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Supporting the spiritual/religious person with existential distress

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

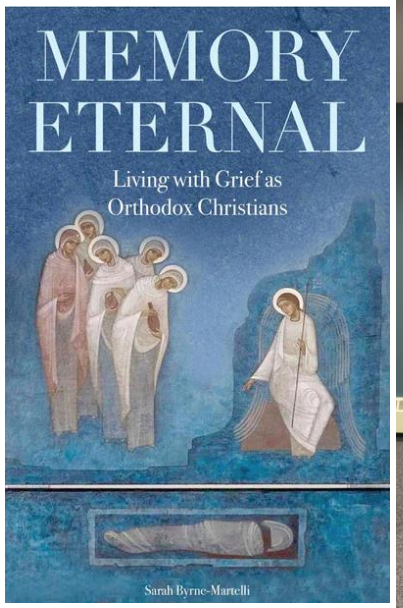
1. Identify best practices for spiritual screening, history, and assessment.
2. Describe the characteristics of negative and positive religious coping.
3. Articulate the relationship between existential distress and hoping for a miracle.

CanMEDS articulates a comprehensive definition of the abilities needed for all domains of medical practice.

These abilities are grouped thematically under seven roles:

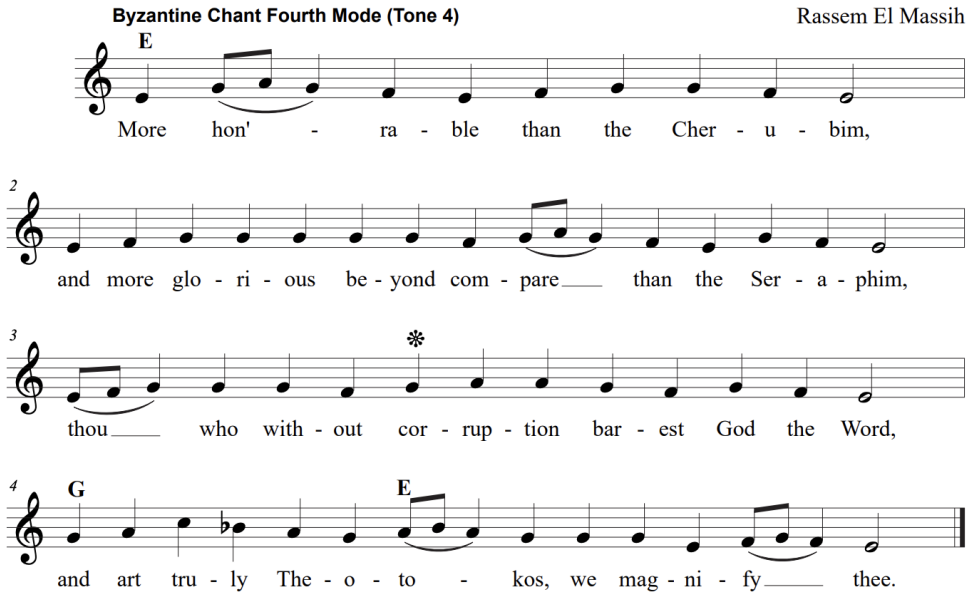
Medical Expert, *Communicator*, *Collaborator,* Leader, Health Advocate, Scholar and *Professional*.

Hello! I’m Sarah.



- Senior Palliative Care Chaplain, Massachusetts General Hospital
- Palliative Care and Hospice Certification Chair, Assoc. of Professional Chaplains
- Cambia Health Sojourns Scholar Leader 2022: *“Spiritual Care Integration in Inpatient Palliative Care Teams”*
- Secretary of the Board, Orthodox Christian Association of Medicine, Psychology, and Religion
- Assistant Professor of Spiritual Care, St. Vladimir’s Orthodox Theological Seminary, NY

Why does this matter? My patient, Gabriel.



Evolution of Spiritual Care Referrals

From:
“The patient is very religious, so they need a chaplain.”
“The patient is not religious, so they don’t need a chaplain.”
“The patient is dying and needs a prayer."

To:
“The patient has spiritual distress about…”
“The family is talking about miracles and healing...”
“The patient is wondering, *What did I do to deserve this?*”
“The patient is ready to die but her sister wants her to fight…”

We address unmet spiritual needs.

