Spiritually Sensitive Assessment and Interventions in End-of-Life Care

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For more information, see: Spiritual Diversity in Social Work Practice, by Edward R. Canda and Leola D. Furman (Oxford University Press, 2010) and https://spiritualdiversity.ku.edu/

Thanks to the Palliative Care Consulting Team (PCCT) at Lawrence Memorial Hospital, Kansas, which developed some materials adapted for this presentation

Principles for Spiritually Sensitive End-of-Life Care



Symbolism of the Lotus:

Blossoming out of Suffering

- Mud and mirky water
 - Authentic encounter with mortality
- Spreading stems
 - Realizing wisdom in daily living and dying
 - Realizing difference between pain and suffering
- Budding flower
 - Resilience and growth and beauty



Spirituality is:

- A process of human life and development
 - focusing on the search for a sense of meaning, purpose, morality, and well-being;
 - *in relationship* with oneself, other people, other beings, the universe, and ultimate reality however understood;
 - orienting around centrally significant priorities; and
 - engaging a sense of transcendence (experienced as deeply profound, sacred, or transpersonal).

Features of Spirituality

- Individuals and groups may express spirituality in religious and nonreligious ways.
- They may express it in private ways and in public, shared ways.
- Spirituality may or may not permeate an individual's daily life and a group's culture.
- As a universal feature of persons and cultures, everyone has spirituality, though they vary in amount of focus on it.
- Healthy spirituality encourages a sense of personal integrity, wholeness, well-being, and caring for others.
- It fosters transpersonal experiences and levels of consciousness, and an expanded sense of identity and connectedness. Example: near death experiences



Religion is:

- An institutionalized (i.e. systematic and organized) pattern of values, beliefs, symbols, behaviors, and experiences that involves
- spirituality
- a community of adherents
- transmission of *traditions* over time, and
- Community support functions (e.g. organizational structure, material assistance, emotional support, or political advocacy) that are directly or indirectly related to spirituality. Examples:

prayer and meditation practices to prepare for death; funerals; rituals to process grief and loss; rituals to honor ancestors; prayers for the dead; rituals for 'wandering spirits'

Principles Guiding Practice

1. Demonstrating Value Clarity

- Self-reflection, especially regarding beliefs and attitudes about the purpose of life and the nature of death and dying
- Appropriate self-disclosure based on benefit to client
- Dialogue and collaboration with client

2. Respecting Diversity

- Appreciation of all types of human diversity, especially regarding varied beliefs and practices about living and dying
- Engagement with locality- specific and culturally-specific approaches, especially spiritual support systems relevant to clients

3. Supporting Strengths and Empowerment

- Relating to people as whole beings: body/mind/spirit/nature/kosmos
- Emphasizing strengths, resources, capacities, and aspirations, especially for end of life planning and wishes
- Promoting well-being and justice, such as for access to palliative care and hospice services, both home and institution based

4. Applying Best Practices

- Competence and humility
- Evidence from an expanded view of inquiry
 - Multiple ways of knowing
- Theoretical and philosophical insights
- Client-centered determination of 'best'



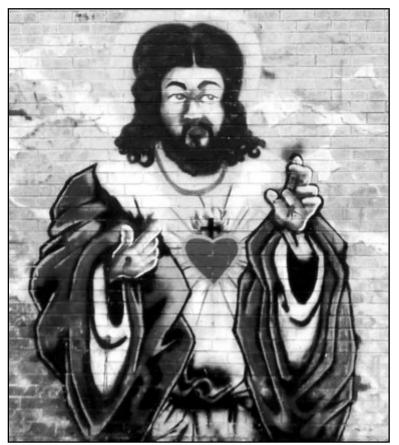
Reflections on the heart/mind

below left image from Centre on Behavioral Health, the University of Hong Kong below right image from onemindonebreath.com





Reflections on compassion

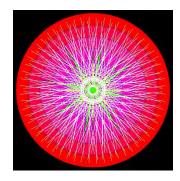


Sacred Heart of Jesus Street Mural, Chicago

> Gwanseum Bosal (Kuan Yin) At Jingwang Temple, S Korea



Qualities of Compassion



- Engaging life, self, and relationships 'with passion'
- 'Suffering together'
- Empathy, but not enmeshment (over-attachment)
- Nonjudgmental, clear awareness (mindfulness)
- Skillful reaching out
- Caring nonattachment to fruits of actions: letting go
 - Ed's story... working as a lay chaplain: 'just being' in silence with patient diagnosed with terminal cancer

Case Illustration with Questions and Discussion



Hospice: The bicyclist's "unfinished business"

- This was a divorced homeless man who came to Lawrence Memorial Hospital (LMH) as he had been losing weight
- He was diagnosed with advanced lung cancer with a very short time to live.
- He had no other support and no health insurance.
- He had unfinished business to take care of after his terminal diagnosis.





