Spiritual Care Generalists and Specialists: Integrating Research and Practice

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Objectives

At the end of this presentation, participants will be able to:

1. Describe current initiatives in spiritual care research

2. Identify best practices for spiritual screening, history, and assessment

3. Utilize a communication framework to address hope and miracles

Clinical Practice Guidelines for Quality Palliative Care (National Coalition for Hospice and Palliative Care, 2018)

Domain 1: Structure and Processes of Care
Domain 2: Physical Aspects of Care
Domain 3: Psychological and Psychiatric Aspects
Domain 4: Social Aspects of Care

Domain 5: Spiritual, Religious, and Existential Aspects of Care: The spiritual, religious, and existential aspects of care are described, including the importance of screening for unmet needs.

Domain 6: Cultural Aspects of Care
Domain 7: Care of the Patient Nearing the End of Life
Domain 8: Ethical and Legal Aspects of Care

Spiritual Care Generalists? And Specialists?

More patient-centered

Truly holistic care

More collaborative

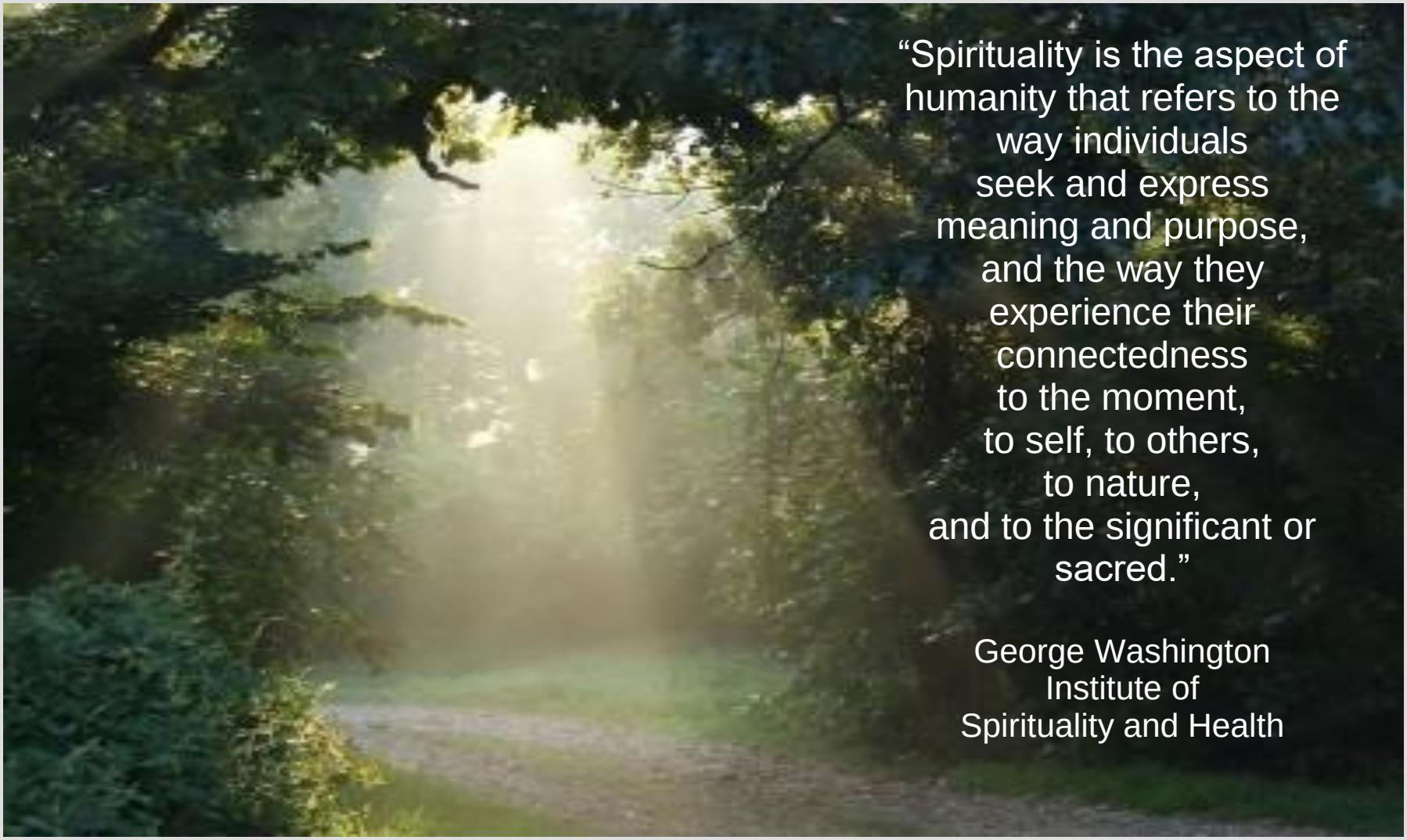
More professionally satisfying

Less isolating

More efficient

Social worker, chaplain, physician, physician, MD Fellow, NP Fellow

What is Spirituality?



Clergy and Chaplaincy work together

Religious Rituals / Practices:
Sacrament of the Sick
Unction / Anointing
Prayer / Chant / Meditation
Fasting / Burial Practices

Board Certified Chaplains: Patient-Centered Care

Board Certified Chaplains