Clergy and Chaplaincy work together

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

Board Certified (US) / Licensed (CA) Chaplains

<u>Association of Professional Chaplains:</u>

Board Certified Chaplain (BCC)

Advanced Practice Chaplain (BCC-PCHAC): Competency essays, Peer committee, Quality Improvement project, Case study, 3 years post-BCC

Chaplaincy, according to Rafael Martelli

"School is so much harder than being a hospital chaplain.

YOU just go in, say Hi, ask people about their feelings, pray with them, and then they give you a hundred dollars.

5th grade is SO much harder!

Obj. 1: Identify best practices for spiritual screening, history, and assessment

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

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

- 68% of advanced oncology patients reported that religion was "very important;" an additional 20% said it was "somewhat important." (Balboni et al., 2017)
- 200 Lebanese cancer patients: Greater spiritual well-being was correlated with greater quality of life and well-being, and with less depression, anxiety, fatigue, and pain. (Rabow et al., 2015)
- 65%-85% of cancer patients find that faith helps them "very much." (Canada et al., 2013)
- 450 Australian cancer patients: Spiritual wellbeing demonstrated a significant, positive association with QOL and fighting spirit. Significant, negative relationship with helplessness/hopelessness and anxious preoccupation. A hierarchical multiple regression showed spiritual wellbeing to be a significant, unique contributor to QOL beyond the core domains of physical, social/family, and emotional wellbeing. (Whitford, 2018)

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.

History, Screening, and Assessment

Spiritual History - Any Clinician

vs.

Spiritual Screen (ongoing) - Any Clinician

vs.

Spiritual Assessment (ongoing) and Interventions - Chaplain

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Palliative Care Specialists Series
Feature Editors: Christopher A. Jones and Arif H. Kamal

Top Ten Tips Palliative Care Clinicians Should Know About Spirituality in Serious Illness

Allison Kestenbaum, MA, MPA,[1] George Fitchett, DMin, PhD,[2] Paul Galchutt, MPH, MDiv,[3] Dirk Labuschagne, MDiv, MPH,[4,i] Shelley E. Varner-Perez, MPH, MDiv,[5,6,ii] Alexia M. Torke, MD, MS,[7] and Arif H. Kamal, MD, MBA, MHS[8]

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., 2021).

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

Spiritual Care Generalists? And Specialists?

More patient-centered

Truly holistic care

More collaborative

More professionally satisfying

Less isolating

More efficient (?)

Social worker, Chaplain, MD, MD, MD Fellow, NP Fellow

A 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

A Spiritual Screen Can Be Done by Any Clinician

Many people turn to spirituality/religion when dealing with illness. Is this true for you? (What is your tradition?)

Is your spiritual practice helping you at this time?
(a source of comfort at this time)

What's the hardest part of this for you?

Where do you find strength?

What's keeping you going through all of this?

Sample 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

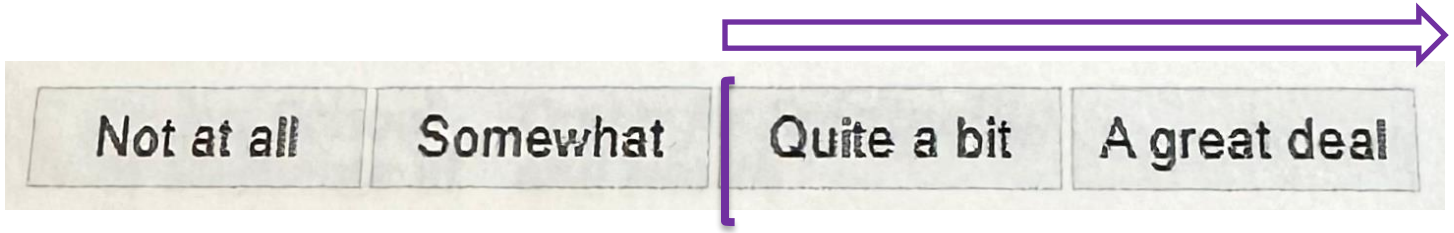
(Distress/suffering experienced secondary to financial issues)

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)