Inter-professional Teamwork for EOLC in Medical and Hospice Settings

Thanks to PCCT and LMH for leadership in developing the slides in this section



World Health Organization's definition of Palliative Care

 Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative Care is..

- Caring for the whole person with respect for personal choices and relief of suffering (physical, emotional, spiritual).
- Comprehensive, specialized care provided by an interdisciplinary team to patients and families living with lifethreatening or advanced severe illness expected to progress toward dying and where care is particularly focused on alleviating suffering and promoting quality of life.

Hospice & Palliative Care: What's the difference ?

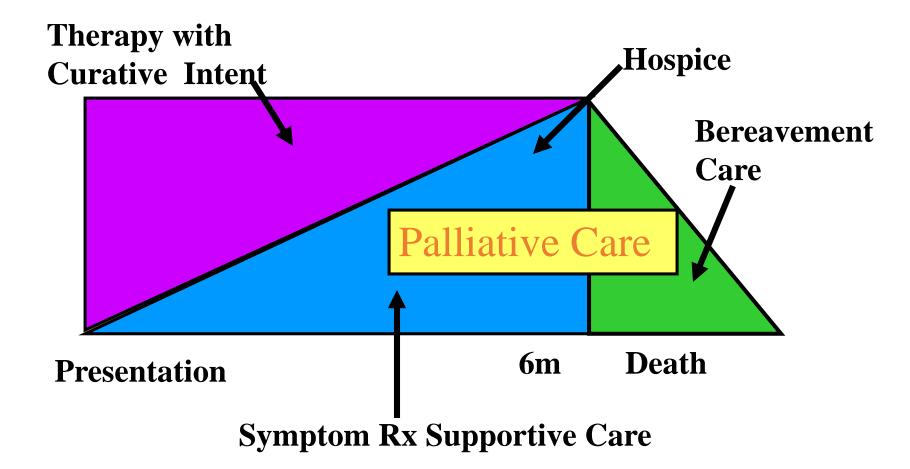
- Hospice is a program of care provided across many settings
- As people progress to the last phase of life, hospice provides comprehensive palliative care
- Hospice pts. often choose to discontinue disease modifying treatments and hospitalizations, opting for care focused on comfort and meaningful quality of life
- Hospice supports patients through the dying process and family support continues through
- н bereavement

- Palliative care is a "philosophy" of care which may include hospice at the end of life phase
- Palliative care begins at the time pf diagnosis of a serious illness
- May be used to complement curative care, other therapies that are appropriate to the goals of care
- Palliative care patients often use disease modifying treatments concurrently with excellent symptom management & begin discussions regarding end of life issues and advanced care planning

Hospice vs. Palliative Care

- Palliative care is <u>**not</u>** synonymous with terminal illness, though there is usually a terminal phase of palliative care.</u>
- This terminal phase tends to be regarded by many acute care hospitals and healthcare providers as the <u>only</u> appropriate time for palliative care.
- However, palliative care can begin <u>earlier</u> in the treatment plan and extends through hospice and beyond end of life to family and loved ones.
- Treatment will <u>enhance quality of life</u> and might <u>positively influence</u> the illness

Palliative Care



Palliative Care Indicators

- Progressive disabling disease
- Frequent hospitalizations
- Life limiting illness
- Quality of life challenges
- Any patient with a condition producing pain or other symptoms which can and must be relieved, reduced, soothed, and prevented.....

