meetings.
- **Family systems intervention may include:**
  - Bringing attention to family dynamics in a compassionate way to encourage more awareness and flexibility with dynamics as they impact patient well-being.
  - Engaging patients and loved ones in a way that allows for the care seeker’s full personhood to be honored in spite of their prescribed role in the family system. For example, approaching a patient who is seen as the “black sheep” or addicted person in the family with a deep appreciation for the aspects of heroism, bravery, and overcoming challenges that make up their life story.
  - Addressing distress that may happen as a result of changes in the family system such as when the matriarch of the family becomes ill and is no longer able to serve as the family organizer and spiritual advisor.
  - Other interventions that take the family as a complex system into account, rather than over-focusing on the individual as the locus of imbalances, problems, and strengths.

Physical Pain and Stress Management

- As part of the palliative care team, chaplains are responsible for assessing their patient’s experience of physical pain. At the beginning of each patient encounter, chaplains should take the time to assess physical pain through asking decisional patients to rate their pain on a pain scale. With decisional and non-decisional patients, noticing affective signs of pain including a furrowing brow, clenching hands, groaning, moving in bed, or pursed lips are effective ways of assessing pain and reporting any concerns regarding pain management to the care team for immediate follow-up
- In a holistic view of health, spirituality cannot be separated from one's physical, psychological and emotional experience. Spiritual beliefs, values, experiences, hopes, and fears are held in the body and are interconnected with a patient's experience of physical disease processes and symptoms, including physical pain and stress.
- Spirituality can serve as a resource for addressing pain when traditional methods of pain management are limited in their capacity to provide relief from suffering.

Physical Pain and Stress Management

- **The following interventions may positively influence a patient's experience of intractable and refractory pain and stress and should be utilized only after patients have received a full pain management assessment and care plan from the medical providers on the team:**
  - **Guided imagery and visualization** can help patients learn to work with the pain as an ally instead of an enemy, leading to a greater sense of empowerment and a reduction in the suffering associated with pain.
  - **Meditation** can impact the subjective experience of pain through influencing the parts of the brain that process pain and attribute emotions to the experience of pain. In empirical studies, areas of brain function that influence pain were significantly altered through the practice of meditation. The patients' experience of pain was significantly improved.
  - **Mindfulness** as an intervention for physical pain can be introduced to patients from any spiritual or religious background and is best introduced in a non-religious manner with patients who do not identify as Buddhist.

Mind-Body Interventions for Symptom Management

- Mindful self-compassion
- Body scanning
- Aromatherapy (if approved by your institution and PC team)
- Grounding practices
- Relaxation techniques
- Yogic breathing
- Appropriate use of touch
- And many more…

Spiritual Counseling

- Though chaplains are not licensed counselors, chaplains draw on counseling techniques to support patients toward healthy and positive coping strategies in relationship to pain. Spiritual and religious beliefs can significantly impact the patient's experience of their pain.
- As was noted above, examples of spiritual counseling techniques include deep listening, life review, family systems interventions, cognitive behavioral interventions, motivational interviewing, reframing, engaging stages of change, spiritually integrated counseling and many other techniques based on the chaplain's utilization of particular theories from the behavioral sciences. Counseling techniques can be drawn upon to help empower patients in relationship to their experience of illness and pain.

Grief and Emotional Distress

- Beginning chaplains learn the art of listening and companioning those who are facing loss and change. Advanced palliative care chaplains learn to assess and engage complex grief with more refined interventions. As has already been addressed previously in this course, grief may be complex in nature.
- **Grief and Mental Health**
  - In providing support for grief and loss, it is important to recognize when care seekers have an underlying mental health challenge, personality disorder or addiction history. Grief for such care seekers can be exacerbated by existing mental health conditions. These patients may need the support of a psychiatrist as they navigate their experience of grief and bereavement

