



INTEGRATING PALLIATIVE CARE INTO THE PCMH-N MODEL

Spiritual, Religious, and Existential Aspects of Care

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Welcome

- Thank you for attending this event. Please ensure you sign in using link in chat box.
- Disclosure information can be found on this PowerPoint presentation.
- Please make sure you attend the entire session and complete the evaluation. Evaluation will be shared at the end of session and link will be included in a follow up email.
- You will receive your CME/CE Certificate after completing the evaluation.
- Deadline for evaluation is 10 business days after training.
- We will be using Active Learning Strategies to support this assessment, such as break out sessions, polling during presentations and question and answer opportunities.
- It is important that you communicate with us that the content presented is clear, understandable and useful for you.
- Please ask questions and seek clarification whenever you have a concern.
- We need for you to share your wisdom and feedback with us.



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Requirements for Completion

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- Complete evaluation. Evaluation will be shared at the end of session and link will be included in a follow up email.
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Social Work

This course is approved by the NASW-Michigan Social Work Continuing Education Collaborative Approval # 121621-01, # CE Hours approved: 2



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Presenter

Frances Jackson, PhD, RN, PRP



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Learning Objectives

- Define spirituality and religion.
- Describe how spirituality impacts the dying patient and their loved ones.
- Discuss the influence of spirituality on the palliative care process.
- Illustrate the role of the palliative care provider in spiritual care.



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Spirituality and Religion

Group Discussion

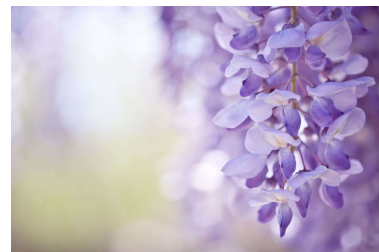


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Discussion

- Define religion.
- Define spirituality.
- Differentiate between the two.
- Can one be spiritual but not religious?
- Conversely can one be religious, but not spiritual?
- Why is any of this important and what does it have to do with end-of-life care?



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Exercise

- Write down 5 things you want to accomplish in your life before you die.
- Now, I want you to do a second list. Only now, you've been told you have one year to live. Twelve months. Write down 5 things you want to accomplish before you die.
- How are the lists the same and how are they different?



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Spirituality and Religion

The Importance of Spirituality and Religion



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The Importance of Spirituality and Religion

Serious Illness vs. End of Life

- *The domains presented in this training have, by design, focused on serious illness, not just terminal care.*
- Many of the issues presented affect both groups.
- However, as most of you can tell, addressing spiritual concerns when you are seriously ill is not the same issue as addressing spiritual concerns when the prognosis is limited.
- Spiritual concerns can be an issue of concern for all patients/clients regardless of diagnosis.
- This presentation will focus on patients who are terminally ill.
- However, the tools that will be discussed can be applied to all patients, regardless of their status.



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The Importance of Spirituality and Religion

Focus

- There is a logical emphasis on the diseases and conditions associated with terminal illness.
- It is important to view the dying person less as a disease to be treated, and more as a person living within a rich and multidimensional life context.



The focus must be on the person, not the diagnosis or the medical problem.



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The Importance of Spirituality and Religion

Spiritual Concerns

- There are a multitude of concerns raised by people diagnosed with terminal illness (Kaut, 2002), including:
 - Physical issues
 - Cognitive and emotional problems
 - Decisions regarding treatment and preparations for the EOL
- In addition, there are concerns about family members and relationships.
- There are fears and anxieties regarding death itself.



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The Importance of Spirituality and Religion

Spiritual Issues



- Amid all of the complex, and inter-connected issues, the bio-medical, social-emotional, and logistical EOL concerns, spiritual concerns emerge as a major area of need (Kaut, 2002).
- Indeed, some researchers argue that spiritual issues are central to the human crisis that develops once a person is told they have a terminal illness.



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The Importance of Spirituality and Religion

Professional Responsibilities

- We have a responsibility to focus beyond the bio-medical and physical aspects of terminal illness.
- We also have a responsibility to intervene with, assess, monitor and discuss the spiritual/religious concerns of our terminally ill patients and clients.

The focus for health care professionals (HCP) is to help the dying person navigate his or her own personal spiritual landscape in a way that **promotes acceptance of life and preparation for death.**



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“Do we not have a right as we are dying,
not only to have our bodies treated with respect,
but also and perhaps even more important, our spirits?
Shouldn't one of the main rights of any civilized society,
extended to everyone in that society,
be the right to die surrounded by the best spiritual care?
Can we really call ourselves a civilization
until this becomes an accepted norm?”