Services Provided

- Pain & symptom management
- Family conferences to assist with goals of care and advanced care planning
- Patient & family education & support
- Decisions about artificial nutrition & hydration
- End of life care
- Assistance with discharge planning
- Collaboration with hospice providers
- Advance directives/medical code status

Role of Social Worker

- Assess patient's and family's needs
- Provide helpful information
- Facilitate reviewing personal history and wishes
- Discuss what to expect in dying process
- Discuss ways of honoring and remembering a person
- Offer culturally and spiritually sensitive grief and loss counseling
- Acknowledge death when it occurs

Small Group Discussion of Relevance to Your End-of-Life (EOL) Care Settings



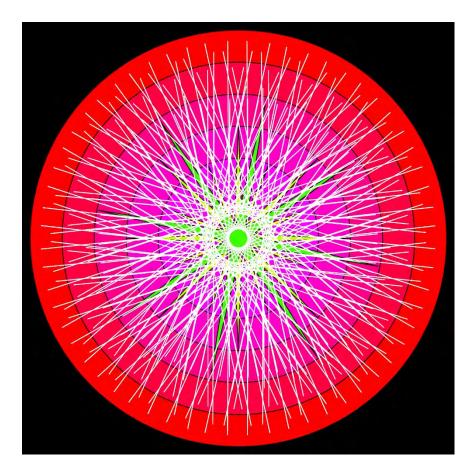
- 1. What specific practices and programs are used to recognize and respond to spiritual diversity?
- 2. How do you express compassion in your EOL work? Give one story.
- 3. How do palliative care and/or hospice function in your setting, if at all? What is similar or different from what we described?

End of Morning Session



How to Have Palliative Care Conversations

- •Comfort
- •Burden-vs-Benefit
- •Suffering
- •Support
- •Quality of Life
- Patient Autonomy



Spiritual Strengths Assessment



- Emphasis on implicit, open ended exploration
- Center on client and family's beliefs and culture
- Priority on client's interest, readiness, and comfort,
 - Including involvement of family and other loved ones and carers, as relevant to client's goals

Case Example: "I am an atheist"



This was a retired biology professor who taught many medical doctors and scientists.

He became disabled at young age from an accident.

Case Example: "Seeing God"



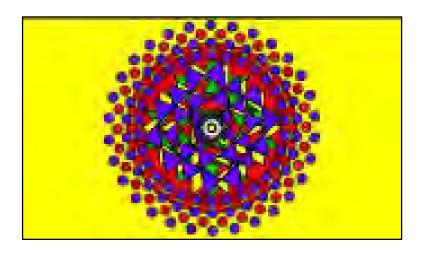
This was a 69 year old, married male who died from heart attack clinically but came back to life after he experienced seeing God.

He had to resolve conflicts with his children first before he could die.

Spiritually Focused Assessment

• Purposes for Spiritual Assessment

- Spiritual assessment can be therapeutic in itself, engendering client **insight**.
- Spiritual assessment can identify:



- Importance of spirituality in the client's life and family, community context
- Components of the client's spiritual perspective relevant to the focus of helping
- **Client's** *interest* in addressing spirituality within the helping process
- **Proper fit** between client's spiritual perspective and the helping professional or agency

Client's desire for referral to or collaboration with spiritual mentors of particular religious or nonreligious spiritual perspectives and styles

 Ways in which the client's past and present spiritual beliefs, values, practices, and group participation (if any) are *helpful or harmful* to self-esteem, coping, wellbeing, and to dealing with the presenting issue • Specific *spiritual strengths*, such as inspirational religious or philosophical texts, music, art; enjoyable participation in religious or nonreligious spiritual support groups; personal practices of prayer, meditation, rituals; spiritually motivated healthy lifestyles; nurturing connection with God, nature, and other sources of profound meaning, sacredness, or transcendence; sense of life meaning and purpose; sources of joy, peace, harmony; qualities of empathy, compassion, wisdom, kindness, generosity, and other virtues; ability to forgive and be forgiven; effective ways of working through challenges and crises; spiritual mentors, healers, and friends

- Spiritually based complementary or alternative healthcare and support practices (such as prayer, ritual, healing visualization, yoga, tai chi, acupuncture, herbs) that might interact with and support helping activities and medications
- Attitudes about death and the afterlife, especially in bereavement counseling and hospice
- The nature of past or recent *peak or pit experiences* that shape the presenting issue
- Intergenerational and current *family and cultural patterns* pertaining to spiritual perspective and relationship dynamics