Disenfranchised Grief	
Example	A young homeless man is admitted to the palliative care service to manage the progression of HIV/AIDS. He is isolated from his family and home community who condemn his gay lifestyle and refuse to visit him in the hospital. The young man is a former evangelical youth leader who left his church community and his family to move in with a gay partner who financially took advantage of him and left him without resources or a home.
Intervention	Validation of grief, loss, and feelings of anger and betrayal; spiritual counseling to allow space for spiritual and religious meaning-making; exploration of forgiveness of self and other in light of betrayal by religious leaders and his community of faith; referral to social work for housing and resources.
Anticipatory Grief	
Example	A woman in her 30s with four children is given the devastating diagnosis of advanced metastatic breast cancer and anticipates a difficult course of treatment that is unlikely to prevent her death. She practices yoga and mindfulness meditation daily.
Intervention	Provide guidance to the patient and her husband about age appropriate spiritual and emotional support for her children; encourage spiritual practices from the Buddhist/Yoga tradition to strengthen positive coping with fear about treatment and anticipated losses; deep listening to offer patient a space to grieve and begin to clarify her goals regarding balancing quality of life and her treatment plan.
Complicated Grief	
Example	A 70-year-old woman is dying of advanced COPD and will soon be admitted to hospice. Six months before her diagnosis, one of her sons was imprisoned for murdering his wife and two children. This patient belongs to a 12-step program. She serves as a sponsor for younger women struggling with alcoholism.
Intervention	Provide emotional and spiritual support for multiple losses; encourage a deeper connection to a higher power; suggest ritual or collage/memorial board to honor each individual loss and its impact; develop quality of life goals that will help maintain patient's connection to her 12-step community once she is home bound.
Ambiguous Grief	
Example	A 55-year-old man is grieving the loss of his wife who is imminently dying after a 20-year struggle with Multiple Sclerosis. He was his wife's primary caregiver for many years. This patient's husband feels guilty about the sense of relief and liberation he feels as he must say goodbye to his beloved life partner. He is an avid hiker and finds a deep sense of peace and greater connection in the natural world.
Intervention	Validate and normalize ambiguous nature of grief; encourage healing connection to the natural world; invite an honoring of all dimensions of this caregiver's experience as equally valuable; encourage self-compassion practice; facilitate a healthy and loving goodbye between the patient and her husband; allow husband time to share his feelings of relief apart from his wife.

Addressing Complicated, Disenfranchised, Anticipatory and Ambiguous Grief

- In addition to assessing positive and negative coping, chaplains are trained to engage grief and loss through deep listening, the gift of presence, and simply witnessing the natural unfolding of painful emotions. Yet, the experience of grief is rarely straightforward and simple and many people will experience grief in complex ways. The role of the palliative care chaplain as an advanced spiritual care practitioner is to help the team identify complex grieving and respond with appropriate interventions.
- When considering complex grieving it is important to consider cultural differences that exist in the ways that people grieve. Certain regional and family cultures value emotional expressiveness, for example, while others may grieve in a more reserved and private manner. The goal of assessing coping is to consider values, beliefs, and practices as they are active in the patient's context and not apart from it. There is always a temptation to define those who cope in a way that is similar to our own as coping in a healthy way, while those whose practices may differ are defined as problematic. Cultural humility will be discussed further throughout the course.

Bereavement

- Forms and book

Resources

- Arnold, S., Herrick, L., Pankratz, V., Mueller, P. (2006). Spiritual well-being, emotional distress, and perception of health after a myocardial infarction. I*nternet J Adv Nurs Pract* 9:1
- Cassell, E. (1995). Pain and Suffering, Encyclopedia of Bioethics 4:1897-1905 (1995)
- Cummings, J. & Pargament, K. (2010). Medicine for the Spirit: Religious Coping in Individuals with Medical Conditions, *Journal of Religions*, 1, 28-53: doi 10.3390/rel1010028
- Edmondson D., Park C., Blank T., Fenster J., Mills M. (2008). Deconstructing spiritual wellbeing: existential wellbeing and HRQOL in cancer survivors. *Psychooncology*. 17:161
- Fitchett, G. (2002). *Assessing Spiritual Needs: A Guide for Caregivers*. Academic Renewal Press, Lima, Ohio
- Monod S., Rochat E., Bula C., Spencer B. (2010). The Spiritual Needs Model: Spirituality Assessment in the Geriatric Hospital Setting. *J Religion Spirituality Aging*. 22: 271-282. 10.1080/15528030.2010.509987.
- Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., et al. (2009). Improving the quality of spiritual care as a dimension of palliative care: The report of the consensus conference. *Journal of Palliative Medicine*, 12(10), 885-904. DOI:10.1089=jpm.20
- Swinton, J. (2012). Oxford Textbook of Spirituality in Healthcare. *Healthcare Spirituality: A Question of Knowledge*, Oxford University Press, 99-104