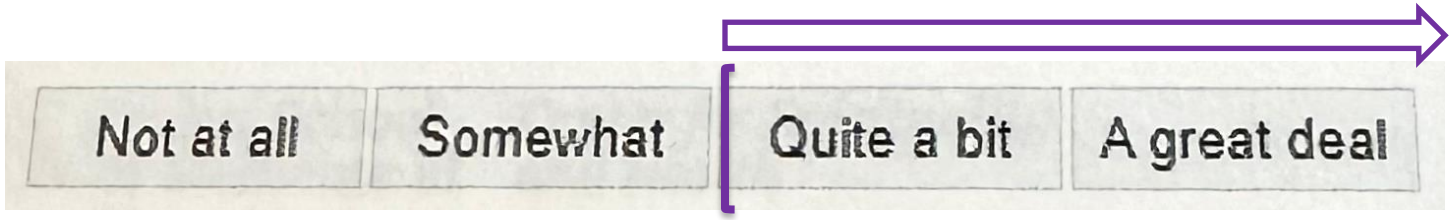
Sample Spiritual Screening Tool: Meaning/Joy

1) Do you struggle with the loss of meaning and joy in your life?



Automatic referral

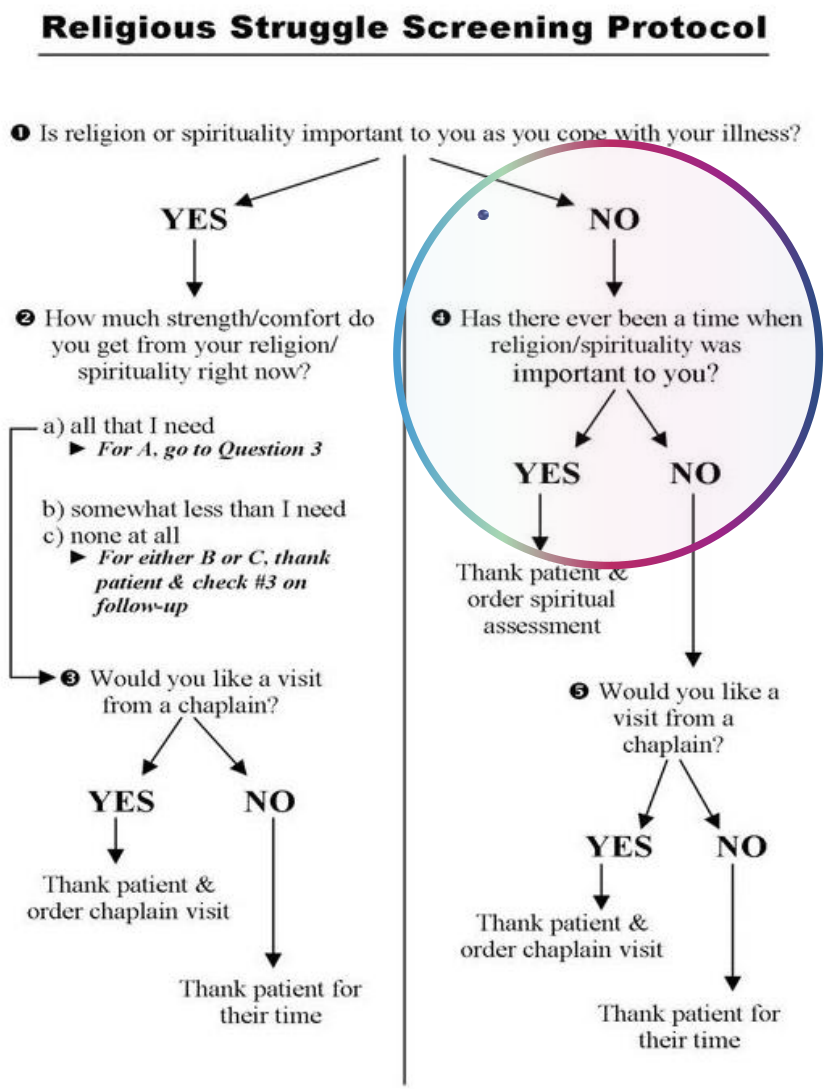
2) Do you currently have what you would describe as religious or spiritual struggle?



Automatic referral

Bahraini S et al. The accuracy of measures in screening adults for spiritual suffering in health care settings: A systematic review. *Palliative and Supportive Care*. 2020.

Sample Spiritual Screening Tool: The Rush Protocol



Fitchett G, Murphy P, King SDW. Examining the Validity of the Rush Protocol to Screen for Religious/Spiritual Struggle. J Health Care Chaplain. 2017 Jul-Sep;23(3):98-112.