Understanding Spirituality

- Spirituality relates to sources of life meaning, purpose, hope, and connection to what has greatest importance to the person.
- Consumers take the lead in defining and naming this, such as spirituality, religion, faith, culture, or worldview.
- Notice and follow their terms such as God, Higher Power, nature, the universe, personal medicine, vision, voice, spirits, angels or anything else.
- Spirituality may be connected with any or all life domains.
- Provider's role is to seek understanding of the person's view, not to impose beliefs, judgments, or terminology.
- Providers focus on the function, actions, and results of people's engaging spirituality related to their recovery goals.
- When necessary to start conversation, providers use a tentative definition of spirituality that is consistent with professional ethical standards (such as bullet 1 and 2 above) and then follow the cues of the consumer.
- Spirituality can sometimes involve difficulties and struggles, such as excessive guilt, bad experience in a religious group, or aggravating symptoms. If so, address within the consumer's recovery goals.

For related information and resources:

- Rapp, C. A. & Goscha, R. J. (2012). The Strengths Model: A Recovery-Oriented Approach to Mental Health Services, 3rd ed. New York: Oxford University Press,
- Starnino, V. R., Gomi, S., & Canda, E. R. (2012). Spiritual strengths assessment in mental health practice. British Journal of Social Work, doi:10.1093/bjsw/bcs179.
- Gomi, S., Starnino, V. R., & Canda, E. R. (2013). Spiritual assessment in mental health recovery, Community Mental Health Journal, doi: 10.1007/s10597-013-9653-z

Spiritual Diversity and Social Work Initiative: http://spiritualdiversity.ku.edu/

Center for Mental Health Research and Innovation: http://mentalhealth.socwel.ku.edu/

This resource was developed by: The Spiritual Diversity and Social Work Initiative & The Center for Mental Health Research and Innovation, School of Social Welfare The University of Kansas

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Assessing Spirituality Within the Strengths Model of Mental Health Recovery

Purpose

This pamphlet provides guidelines for assessing spirituality when using one of the primary tools of the Strengths Model: the Strengths Assessment.

The Strengths Model supports the mental health recovery process by focusing on people's personal and environmental strengths and resources. A Strengths Assessment assists the worker and client to explore collaboratively the strengths and resources a person can use to achieve meaningful and important life goals.

The Strengths Assessment identifies strengths in various life domains including:

Home/Daily Living Assets (Financial/Insurance) Employment/Education Supportive Relationships Wellness/Health Leisure/Recreational Spirituality/Culture

The recommendations included in this pamphlet focus on assessment of spirituality in the Spirituality/Culture domain and also as it may connect with any other life domain.

Principles for Assessing Spirituality

- · Use a person-centered approach.
- Develop a trusting therapeutic relationship.
- · Support the person's strengths and resources.
- Identify and describe them in usable form.
- Engage in natural conversation.
- Use a flexible and individualized approach.
- Focus on the person's priorities.
- Assess the person's readiness and interest.
- · Identify whether the person wishes to address spirituality in the recovery process.
- If the person wishes to address spirituality. then identify relevant goals as connected to any life domain.
- · Identify practical actions to achieve the goals.
- · Encourage the actions, and, if the client wishes, assist.
- If there is no interest, discontinue.
- Offer questions and suggestions as invitations to clients, not as expectations,
- · Choose, adapt, or change our suggested questions (see other side) to fit the situation.

Suggested Questions for Assessing Spirituality

When beginning a conversation about spirituality, some words you can use:

Indirect Approach

- · What gives you hope?
- What helps you feel good about your life?
 Tell me about a time in your life when you really felt at peace.
- When do you feel most positive toward yourself?
- · What brings inspiration to your life?

Direct Approach

- How do you use spirituality (or religion, faith, etc.) to get through tough times? For example, do you meditate, pray, go to a religious event, visit nature, or do any rituals?
 Holidays are coming soon. What are your plans or family celebrations?
 Is spirituality important to you? If so, how?

- What motivated you to start your spiritual journey in life?
 Has spirituality been helpful to you? Would you be willing to share examples?

Following up when clients mention about spirituality:

Inviting More Conversation

- · You mentioned your spirituality (or religion, faith, etc). Is it okay if I speak with you more about it?
- You mentioned that your (family member, friend, religious group, or mentor, etc.) helps you with your spirituality. Could you say more about that?

Following up: [Regarding anything mentioned]

Please give a specific example of how that works for you.