Questions and Discussion

Patient History

Presented by Paul Zelensky, MD

Hospice and Palliative Medicine Fellow

How Can Spiritual and Social Dilemmas be Actively Addressed by IDT Staff?

Brief History of Serious Illness and Other Comorbid Disorders

70 y/o male with history of Stage IV lung adenocarcinoma, HTN, DM, bronchitis, CKD 4, BPH, spinal metastasis with large sacral ulceration who was seen by home hospice, who came to VCUHS 3 months after diagnosis. was found to have large amounts of bloody drainage from sacral wound. Patient was seen by ortho but had declined further surgical intervention and was transferred to the palliative care unit for end of life care. In the palliative unit he was started on medications for delirium and pain; and started to decline slowly, and lost his ability to swallow. Patient was evaluated and accepted to inpatient hospice [approx. two weeks later], where he continue to receive full IDT support, and medications for pain and delirium subcutaneously [Two days later,] he passed away peacefully with his best friend […] at his side […] An autopsy was offered by patient's family declined.

Pertinent Physical Exam, Lab, or Imaging Findings, Including Assessment of Functional Status:

- Patient bed bound, large open ulceration to sacrum.
- Paraplegic

Patient Social and Spiritual History

- Patient married, had adult children from previous marriage.
- Identified with Methodist church.
- Patient had complicated relationship with adult children, who were threatening patient and current wife due to questions regarding anticipated inheritance.
- Patient frequently had tearful encounters, endorsed feeling guilt about his life and actions.

Patient Symptom Assessment

- Agitation
- Depression
- Anxiety

Patient Advance Care Planning Documents:

Advance Directive, Durable DNR

Case presentation
Sarah West, MD

Brief history
This is a 27 yo F with metastatic chondroblastic osteosarcoma s/p multiple orthopedic procedures, including most recent thoracic tumor debulking w/extension of T4 laminectomy, neurogenic bladder/bowel, recurrent UTIs, asthma, and PE who was admitted to Orthopedic Surgery from the ED for increasing back pain found to be in shock.

Current meds and therapies
Antibiotics, high-flow oxygen, therapeutic Lovenox, (Erdafitinib in view of FGFR mutation,
Morphine 30 SR every 8 hours, dilaudid 1 q3h, oxy 20 q3h, lidocaine patch, gabapentin 300 at bedtime

Pain
Agitation
Anorexia
Anxiety
Has advance directive

Accessing CME and CEU Credits

Claim CME / CEU at www.vcuhealth.org/pcecho

VCU Health Palliative Care ECHO

Our VCU Health Palliative Care ECHO program partners with community practices caring for patients with serious illness and applies our interdisciplinary care team - a mix of physicians, nurses, social workers, psychologists, chaplains and more - to provide patient care support and education throughout Virginia.

We have a long-standing palliative care program with an inpatient unit, consult service and supportive care clinic to provide serious illness care. Many communities in Virginia do not have access to palliative care and we're here to help.

- View Palliative Care ECHO sessions (CME/CEU available).
- Register now for an upcoming clinic.
- Submit a case study (registered participants only).
- Live Session Participants: Claim CME/CEU.

Contact us for more information or help with any questions about our program.