Sogyal Rinpoche, 1992, p. 209



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The Importance of Spirituality and Religion

World Health Organization Definition

- WHO defines EOL care as the active, total care of patients whose disease is not responsive to curative treatment.
- *When control of pain, of other symptoms, and of psychological, social, and spiritual problems are paramount.*
- There is evidence that how one thinks, feels, and copes with an illness can impact bodily symptoms, illness progression, and ultimately, one's prognosis.



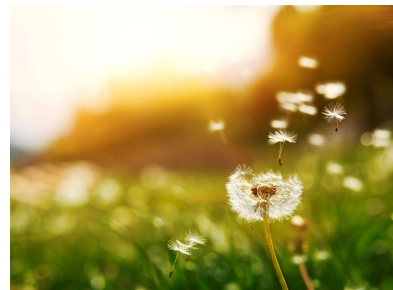
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The Importance of Spirituality and Religion

Spirituality

- Spirituality is often the foundation that gives individuals a sense of the meaning and purpose of life.
- A sense of meaning helps create unity of challenging life circumstances, like dying.
- In this context, atheism is also a belief system. That that belief system holds that religion is unhelpful or harmful doesn't matter. It is still a belief system.



Spirituality is about a journey
to find meaning and acceptance



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Spirituality and Religion

Definitions



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“Spirituality is a journey that typically encompasses the search for existential meaning, whether in the context of a well-defined religion or not. The search may, or may not, include a sacred component or a belief in an entity greater than oneself. Thus, spirituality is defined as the ways in which people understand and seek transcendent meaning and value.”

Sulmasy, 2002



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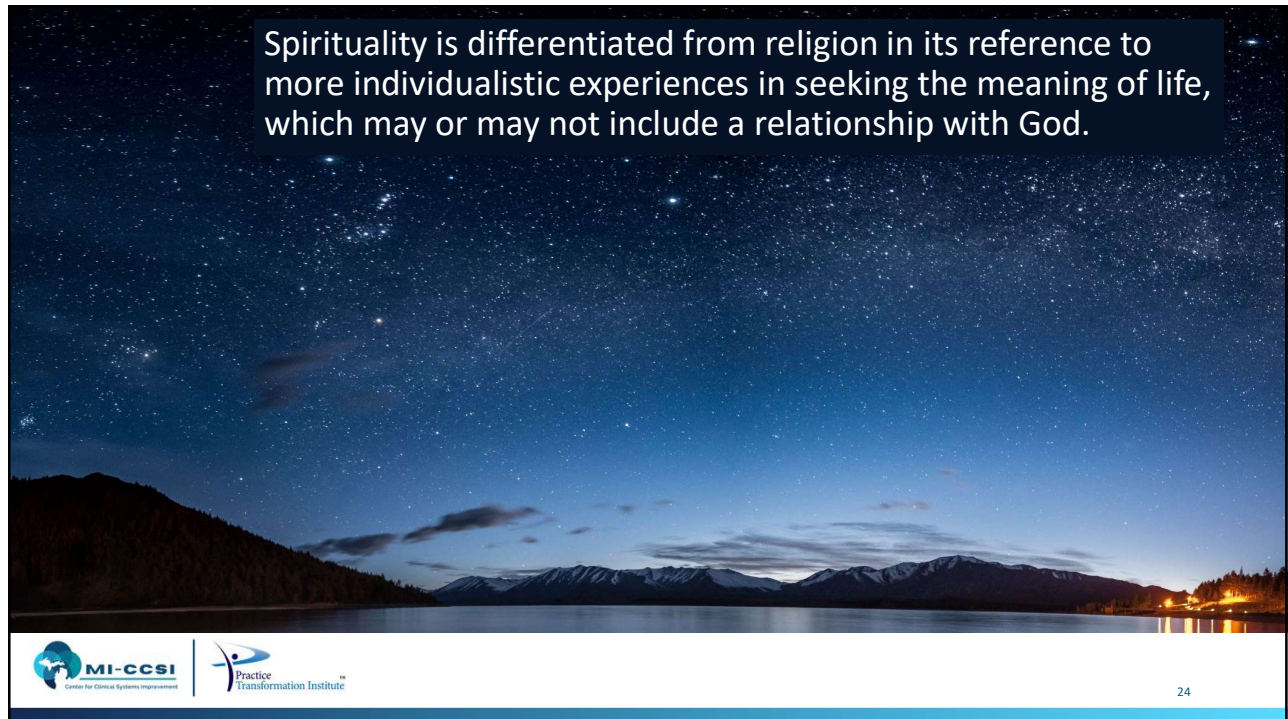
Existentialism