"School is so much harder than being a hospital chaplain. You guys just go in, say Hi, ask people about their feelings, pray with them, and then they give you a hundred dollars. 2nd grade is SO much harder!" – my child

Evolution of Spiritual Care Referrals

From:
"The patient is dying and needs a prayer…"
"The patient is *very religious*, so they need a chaplain."
"They are *not religious*, so they don't need a chaplain."

To:
"The patient has spiritual distress about…"
"The family is talking about miracles and healing..."
"The patient is ready to die but sister wants her to fight…"

We address unmet spiritual needs.

Objective 1: What's the latest in Chaplaincy research?

- 1. Religion/spirituality is one of the most important resources for coping with serious physical illness.
- 2. Despite the importance of religion/spirituality to patients and their family caregivers and clinical guidelines, patient and caregiver spiritual concerns are frequently overlooked by healthcare professionals.
- 3. Spiritual distress is associated with poorer health outcomes.
- 4. Spiritual care is especially important for patients at the end of life.

1. Religion/spirituality is one of the most important resources for coping with serious physical illness.

65%-85% of cancer patients find that faith helps them “very much.” (Canada et al., 2013)

68% reported that religion was “very important;” an additional 20% said it was “somewhat important.” (Balboni et al., 2007)

325 Latin American patients with advanced cancer: 315 (97%) considered themselves spiritual and 89% considered themselves religious. (Delgado-Guay et al., 2021)

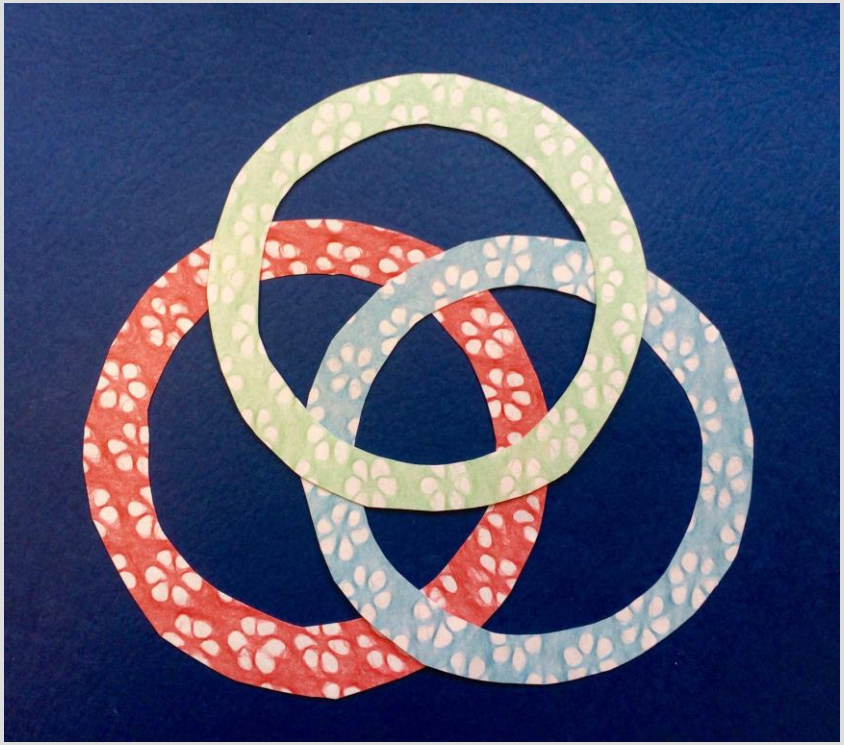
2. Patient and caregiver spiritual concerns are frequently overlooked by healthcare professionals.