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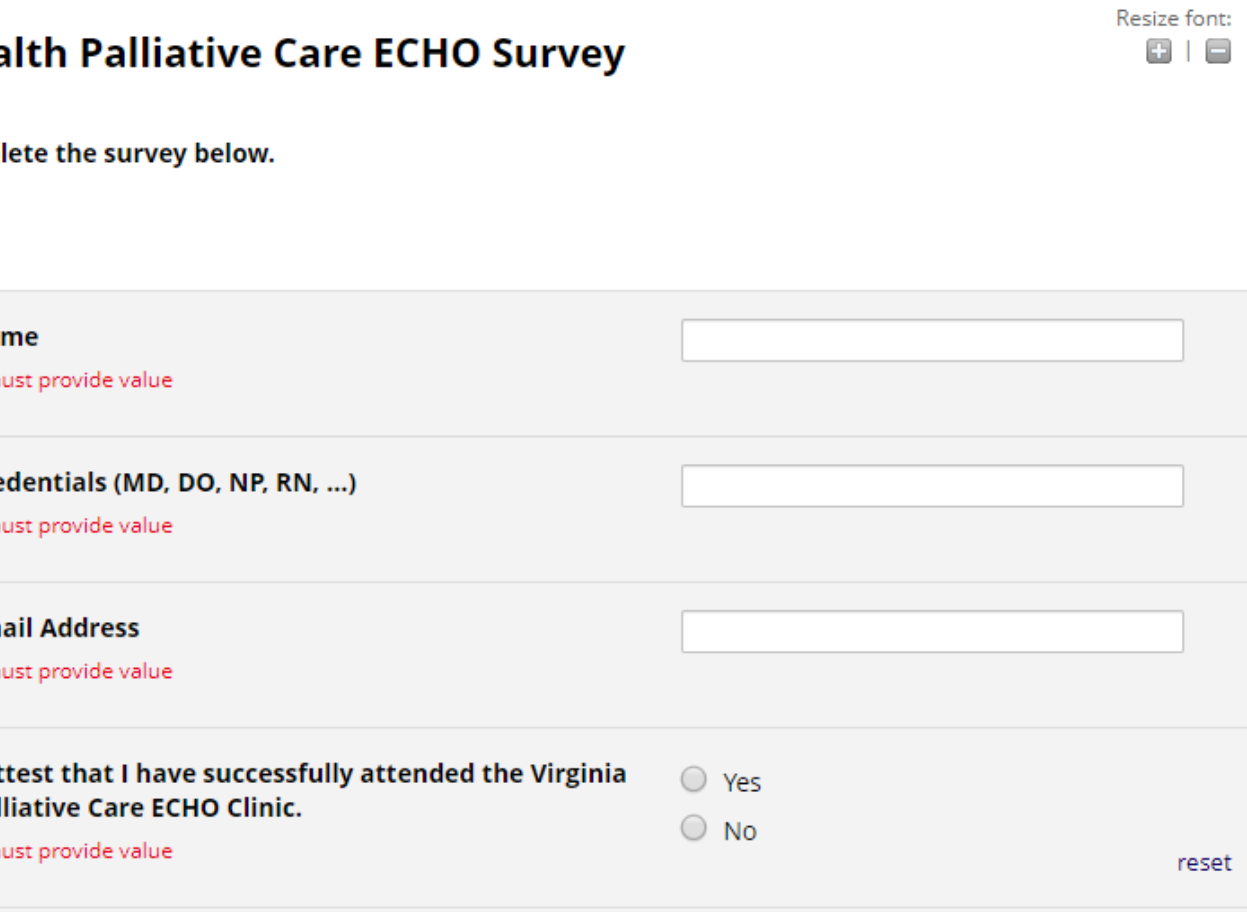

Resize font:

VCU Health Palliative Care ECHO Survey

Please complete the survey below.

Thank you!