- Existentialists believe that we are born without purpose into a world that is irrational.
- We are self-determining agents who make meaningful, authentic choices and find our own meaning.
- The nature we have as humans is the nature we make for ourselves. Thus, our choices and actions are very important.
- We decide for ourselves what is right or wrong and what is good or bad.

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Spirituality is differentiated from religion in its reference to more individualistic experiences in seeking the meaning of life, which may or may not include a relationship with God.



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Spirituality

5 Attributes that describe the essence of spirituality at the EOL

1. Meaning

Deriving purpose in one's existence, making sense of one's life.

2. Belief

Spiritual and religious beliefs facilitate hope and something to believe in.

3. Connecting

Relationships with self, others, a Higher Power, and nature.

4. Transcendence

An experience and appreciation of a dimension beyond the self; expanding self-boundaries.

5. Values

Including cherished beliefs and standards, related to truth and beauty, and those things that are worthy of thought.



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Religion

Definition



- Some argue that religion is associated with rigid, social structures and institutions.
- Religion refers to both the outward demonstrable practice of spiritual understanding and the collective framework of beliefs, values, codes of conduct, and rituals, specific to a particular group of believers.
- Thus, religion is a more orthodox form of spirituality.



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Religion vs. Spirituality

- *Not everyone has a religion.*
Sulmasy, 2002
- Anyone who is seeking for ultimate meaning of their life, has spirituality.
- It can be argued that the issues surrounding the meaning of life, the value of life, life's relationships are particularly important for the palliative patient, regardless of their religious/spirituality beliefs.



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Spirituality and Religion

“To die believing that one’s life and death have been of no value is the ultimate indignity.

To die believing that there is no meaning to life, suffering, or death is abject hopelessness.

For the clinician to ignore these questions at the time of greatest intensity may be to abandon the patient in their hour of greatest need.”

Sulmasy (2002)

What does this statement mean to you as a HCP?



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Spirituality and Religion

Influence of Spirituality on Serious Illness Care



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Influence of Spirituality on Serious Illness Care



- We treat the patient as a whole person by addressing their unique life experiences, exploring their values and how that affects their EOL decisions, and exploring their beliefs with the goal of promoting and supporting a sense of personal dignity.

Moss & Dobson, 2006

- If the goal is holistic patient management, then we have to adopt a broad perspective that includes the spiritual/religious dimension of our patients.

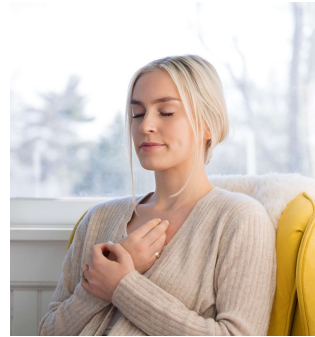


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Influence of Spirituality on Serious Illness Care

- For most people, their spiritual/religious belief system creates a lens through which the individual interprets and reacts to the dying process.
- If you want to help them navigate that process, if you want to help them to find meaning in their living and their dying, then the spiritual/religious realm has to be addressed ***to the extent the patient wants it explored.***



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Influence of Spirituality on Serious Illness Care

- To some, the nature of spirituality is most readily reflected in religious tradition. Kearney & Mount, 2000)
- This tradition is a source of meaning for billions of people around the world.
- The history, rituals, sacred writings, and other symbols associated with religious beliefs not only provide direction and purpose in life, but they also serve as a source of strength and structure as death approaches.
- In one study, 90% of the respondents reported that being at peace with God was a major issue for them as they approached death.

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Influence of Spirituality on Serious Illness Care

- For some people, there is a strong need to reconcile before they die.
- They want to resolve age-old family conflicts.
- They want to try and fix issues and problems that may have festered for years.
- And many of them want to reconcile with a higher power.
- For some, the religious dimension of spirituality may be most evident in this need for religious reconciliation and asking for forgiveness.