- 249 goals-of-care conversations that took place in in 13 ICUs across the US were recorded, transcribed and analyzed.
- Discussion of religious or spiritual considerations occurred in 40 of 249 conferences (16.1%).
- In only 8 conferences, in response to surrogates' religious/spiritual statements, did health care professionals attempt to further understand surrogates' beliefs.
- Chaplains were present in only 2 of the conferences.

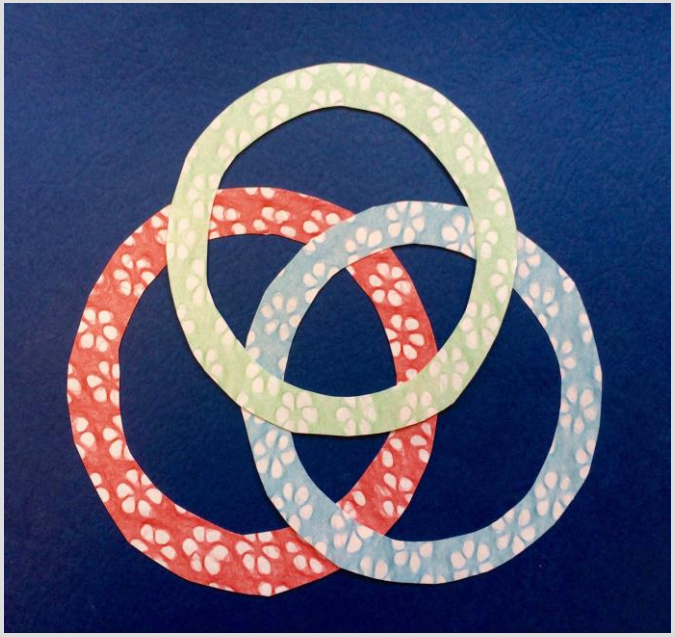
Ernecoff NC, Curlin FA, Buddadhumaruk P, White DB. Health Care Professionals' Responses to Religious or Spiritual Statements by Surrogate Decision Makers During Goals-of-Care Discussions. JAMA Intern Med. 2015 Oct;175(10):1662-9.

2. Patient and caregiver spiritual concerns are frequently overlooked by healthcare professionals.

- *Religious and spiritual (R/S) values* often guide meaning-making, coping, comfort, peace, quality of life, grief and loss
- R/S coping can be *negative* or *positive* and can profoundly affect decision-making



3. Spiritual distress is associated with poorer health outcomes.

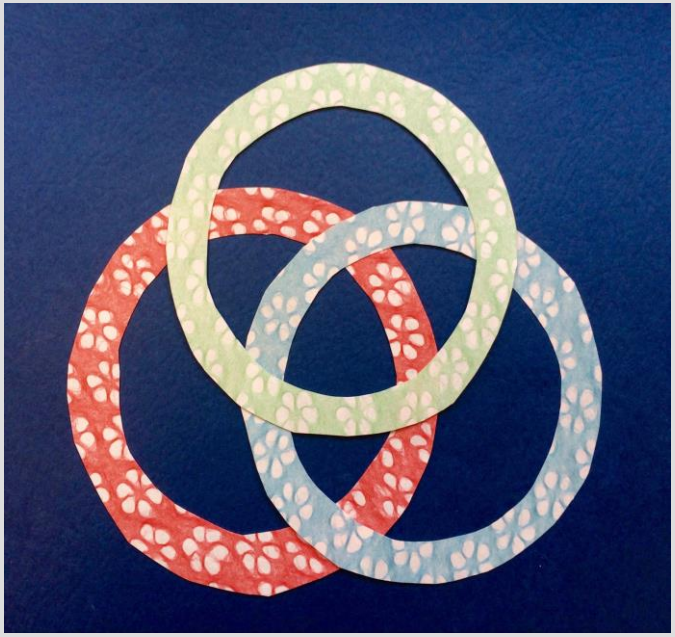


Spiritual Distress:

A person's "impaired ability to experience and integrate meaning and purpose in life through connectedness with self, other, art, music, literature, nature, and/or power greater than oneself."