Name
* must provide value

Credentials (MD, DO, NP, RN, ...)
* must provide value

Email Address
* must provide value

I attest that I have successfully attended the Virginia Palliative Care ECHO Clinic.
* must provide value

- Yes
- No

reset

View recorded sessions at www.vcuhealth.org/pcecho

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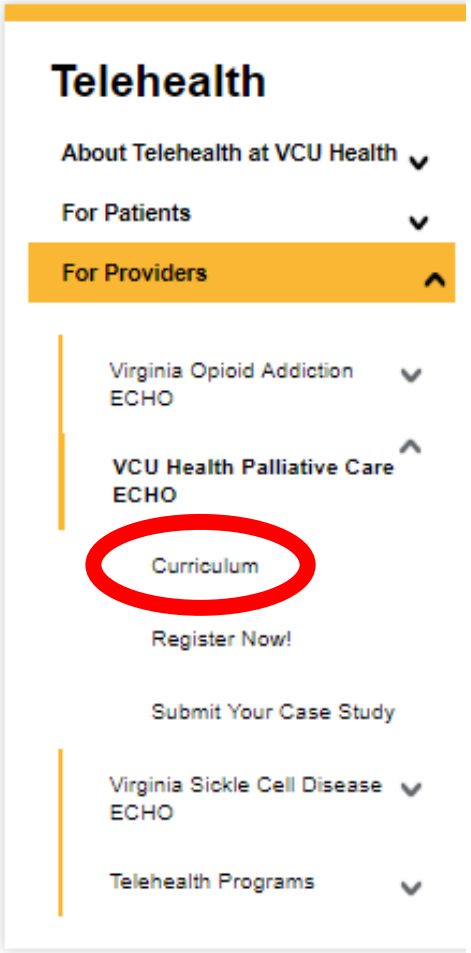
About Palliative Care



Project ECHO
Virginia Commonwealth University

Curriculum

Register now for an upcoming clinic on palliative care.

Upcoming Clinics

Mindfulness and Provider Self Care

June 13, 2019

Previous Clinics

Introduction to Palliative and Supportive Care

Feb. 14, 2019

View session for CME

Presented by Danielle Noreika, MD

Learning Objectives:

- Define palliative care and differentiate from hospice.
- Describe reasons for referral to palliative care.
- Describe basic structure of palliative care team.

Telehealth

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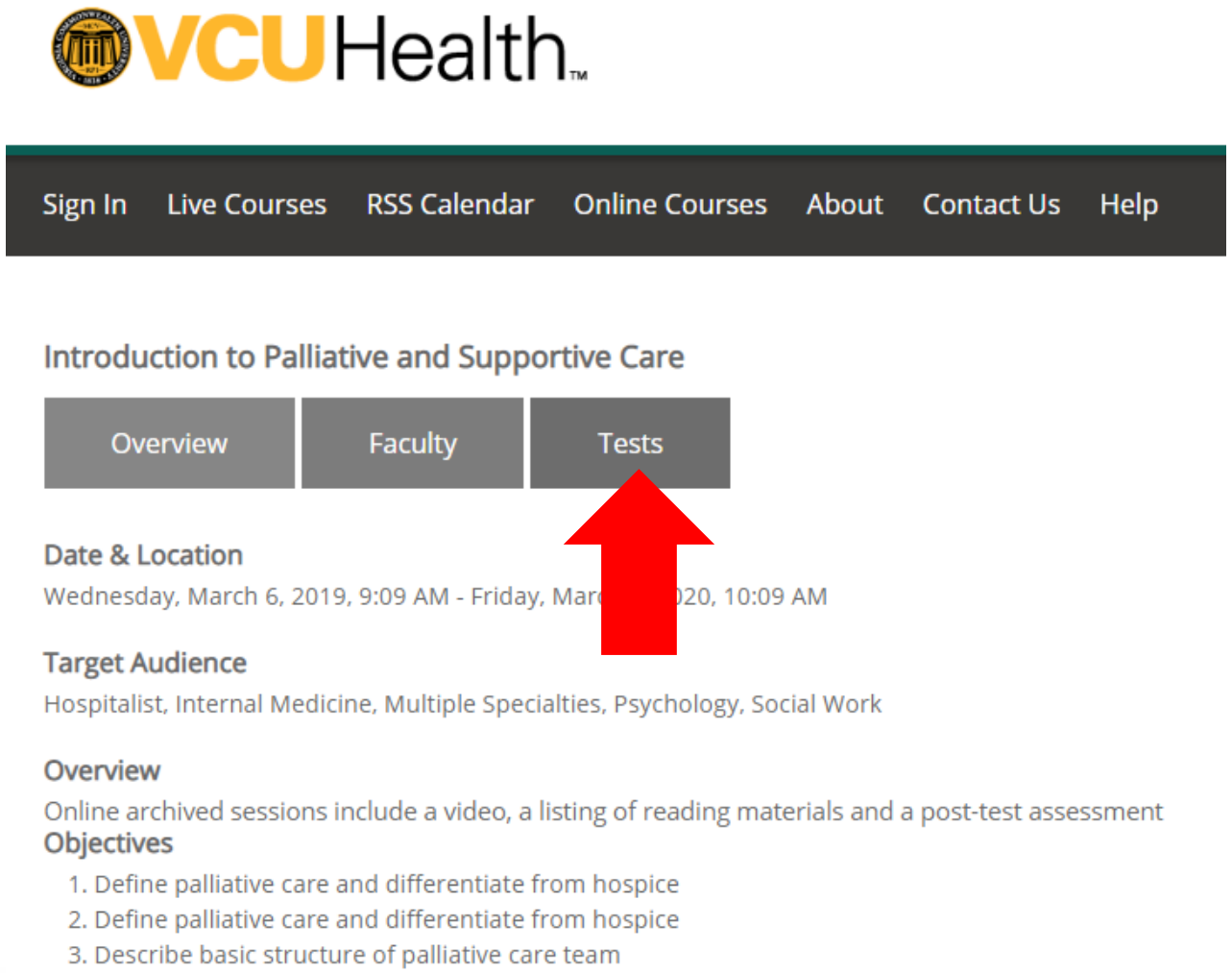
View previously recorded ECHOs for CME