Moving to Action

- You described what gives you a sense of hope (or peace, inspiration, etc.), Would you like to talk more about how this might connect with your recovery goals?
 You mentioned ways that spirituality (or religion, faith, etc.) has been (or is) helpful to you. Would you like to discuss how that could be applied to your recovery goals?
 You mentioned ways that you've had difficulties or struggles with spirituality. Would you what you've had difficulties or struggles with spirituality. Would you have that you've had difficulties or struggles with spirituality.
- you like to address that in your recovery goals?
- · Can you describe (the spiritual strength) in terms of something specific you can do to support your goals?
- · Can you share examples of how you can use (the spiritual strength) to support your goals?
- . Would you like to take this action on your own or would you like me to play a role in helping?
- Would you like help to access any supports or sources of information that could help you
 take this action? If so, please tell me what I should keep in mind about your beliefs and interests to help me make this connection.

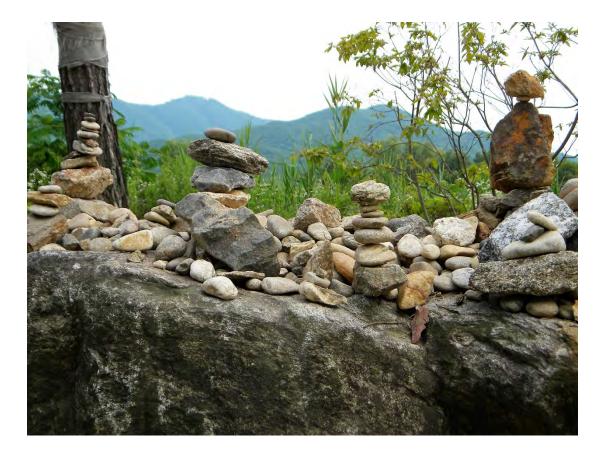
Adapting Flexible Questions to End of Life Settings

- When you think about your [choose an appropriate word to match the client's situation and comfort level: such as "current situation, diagnosis, illness, approaching death"]
 - What helps you to find a sense of peace, harmony, happiness, or comfort?
 - What are the most important things you want to accomplish?
 - What has been a source of hope, wisdom, or coping in the past that you could apply to this situation?
 - What connections with people, nature, or spiritual beings or energies are most valuable to you?
 - If you have any important beliefs, rituals, or practices of meditation or prayer, please describe how they relate to your situation? How might they be helpful or not helpful?
- Follow up with explorations, such as "please tell me more about that" or "please give an example" or "please tell me a story about that".

Moving to Action

- You described [whatever you noticed as main message of the client] as being valuable or helpful to you. Would you like to talk more about how this might be important to your present situation?
- You mentioned ways that you have had difficulties or struggles with [whatever you noticed as main message of the client]? Would you like to talk more about how this might be important to your present situation?
- Please describe how you can use [any religious/spiritual or other support or resource identified] to help you deal with your situation in the best way?
- You identified that [whatever is main goal] is something you want to accomplish. What can be done to help accomplish that?
- Would you like to take this action on your own or would you like me or someone else to help you to do this?
- Let's plan the next activity to help make this happen.

Audience Application Exercise and Discussion



Follow ups: Please tell me more about that. Please tell a storyED about that. Please give an example of that.

- What helps you to find a sense of peace, harmony, happiness, or comfort?
- What are the most important goals in your life? How do they relate to your present situation?
- What was a source of hope, wisdom, or coping in the past that you could apply to your current situation?
- What connections with people, nature, or spiritual beings or energies are most valuable to you?
- If you have any beliefs, rituals, or practices of meditation or prayer that are important to you, please describe them.