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Influence of Spirituality on Serious Illness Care

- When spirituality and EOL intersect, even the person who is not religious may want to examine the essence of self and their existence.
- For some, spirituality becomes this gestalt – that is the summation of diverse aspects of life that collectively gives meaning to a person's existence.
- This search for personal meaning becomes a major issue for many terminally ill patients.
- The final work of our lives is to make meaning of our life and come to terms with our death.

Kaut, 2002



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Religion and Serious Illness Care

- In EOL care, religion and religious traditions serve 2 primary functions:
 - It provides a set of core beliefs about life events; and
 - It establishes an ethical foundation for clinical decision making
- Religious doctrine provides a framework for understanding the human experience of death and dying for patients, family members, and HCP.

Daaleman & VanderCreek, 2000, p. 2514



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Religion vs. Spirituality

- Religious and faith traditions may be part of the “scaffolding” that helps patients construct meaning as death approaches.
- Spirituality is often viewed as the actions and interactions of a person who is attempting to create a personally meaningful world.
- Many look for meaning in their life, regardless of afterlife beliefs.
- On your reference list is an article by Swihart (2020). It lists a large number of different religions and their beliefs about death, pregnancy, diet, health, rituals, and symbols.



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What's It All About?

- How does a person find meaning in their life? Most of it comes from external sources:
 - family
 - work/ important causes
 - higher power
- What is important is to view ***spirituality not as a compartmentalized feature of treatment***, but as an attitude that infuses the overall approach to whole-person care regardless of one's defined role in caring for the person who is seriously ill.



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Spirituality and Religion

Communications



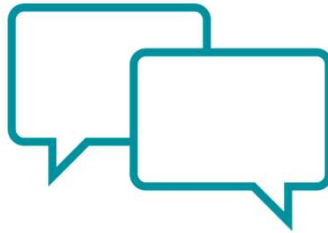
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The Role of the Palliative Care Provider

■ Communication

- This is an area of concern for most HCPs.
- There are patients who are not ready to discuss their mortality.
- Sometimes the family will ask staff not to tell a patient they are dying.



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What Not to Say

■ Avoid the following:

- I know what you're going through (I lost my mother too; I know what it means to lose one's mother).
- If it was me, this is what I would do.....

- These statements turn the focus away from the patient and focus instead on the HCP.



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What Not to Say

- Avoid the Christmas Present Syndrome.
- Don't try and answer unanswerable questions.
- Instead of focusing on the question, respond to the pain, focus on their feelings:
 - "This sounds like it is really difficult for you."
 - "What is the hardest part of this for you?"
- If you don't think of any of the above fits:
 - "Do you want to talk about it?"
 - "How can I help you?"



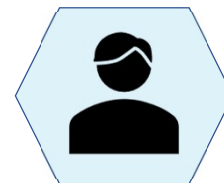
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What To Do or Say

Active Listening

1. Don't just respond to the words but listen for the meaning behind the words.
2. Reflect back what the patient is saying. It tells the patient that you are listening.
3. "You said this is really hard for you. Can you tell me more about that?" is a statement that reflects what the patient said, but also opens the door for them to further explore their feelings.



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What To Do Or Say

Affirm Their Life

1. When you have faced crises in the past, what helped you get through them?
2. What have you achieved that makes you the most proud?
3. Are there things you want or need to do that will help make things easier for you?
4. Encourage those who are interested, in writing a life review (dignity therapy).



What To Do Or Say

Recognize When You Need Help

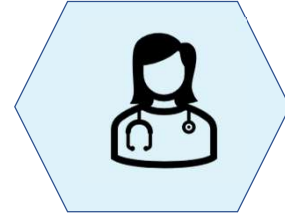
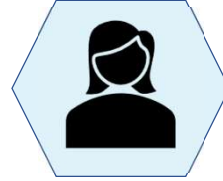
1. There will be that case where a chaplain consult might be best.
2. Facilitate calling in someone from their faith community.
3. Sometimes people really do need therapy to try and manage deep psychological issues and pain.