Betty Ferrell and Christina Puchalski, *Making Health Care Whole*

3. Spiritual distress is associated with poorer health outcomes.



Greater physical pain. (Delgado-Guay, 2016)

Functional limitations, greater depressive symptoms, and poorer QOL among older medical patients. (Pargament et al., 2004)

Significant predictor of increased mortality among older medical patients, even after controlling for demographic, physical health, and mental health factors. (Pargament et al., 2001)

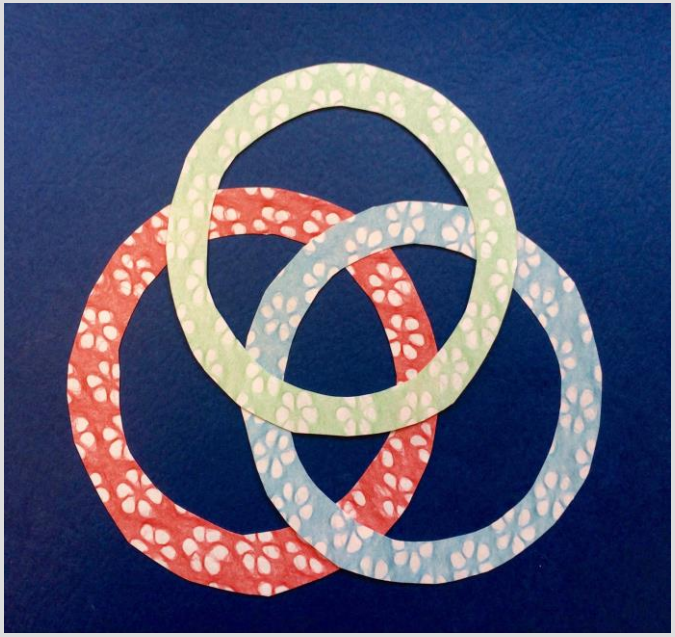
Increased risk of suicidal ideation. (Trevino, 2014)

Diminished QOL. (Jafari, 2015)

Increased anxiety. (Delgado-Guay, 2016)

Requests for euthanasia/PAD. (Radbruch, 2016)

4. Spiritual care is especially important for patients at the end of life.



When patients with serious illness received hospital-based spiritual care, they had **higher quality of life** at EOL and were more likely to receive **comfort-focused care** and **less likely to receive futile aggressive care** (ICU, ventilation) in the last week of life (Balboni et al., 2010).

Patients who reported their spiritual needs were inadequately supported by the health care team: **higher cost of care in the last week of life**; on average $2,100 higher compared to those who reported their spiritual needs were largely or completely supported by the health care team (Balboni et al., 2011).

Survey of 3,585 US hospitals: those with chaplaincy services had higher levels of patient enrollment in **home hospice care** (Flannelly et al., 2012).

Objective 2. Identify best practices for spiritual screening, history, and assessment