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
- More medication, but the same amount of pain
- Evidence of negative religious/spiritual coping

Obj. 2: Describe the characteristics of negative and positive religious coping

Spirituality and religious practices can strengthen coping

How can existential or spiritual strengths be fostered in palliative care? An interpretative synthesis of recent literature

Marc Haufe ,[1] Carlo Leget,[1] Marieke Potma,[1] Saskia Teunissen[2]

BMJ Supportive & Palliative Care
2024;**14**:279–289.

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

Positive religious coping

Meditating brings me peace and helps me cope

Negative religious coping

God is punishing me and I deserve to suffer

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.

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

Positive religious coping

I'm praying for a miracle and I trust that God loves me

Negative religious coping

We can't discuss goals of care because that's negative

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.

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

Positive religious coping

I'm struggling with my diagnosis, and I know everything is impermanent

Negative religious coping

I didn't pray hard enough

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.

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., 2014)

Significant predictor of increased mortality among older medical patients, even after controlling for demographic, physical health, and mental health factors.
(Pargament et al., 2011)

Increased risk of suicidal ideation.
(Trevino, 2014)

Increased anxiety. (Delgado-Guay, 2016)

Requests for MAiD. (Radbruch, 2016)

Diminished QOL. (Jafari, 2015)

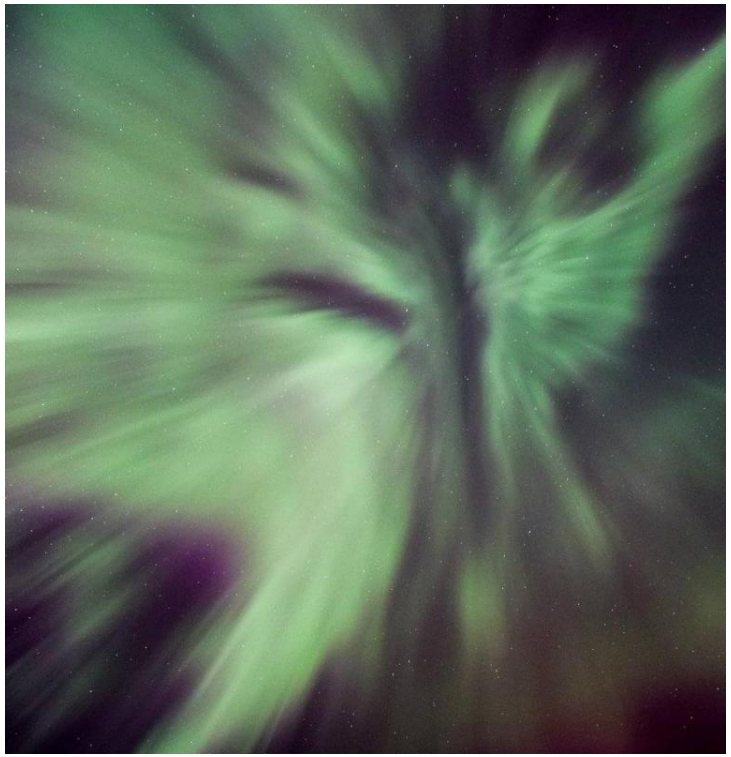
Andrea: Non-religious; Some existential distress, which resolved

52y end stage liver disease
Facing EOL; dialysis sustaining but not curative. Spiritual, not religious.