Click “Tests” to view video of the session and take a short quiz for continuing education credit



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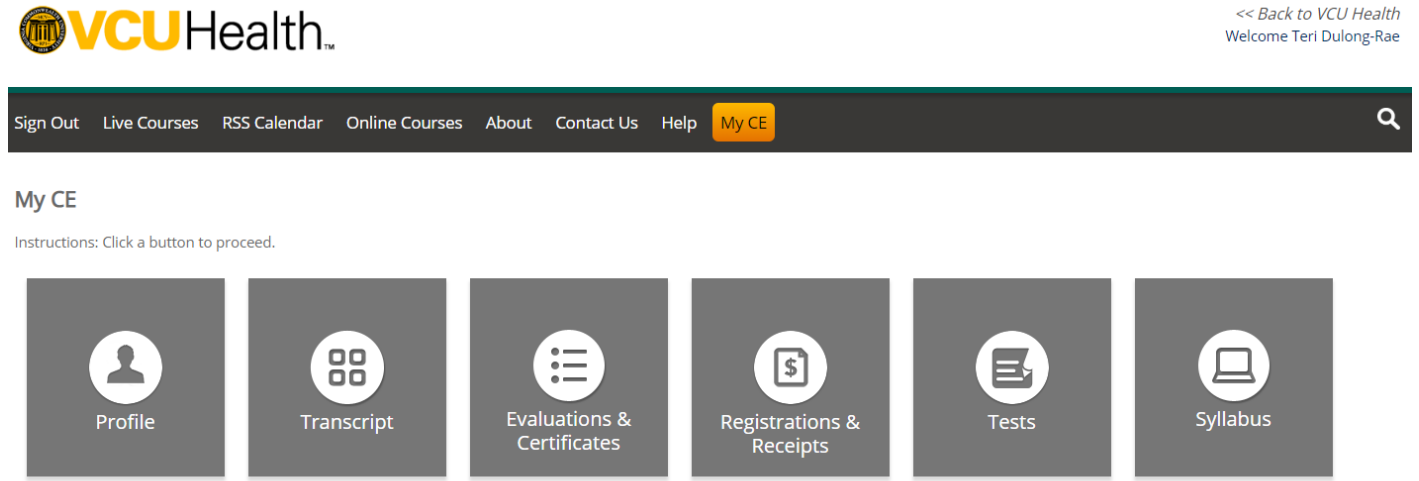
- Go to vcu.cloud-cme.com and click “My CE”
- Log in with the email you used to register for our ECHO session