Spiritual History - Any Clinician

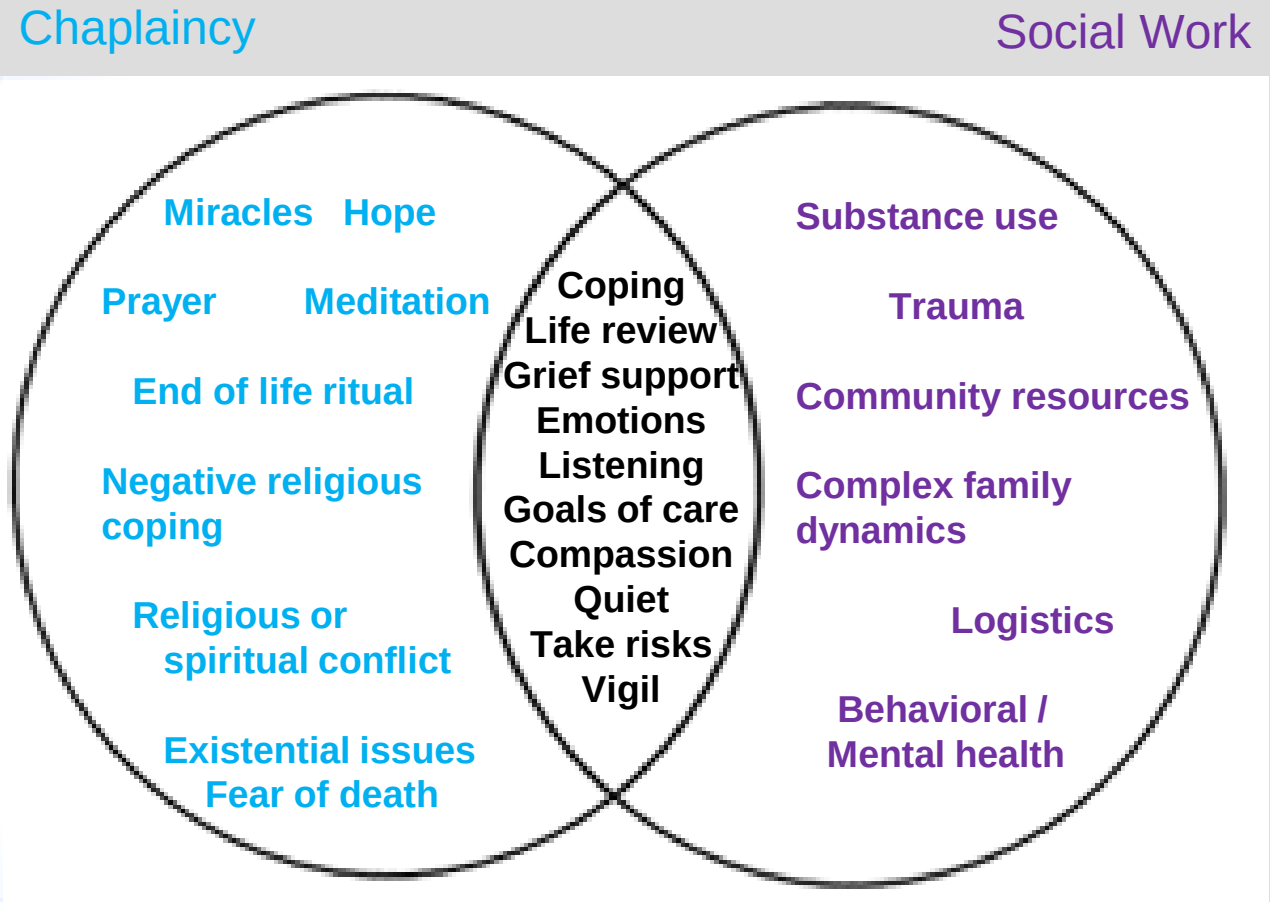
vs.

Spiritual Screen - Any Clinician

vs.

Spiritual Assessment - Chaplain

How do Chaplaincy and Social Work overlap?



What is a Spiritual History?

- Spiritual History can be done by any clinician

Questions to gather information about the patient's and family's background, community, religious/spiritual preference, and how this might impact care

Part of a good social history

Spiritual History Tool: FICA

F: Faith

Do you have a faith/spiritual belief? Do you have spiritual beliefs that help you cope with stress?

I: Influence

Are these beliefs important to you? How do they influence your care for yourself?

C: Community

Are you part of a spiritual or religious community?

A: Address

How would you like your provider to address these issues with you?

Puchalski CM, Romer AL. Taking a spiritual history allows clinicians to understand patients more fully. J Pall Med 2000;3:129-37. Copyright, Christina M. Puchalski, MD, 1996. Also see: www.gwish.org

What is a Spiritual Screen?

"A quick determination of whether a person is experiencing a serious spiritual/religious crisis and therefore needs an immediate referral to a professional chaplain…Good models of spiritual/religious screening employ a few simple questions, which can be asked by any health care professional in the course of an overall screening."