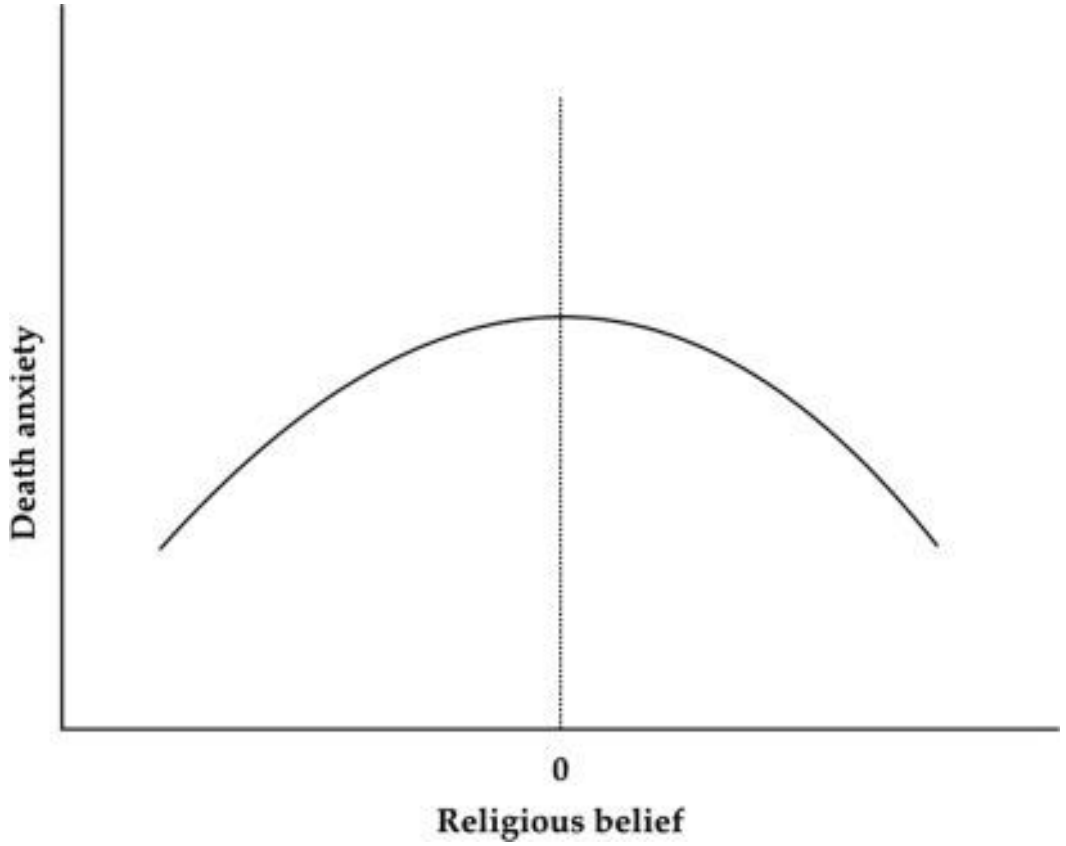
T.S. Eliot. Thoreau. Madonna.

Byock: “Four things that matter most.”

“After I die, I will whisper the poems of Whitman in your ear.”



Existential Distress, Religiosity, & Death Anxiety



"The relationship between religiosity and death anxiety is curvilinear. Consequently the highest death anxiety was expected among patients with an average centrality of religiosity."

Religiosity and death anxiety among cancer patients: the mediating role of religious comfort and struggle. Rybarski et al., 2023.

Low Religiosity can lead to Greater Distress

People with low *[but not zero]** religiosity require special help because they can experience fear, anger, God abandonment or a feeling of being punished by God.

Being positively involved in religion can help the patient to distance themselves from their current problems.

It also facilitates reflection on existential issues, returning to the most important, sometimes neglected values and redefining the meaning of life." Rybarski et al., 2023

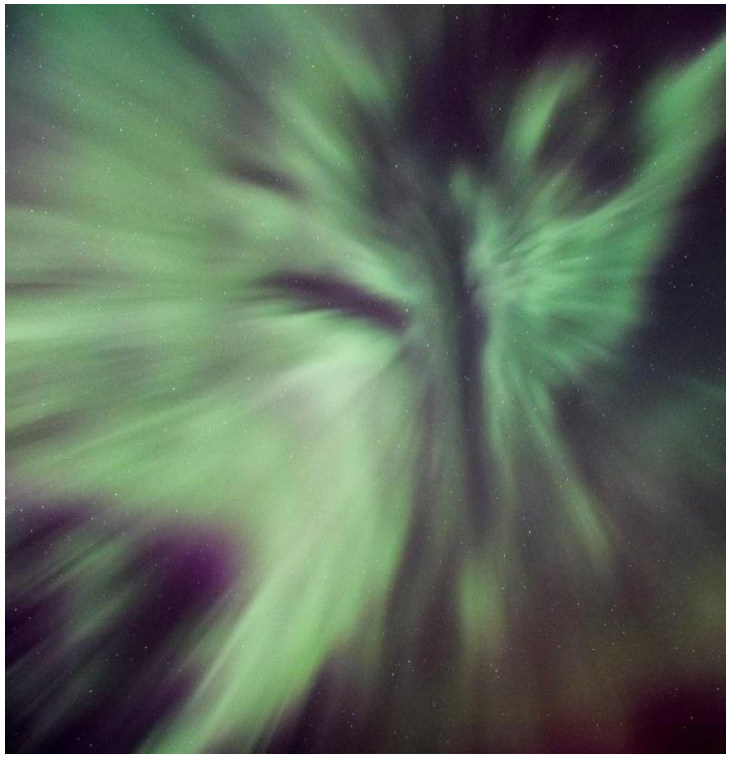
Elaine: Moderately religious; High existential distress

75y gyn oncology patient.
Facing end of life; multiple clinical trials.
Catholic, somewhat religious. Xmas / Easter.
Stresses: divorce, worries about adult children, “terror.”
Trying everything medical available.
Joys: cooking, family time.