Audience Feedback Requested



- What was your experience asking the questions?
 - What worked well or could be improved?
- What was your experience answering the questions?
 - What worked well or could be improved?
- How did you need to adapt the wording to be comfortable or relevant in this situation?
 - In English
 - In Chinese

Methods to Promote Professional Development for Workers



Qualities of the 'Splitting Apart' Hexagram from the Chinese *Book of Changes (#23)*

- Mountain above Earth
- A collapsing structure (like a roof about to fall in)



- Nurturing and supporting (earth)
- Stability, equanimity, elevation of consciousness, openness to Heaven, and generosity to those below (mountain)
- Hexagram image from <u>http://www.ichingmeditations.com/ching-hexagrams/hexagram-23-splitting-apart/</u>
- Left photo of Canadian Rocky Mountains

Supports for Professional Development

• For Self

- Mindfulness practices
 - Nonjudgmental clear awareness of moment to moment
- Processing Complex or Stressful Thoughts and Feelings
 - Journaling
 - Clinical supervision
 - Discussion with trusted colleagues and friends
- Staying Energetic and Vibrant
 - Exercise, sauna, yoga, tai chi, etc.
 - Religious/spiritual rituals, meditation, prayer

For Work Setting

- Continuing Education workshops for staff/volunteers
- Individual ongoing continuing education, supported by organization with release time and funding
- Teamwork meetings of mutual support, beyond just task work
- Need beautiful spaces for practice of quiet, reflection, meditation
- Inspirational and calming decorations in personal and public spaces
- Engagement with nature within and around the work place

Collaboration and Referral Methods for Spiritually Sensitive EOLC



Palliative Care Consulting Team (PCCT)

- The PCCT is an interdisciplinary team (IDT)
- Palliative Care patients experience aspects of physical, emotional, spiritual, & social issues in life. As do their families...
- The PC IDT incorporates expertise in each area to promote a more effective holistic approach to the complex needs of patients & families



The PC Team, continued

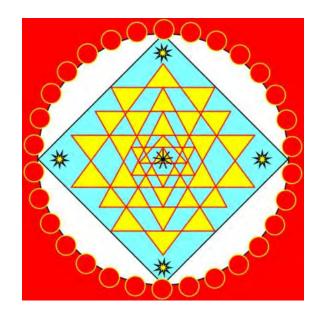
- Excellent communication
- Team conferences
- IDT approaches to patient/family meetings
- Role blending to provide coordinated, comprehensive care
- Roles are dynamic, changing, growing, and overlapping
- This requires close TEAM WORK....

The Palliative Care Consultation Team at LMH aims to:

- Address physical, spiritual, and emotional suffering
- Support family and caregivers
- Facilitate goals of care and decision making
- Communicate patient's wishes for care to other providers
- Provide educational opportunities for patients, families, community organizations, & health care providers.

Examples of Referral

- Religious and Cultural Support Systems, e.g.
 - Christian
 - Buddhist
 - Native American



- Importance of Knowing Resources in the Community and Best Match to client interest and comfort
 - Proactive study of spiritual diversity in client/patient population and the community and making connections
 - Discussion with client

Case Example: "Going Home"– Hospice

- An African American woman was admitted to Intensive Care Unit one day after becoming a hospice care patient at daughter's home in Lawrence.
- She had bi-lateral above knee amputations, diabetes, dialysis dependence, and pneumonia. She was unresponsive but breathing.
- She was visiting a daughter in Lawrence but her home was 1,000 miles away from here.
- She never spent a winter in a cold climate.
- The daughter who lives with patient in another state wanted to take her 'home."

Audience Small Group Discussion of Application



What did you learn from this workshop that can be applied in your setting?

What needs to be changed or improved in order to be applied in your setting?

Please prepare to report to the audience at least one example of each.

Q&A and Conclusion



Note:

- All photographs are by Ed Canda from a Korean lotus garden; all mandalas are by Ed Canda
 - All online-based images are from Creative Commons, unless indicated otherwise

Recommended Readings

- Spiritual Diversity in Social Work Practice, 2nd edition, by Edward R. Canda and Leola Dyrud Furman (Oxford University Press, 2010).
- *Spirituality, Religion, and Aging,* by Holly Nelson-Becker (Sage, 2018).
- Integrative Body-Mind-Spirit Social Work, 2nd edition, by Mo Yee Lee et al. (Oxford, 2018).
- The Journal of Social Work in End-of-Life & Palliative Care
- National Hospice and Palliative Care Organization (USA) website:
 - https://www.nhpco.org
- Hospice Fact Sheet for Spiritual Care Staff:
 - <u>https://www.dom.pitt.edu/dgim/iepc/HospiceFactSheets/SpiritualCare.pdf</u>
- Introductory Guide to Hospice and Palliative Care Social Work
 - <u>https://www.onlinemswprograms.com/features/guide-to-hospice-palliative-care-social-work.html</u>