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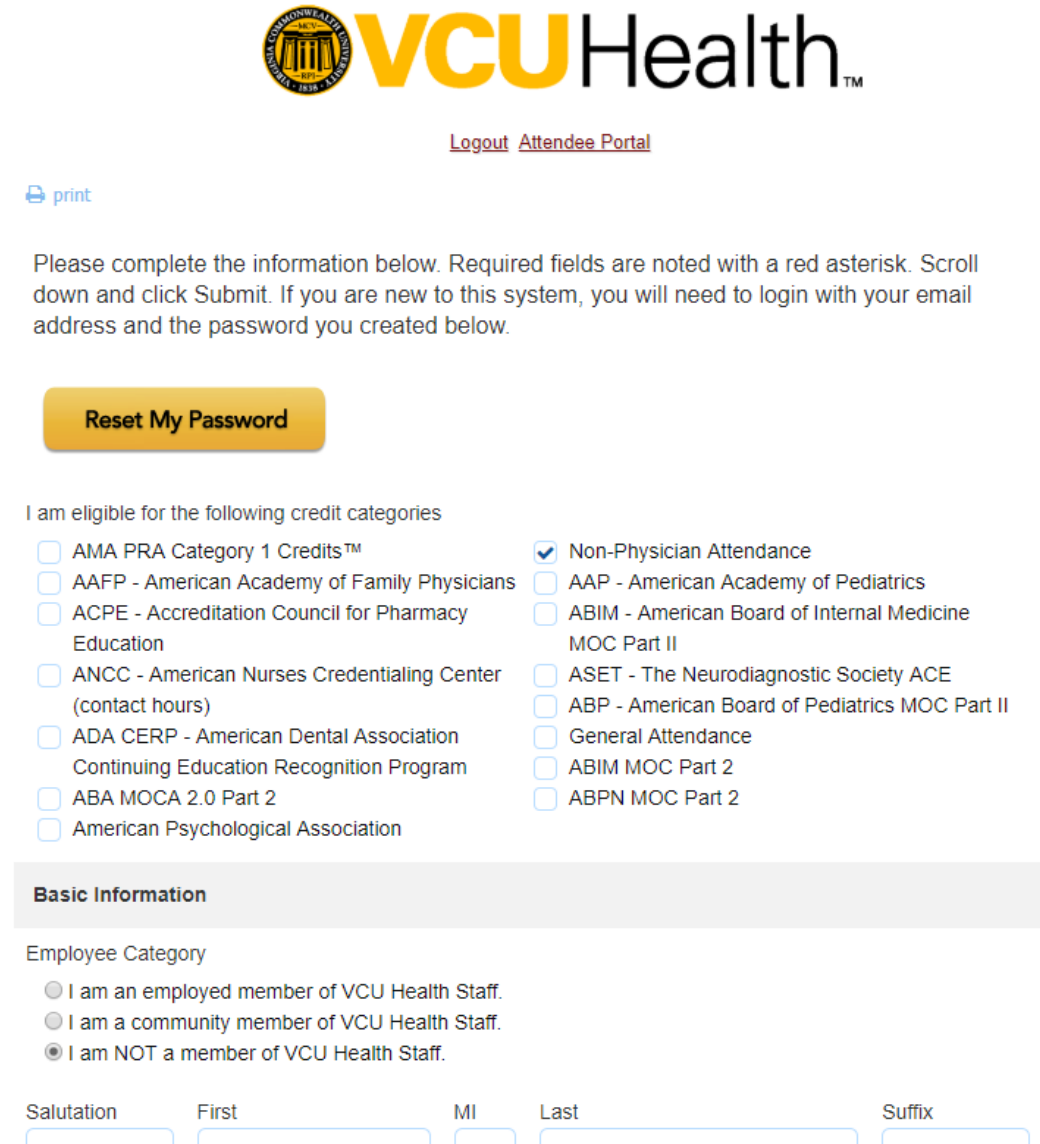

THANK YOU!

We hope to see you at our next ECHO