Psalm 23. (Grandmother). Unexamined theology.

Compartmentalization: “The Box.”

“Why me? Why now? I was a good person. There are murderers who live a long time! I don’t deserve this.”

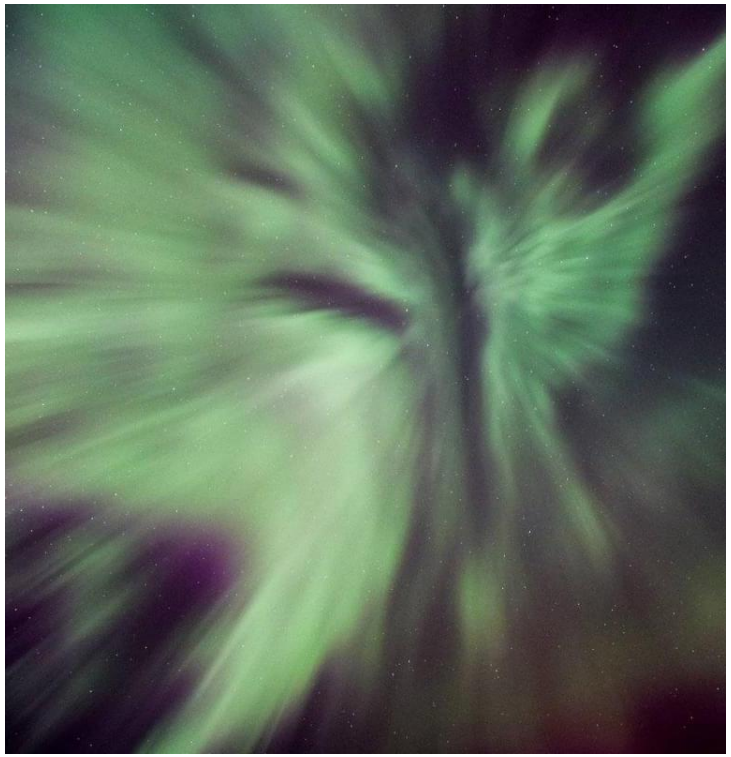


John: Highly religious; Some existential distress, which resolved

62 yr old, new pancreatic cancer.
Ukrainian Orthodox: devout.
Updated scans, change in prognosis, electing Hospice care. Becoming bed-bound and dependent for all ADL's.

Prayer; the remembrance of death; write letters to loved ones; monastic practice (ossuary).

"Well, now I will have lots of time to pray. I know it's coming, and I have time to prepare."



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."

1) 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."

2) 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."

3) 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'm sure my parents are in Heaven. But that's probably not where I'm going."

4) Concern or fear about dying or death

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

5) 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?' Why do I deserve this?" Why is God like this?

6) Religious or spiritual struggle

Need for immersion baptism, cryonic preservation

7) Other issues

Obj 3. Articulate the relationship between existential distress and hope for a miracle

Existential Distress can lead to Hope and Miracle Language

- “Well, it’s in God’s hands.”
- “Only God knows when my time has come.”
- “We want to do everything, and if we don’t, aren’t we basically killing him?”
- “You say there’s nothing to do but I still have hope.”
- “She’s not giving up. She’s a fighter!”
- “I feel like I’m playing God.”
- “This always happens. She’ll get better, just like last time. We just need more time.”

Reflection: Who's in charge here?

When Patients Utilize Spiritual Language to Hope for a Miracle…

"They just don't get it."

- 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.

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.

For Gabriel, Andrea, Elaine, and John.

“I said to my soul, be still,
and wait without hope,

for hope would be hope for
the wrong thing;

wait without love,

for love would be love of the
wrong thing;

there is yet faith,

but the faith and the hope
and the love are all in the
waiting. – T.S. Eliot