Fitchett, G., & Canada, A. L. (2010). The Role of Religion/Spirituality in Coping with Cancer: Evidence, Assessment, and Intervention. J. C. Holland (Ed.). *Psycho-oncology*, New York: Oxford University Press.

A Spiritual Screen Can Be Done by Any Clinician

Is your religious or spiritual practice important to you?
If so, how can we support you while you are here?

Where do you find strength?

What's keeping you going through all of this?

What's the hardest part of this for you?

What are you hoping for?
What are you worried about?

Spiritual Screening Tool – ESAS-FS

Can you rate your "spiritual pain" – pain deep in your soul/being that is not physical?

Delgado-Guay et al., 2016

Edmonton Symptom Assessment Scale (ESAS–FS)

Please circle the number that best describes your symptoms:

No Pain	0 1 2 3 4 5 6 7 8 9 10	Worst Pain
No Fatigue	0 1 2 3 4 5 6 7 8 9 10	Worst Fatigue
No Nausea	0 1 2 3 4 5 6 7 8 9 10	Worst Nausea
No Depression	0 1 2 3 4 5 6 7 8 9 10	Worst Depression
No Anxiety	0 1 2 3 4 5 6 7 8 9 10	Worst Anxiety
No Drowsiness	0 1 2 3 4 5 6 7 8 9 10	Worst Drowsiness
No Shortness of Breath	0 1 2 3 4 5 6 7 8 9 10	Worst Shortness of Breath
Best Appetite	0 1 2 3 4 5 6 7 8 9 10	Worst Appetite
Best Feeling of Well-being	0 1 2 3 4 5 6 7 8 9 10	Worst Feeling of Well-being
Best Sleep	0 1 2 3 4 5 6 7 8 9 10	Worst Sleep
No Financial Distress	0 1 2 3 4 5 6 7 8 9 10	Worst Financial Distress

(Distress/suffering experienced secondary to financial issues)

No Spiritual Pain	0 1 2 3 4 5 6 7 8 9 10	Worst Spiritual Pain

(Pain deep in your soul/being that is not physical)

Screening Triggers for Spiritual Assessment by a Chaplain

- Concerns about healing, hope, and miracles
- Religious or existential conflict within the family
- Struggles to find meaning
- Fear of death or dying
- End-of-life spiritual ritual
- Negative religious coping

Religious / Spiritual coping can be *positive* or *negative*

Positive religious coping

Prayers bring me peace

Negative religious coping

I'm afraid I'm going to Hell

Pargament, K. I. et al. (2000). The many methods of religious coping: Development and initial validation of the RCOPE. *Journal of clinical psychology*, *56*(4), 519-543.

What is a Spiritual Assessment?

"A more extensive [in-depth, on-going] process of active listening to a patient's story as it unfolds in a relationship with a professional chaplain and summarizing the *needs* and *resources* that emerge in that process. The summary includes a spiritual care *plan* with *expected outcomes* which should be communicated to the rest of the treatment team."

Fitchett, G., & Canada, A. L. (2010). The Role of Religion/Spirituality in Coping with Cancer: Evidence, Assessment, and Intervention. J. C. Holland (Ed.). *Psycho-oncology*, New York: Oxford University Press.

What Spiritual Assessment do we use?

PC-7 Spiritual Assessment: Fitchett et al., JPM 2019: the first quantitative, evidence-based spiritual assessment tool.

PC-7 being assessed in two current multisite studies: a prevalence study and a validation study.

"Describing the Prevalence and Correlates of Unmet Spiritual Concerns in Palliative Care Patients Near End of Life." MGH IRB Protocol Number: 2020P002899 (ongoing). PI: Byrne-Martelli. Multisite study.