What To Do Or Say

Silence

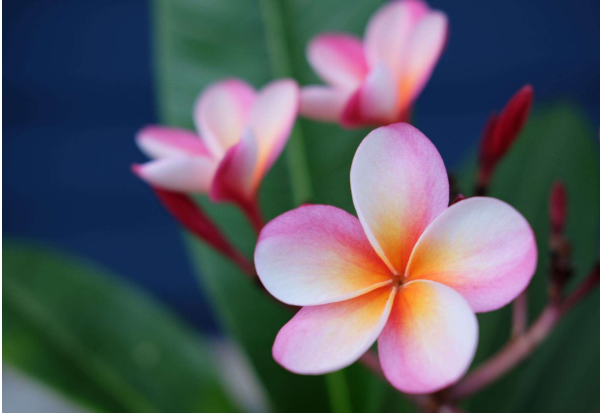
1. There may be times when your principal role is to “hear and accept” what the seriously ill person wants to say about their life.
2. Don’t feel the need to respond.
3. Sometimes the best communication tool is silence.



Spirituality and Religion

Assessments

Spiritual/Religious Assessment



- The process of spiritual assessment requires establishing a relationship with clients, usually over time.
- Asking specific questions about spiritual or religious beliefs are normally most effective when patients already have a specific religious or spiritual perspective on life and death.

Kagawa-Singer & Blackhall, 2001



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Spiritual/Religious Assessment

- There will be some patients where the focus will not be on religion.
- What may be needed more than anything is someone to listen to the patient's personal history and understand their struggle to assign meaning to life and death.
- Within that context, also identifying what physical and psychological issues and relationships are having the most impact on their journey can also be helpful.

Kaut, 2002

What makes this situation unique, is that death represents a problem with no solution.



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Spiritual/Religious Assessment

- A spiritual history is a starting point.
- It may or may not involve discussing God, a higher power or even religion.
- Some basic rules are:
 - Sit down, try to be at eye level
 - Tell the patient why you are there
 - Ask if this is a good time to talk
 - Tell them you want to do a spiritual assessment to make sure you and the other HCP are being responsive to all their needs and affirm that they are interested in doing an assessment



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Benefits of Spiritual Assessment

Deeper understanding of the patient

Gives direction on modifying the care plan to account for spiritual issues.

May result in a referral to a chaplain.

Can enhance trust between the patient and HCPs.

It is holistic care.

May alter the course of the illness.



Neely & Minford, 2009

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Assessment

FICA

Table 1. FICA Spiritual History Tool

Category	Sample questions
Faith and belief	Do you have spiritual beliefs that help you cope with stress? If the patient responds "no," consider asking: what gives your life meaning?
Importance	Have your beliefs influenced how you take care of yourself in this illness?
Community	Are you part of a spiritual or religious community? Is this of support to you, and how?
Address in care	How would you like me to address these issues in your health care?

Adapted with permission from The George Washington Institute for Spirituality and Health. FICA spiritual history tool. <http://www.gwumc.edu/gwish/clinical/fica.cfm>. Accessed March 10, 2011.

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Assessment

F.A.I.T.H.

Faith/spiritual beliefs

- Do you have any particular faith, religion, or spiritual beliefs?
- What gives your life meaning?

Application

- In what ways do you apply your faith in your daily life?

Influence

- How do your faith and spiritual beliefs influence your life, attitudes, behaviors

Talk/Terminal Events Planning

- Do you have anyone you trust to talk to about spiritual or religious issues

Help

- How can we help you



Breakout

FICA

F: What is your faith or belief?

- Do you consider yourself spiritual or religious?
- What things do you believe in that give meaning to your life?

I: Is it important in your life?

- What influence does it have on how you take care of yourself?
- How have your beliefs influenced your behavior during this illness?
- What role do your beliefs play in regaining your health?

C: Are you part of a spiritual or religious community?

- Is this of support to you and how?
- Is there a person or group of people you really love or who are really important to you?

A: How would you like me, your healthcare provider, to address these issues in your healthcare?

Instructions

1. In your dyad, determine who will be the patient and who will be the HCP.
2. Using your FICA Tool, the HCP asks the questions.
3. Patient:
 - How did you feel answering these questions
4. HCP:
 - Rate on a scale of 1-5 how comfortable were you asking these questions?
 - Identify which questions made you the most uncomfortable?
 - Report out for your group.

NOTE:

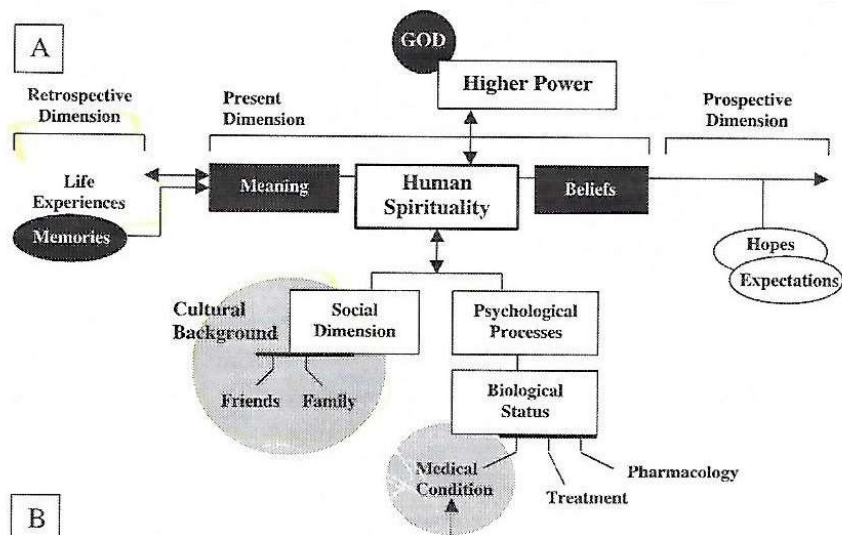
The first reference on the reference list, the article by Balboni, lists 16 tools that can be used for spiritual assessment. I encourage you to access that article if you would like to explore other tools that you might find useful.

There is also a non-profit organization for atheists and agnostics that might be helpful:
<https://centerforinquiry.org/about>



Assessment

Kaut Spiritual Model



Assessment

Kaut Spiritual Model

- This model is predicated on the belief that if a person is spiritual, their spirituality is likely to be expressed in observable attitudes, beliefs, and behaviors.
- Spirituality is who we are in the present, yet it also incorporates what we were in the past.
- Spirituality is also future-directed and may be translated into this hope of transcendence beyond the finality of life.
- The elements of a dying person's spiritual self can be defined according to his or her present beliefs within the context of historical influences and personal perspectives on existence beyond death.
- In this model, searching for and defining spirituality in the life of a dying person requires more than just asking "Do you consider yourself to be a spiritual person?"

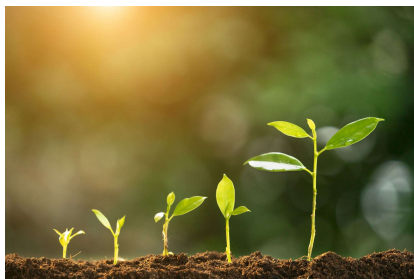


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Assessment

Kaut Dimensions



Retrospective

- The HCP Explores the patient's life experiences and the notion of "meaning."
- Memories provide a historical context that can influence a person's present spiritual dimension.



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Assessment

Kaut Dimensions

Present

- The HCP links the meanings derived from the Retrospective Dimension to how those life experiences and memories influence the present.
- Factors to consider include how one's cultural background, including family and friends, biomedical status, psychological processes, even current medical treatment affects one's current spiritual dimension.
- Together, the Retrospective and Present Dimension combine to form the patient's beliefs about spirituality.

Prospective

- The beliefs identified in the Present Dimension influence future hopes, fears, and expectations.



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Spirituality and Religion

Practice



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Breakout

Role Playing

- This exercise will use the handout pages 2 and 3.
- We will project the handout.

Instructions

1. Instructions
2. In your dyad, determine who will be the patient and who will be the HCP.
3. Act out the scenario on the left. Then act out the Good Communication scenario on the right .
4. The patient will
 - a. Reveal what was going through your mind when your HCP said the “wrong” things.
 - b. Contrast that with the HCP saying the “right” things.
 - c. Report out for your group.



HCP Script

The patient has terminal cancer. They are at home and you're at the patient's house in your professional role. Your "job" in this scenario is to say all the wrong things:

1. You'll be okay.
2. Stop your whining. Things could be worse. You could have died in your twenties.
3. You haven't figured that out yet?
4. I thought you were religious. How can you have any doubts about the future?
5. If I were you, I would.....
6. I don't know why you're worried about your kids. They have their own lives to live.

You: Hi Mr/Ms. Jones. How are you doing today?

Patient: I'm feeling a little down today.

You: Oh. Why is that?

Patient: Look, I know I'm dying. Normally, I cope with it pretty well, but today, I'm feeling more afraid of dying. I don't understand why this is happening to me.

You: You'll be okay. After all, you're not dead yet, right?

Patient: Well, no, but I'm worried about a lot of things. I'm worried about my kids. I'm afraid of death. What's it like to die? Will I suffer?