PC-7 Spiritual Assessment: Fitchett et al., JPM 2019

Theme	**Indicators** (These indicators are meant to be suggestive not exhaustive)	Score
Need for meaning in the face of suffering	• The patient is having difficulty coming to terms with changes in things that gave meaning to life (e.g., grief related to key relationships, illness, frailty, dependency). • The patient expresses despair or hopelessness about these changes.	
Need for integrity, a legacy, generativity	• The patient questions the meaning of their life; whether the life they have lived has meaning. • Patient has painful regret about some or all of life they have lived.	
Concerns about relationships: family and/or significant others	• The patient has unfinished business with significant others (e.g., need to overcome estrangement, need to express forgiveness, need for reconciliation; unfulfilled expectations about others) • The patient has concern that they are a burden to their family/friends.	
Concern or fear about dying or death	• The patient has concerns about dying: unready for death, the patient is impatient for death. • The patient has fear of pain or of pain in dying	
Issues related to making decisions about treatment	• The patient needs assistance with values-based advance care planning • The patient is confused or distressed about end-of-life treatment or about making choices about end-of-life treatment.	
Religious/spiritual struggle	• The patient wonders whether they are being abandoned or punished by God. • The patient is alienated from formerly meaningful connections with religious institutions or leaders.	
Other Dimensions	• The patient identifies a need for assistance to perform important rituals, religious or otherwise. • Other spiritual concerns	

Applying the PC-7 Spiritual Assessment

"I'm so weak. I can't even pick up my five year-old. All I can do is sit in a chair. I'm not who I used to be."

Meaning in the face of suffering

"If I can't get these legal issues settled, and bring justice to my daughter, then my life will have no meaning. My whole life will have been for nothing."

Need for integrity, a legacy, generativity

"My daughter needed me. And I wasn't there for her. I'm all she has. And now she is going to be alone."

Concerns about relationships

Applying the PC-7 Spiritual Assessment

"I saw my Dad die at home and it was horrible. I don't want to die like that."
"I don't think I'm going to see my Mom in Heaven. She was amazing. I've done a lot of bad things in my life. I should have known better."

Concern or fear about dying or death

"Stop questioning your faith! Don't you trust God's word? Try the treatment."

Issues related to making decisions about treatment

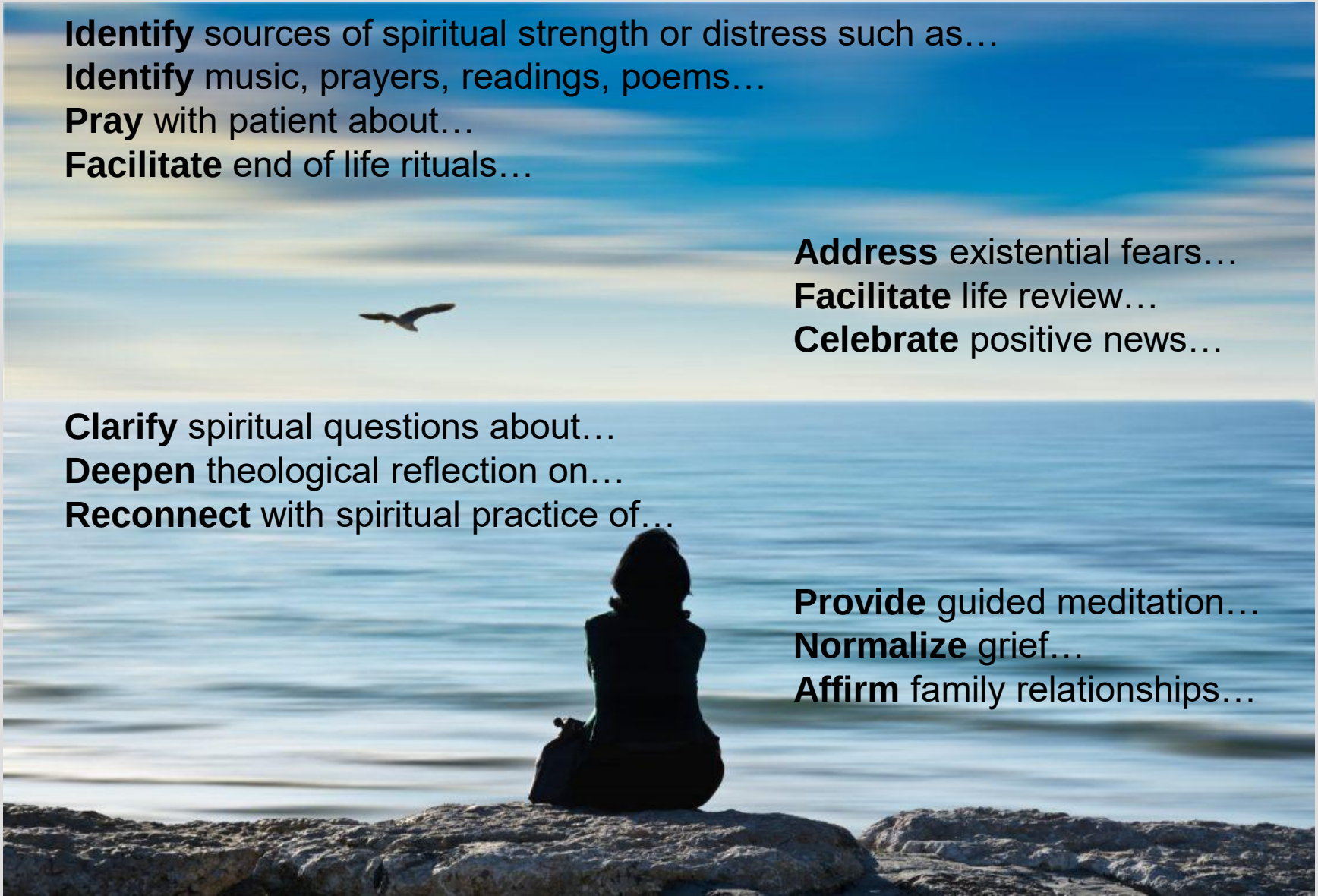
"I was raised not to ask questions like 'Why me?' You just deal with it. Like when my mom died, and my niece died. But now it's like, 'Why me, God? What did I do?'"