You: Well, it's not realistic to think anyone can go through life and not have some suffering
Patient responds and the two of you improvise.

Patient Script

You are at home. Your HCP is here. You have the following concerns:

- You're afraid of dying
- You're worried about your kids
- You're not sure what to do about your property
- You don't want to be in pain and you don't want to suffer

HCP: Hi Mr/Ms. Jones. How are you doing today?

You: I'm feeling a little down today.

HCP: Oh. Why is that?

You: Look, I know I'm dying. Normally, I cope with it pretty well, but today, I'm feeling more afraid of dying. I don't understand why this is happening to me.

HCP: You'll be okay. After all, you're not dead yet, right?

You: Well, no, but I'm worried about a lot of things. I'm worried about my kids. I'm afraid of death. What's it like to die? Will I suffer?

HCP: Well, it's not realistic to think anyone can go through life and not have some suffering

You respond and the two of you improvise

Instructions

1. In your dyad, determine who will be the patient and who will be the HCP.
2. Act out the scenario on the left. Then act out the scenario below.
3. The patient will
 - a. Reveal what was going through your mind when your HCP said the “wrong” things.
 - b. Contrast that with the HCP saying the “right” things.
 - c. Report out for your group.

Good Communication Scenario

Now let's do this again, but with good communication techniques. This time, the say things like:

1. This sounds like it is really hard for you
2. What do you fear the most?
3. How can I help you?
4. Do you want to talk about it?
5. Have you shared your concerns with your pastor? Would it be helpful to speak to him?
6. Using Good Communication Techniques

HCP: Hi Mr/Ms. Jones. How are you doing today?

You: I'm feeling a little down today.

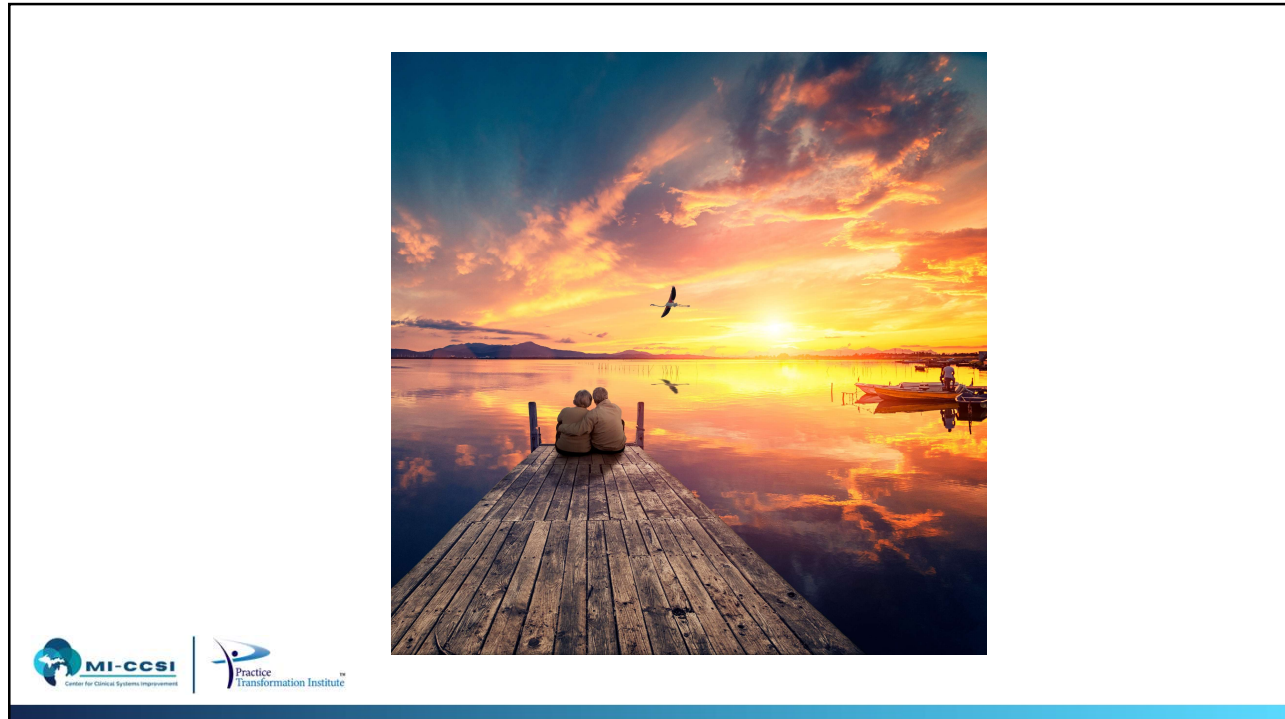
HCP: Oh. Why is that?