Religious or spiritual struggle

Need for immersion baptism, cryonic preservation

Other issues

Spiritual Interventions



Identify sources of spiritual strength or distress such as…
Identify music, prayers, readings, poems…
Pray with patient about…
Facilitate end of life rituals…

Address existential fears…
Facilitate life review…
Celebrate positive news…

Clarify spiritual questions about…
Deepen theological reflection on…
Reconnect with spiritual practice of…

Provide guided meditation…
Normalize grief…
Affirm family relationships…

Objective 3. Utilize a communication framework to address hope and miracles

- “Well, it’s in God’s hands.”
- “Only God knows when my time has come.”
- “We believe in miracles.”
- “We want to do everything, because if we don’t, we’re basically killing him.”
- “I’m not giving up. I’m a fighter.”

Navigating Hope and Miracles: For all clinicians

- Recognize that spiritual beliefs affect decision-making in a variety of ways
- Begin with curiosity and seek clarity
- Align with their hopes for a miracle
- Explore how previous miracles may impact their current point of view

Byrne-Martelli, S., & Rosenberg, L. B. (2022). Communication Strategies When Patients Utilize Spiritual Language to Hope for a Miracle #433. Journal of Palliative Medicine, 25(3), 506-507.

Navigating Hope and Miracles: For all clinicians

Byrne-Martelli, S., & Rosenberg, L. B. (2022). Communication Strategies When Patients Utilize Spiritual Language to Hope for a Miracle #433. Journal of Palliative Medicine, 25(3), 506-507.

“They just don’t get it.”

Clinicians often worry that patients who are hoping for a miracle lack insight into the seriousness of their underlying illness. However, hoping for a medical miracle can be a proportionate coping mechanism that implies a certain level of clinical insight; otherwise, that patient likely would not feel the need to hope for one.

Navigating “Unrealistic Hope” : The AMEN Protocol

Affirm the patient’s belief. Validate his or her position:
“Ms. X, I am hopeful, too.”

Meet the patient or family member where they are:
“I join you in hoping (or praying) for a miracle.”

Educate from your role as a medical provider:
“And I want to speak to you about some medical issues.”

No matter what; assure the patient and family you are committed to them: “No matter what happens, I will be with you every step of the way.”’

Cooper, R. S. et al. (2014). AMEN in challenging conversations: bridging the gaps between faith, hope, and medicine. *Journal of oncology practice*, *10*(4), e191-e195.