You: Look, I know I'm dying. Normally, I cope with it pretty well, but today, I'm feeling more afraid of dying. I don't understand why this is happening to me.

HCP: You say that normally you cope with this pretty well. Has something happened that's making it more difficult for you to cope with it today?

You: I'm worried about a lot of things. I'm worried about my kids. I'm afraid of death. What's it like to die? Will I suffer? I find I'm having doubts about my faith. Is there really a heaven?

HCP respond then the two of you improvise



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Assessment Spirituality and Serious Illness Handout

Box 1. Assessing the Spiritual Issues Raised by Serious Illness, Especially at the End of Life

First, establish an empathic connection with the patient (or the patient's family). Often, nothing more will be required to engage the patient in significant spiritual sharing. Only then, consider moving to more specific questions.

Opening

"It must be very hard for you to find yourself (your loved one) so sick. How are you holding up?"

Questions of Meaning

Patient/family questions

- "What is the meaning of my illness?"
- "What is the meaning of my suffering?"
- "What is the meaning of my death?"
- "Will any meaning persist beyond my death?"

Clinician questions

- "Have you thought about what all this means?"
- "Would there be anything for which you might hope even if you (your loved one) are not cured?"
- "Do you attach any spiritual significance to the word 'hope'?"

Questions of Value

Patient/family questions

- "How does my value relate to my appearance?"
- "... my productivity?"
- "... my independence?"
- "Is there anything about me that is valuable when these are threatened?"
- "Is there anything valuable about me that will persist beyond death?"

Clinician questions

- "Are you able to hold onto a sense of your own dignity and purpose?"
- "Do you feel that people in the hospital/your family/your friends/your congregation really care about you (your loved one) as a person?"
- "Are there any spiritual or religious resources upon which you can draw to help see you through this?"

Questions of Relationship

Patient/family questions

- "Am I estranged from any family or friends?"
- "Who have I wronged? Who has wronged me?"
- "Am I loved? By whom?"
- "Does love endure beyond the grave?"

Clinician questions

- "How are things with your family and friends?"
- "Is there anyone with whom you need to 'make up'?"
- "Is there anyone to whom you need to say 'I love you' or 'I'm sorry'?"
- "If you're a religious person, how are things between you and God?"

Closing Comments

"I can't do everything—that's why we work as a team. I think we've covered some very important ground here, but there's so much more to talk about. If it's okay with you I'm going to send Rev S to see you later today. Also, I'd like to tell her a little about what you've just shared with me, so she can be better prepared. Would that be okay?"

Based on Sulmasy.^{19(p97-112)}



Sulmasy, 2006

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Assessment

Hope Questions Handout

Table 2. HOPE Questions for Spiritual Assessment

Category	Sample questions
H: sources of hope	What are your sources of hope, strength, comfort, and peace? What do you hold on to during difficult times?
O: organized religion	Are you part of a religious or spiritual community? Does it help you? How?
P: personal spirituality and practices	Do you have personal spiritual beliefs? What aspects of your spirituality or spiritual practices do you find most helpful?
E: effects on medical care and end-of-life issues	Does your current situation affect your ability to do the things that usually help you spiritually? As a doctor, is there anything that I can do to help you access the resources that usually help you? Are there any specific practices or restrictions I should know about in providing your medical care? If the patient is dying: How do your beliefs affect the kind of medical care you would like me to provide over the next few days/weeks/months?

Adapted with permission from Anandarajah G, Hight E. Spirituality and medical practice: using the HOPE questions as a practical tool for spiritual assessment. Am Fam Physician. 2001;63(1):87.



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Learning Objectives Recap

- Define spirituality and religion
- Describe how spirituality impacts the dying patient and their loved ones
- Discuss the influence of spirituality on the palliative care process
- Illustrate the role of the palliative care provider in spiritual care



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Requirements for Completion

- Sign in and attend entire session.
- Complete evaluation. Evaluation will be shared at the end of session and link will be included in a follow up email.
- You will receive your CME/CE Certificate after completing the evaluation.
- Deadline for evaluation is 10 business days after training.



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Questions?

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Thank you

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