



Spiritual Care in Older Adults

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Spiritual: of, relating to, or affecting the human spirit or soul as opposed to material or physical things.

What is spirituality?

“The aspect of humanity that refers to the way individuals seek and express **meaning and purpose** and the way they experience their **connectedness** to the moment, to self, to others, to nature, and to the significant or sacred” (Puchalski et al 2009)



What is religion?

“A subset of spirituality, encompassing a system of **beliefs and practices** observed by a **community**, supported by **rituals** that acknowledge, worship, communicate with, or approach the Sacred, the **Divine**, God (in Western cultures), or **Ultimate Truth**, Reality, or Nirvana (in Eastern cultures)” (Marin et al)



Spirituality ≠ religion

Other ways to find meaning, purpose,
and transcendence

Family/Friends

Religion/Beliefs/Rituals

Nature

Meditation

Photos/Memories

Self-care

Art

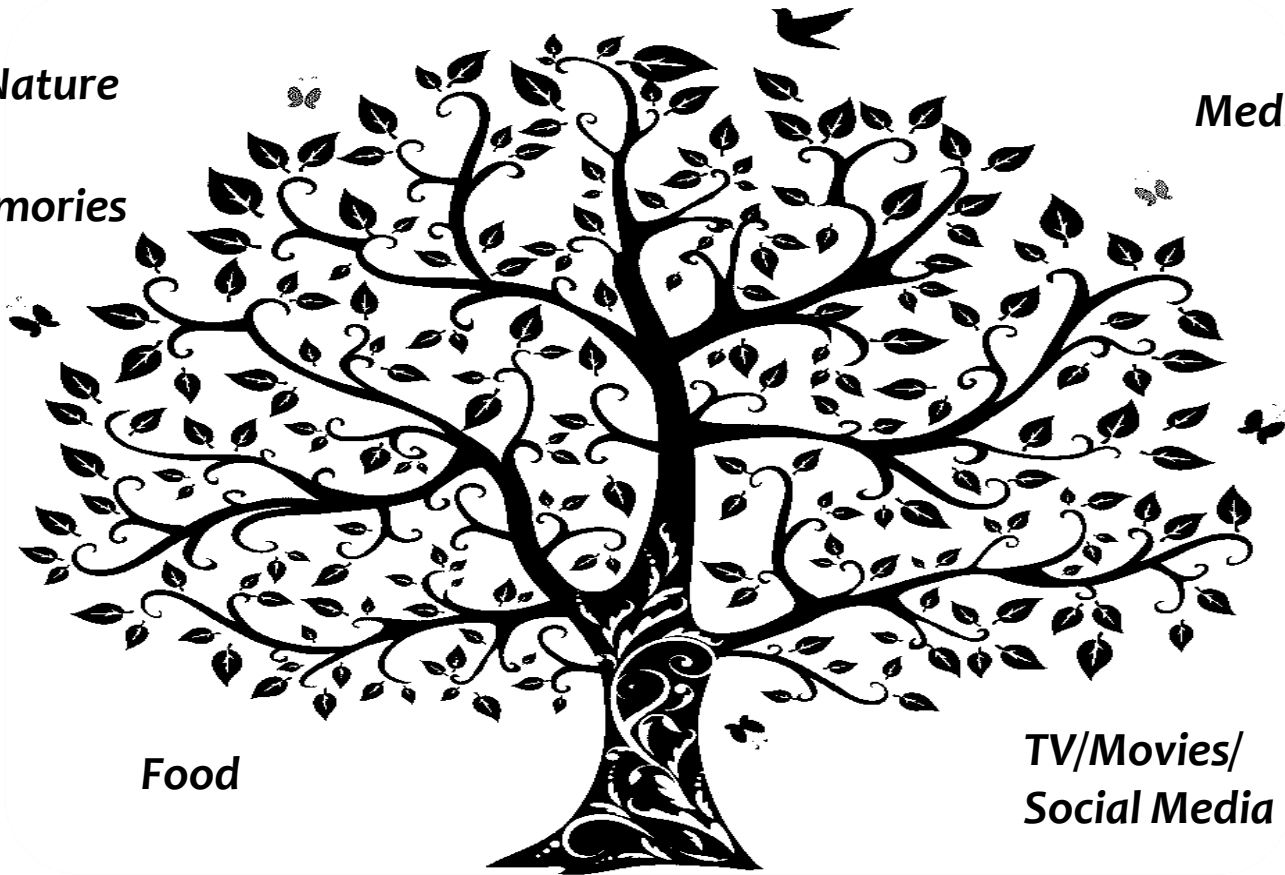
**Hobbies/
Interests**

Music

Pets

Food

**TV/Movies/
Social Media**



Spirituality in the U.S.

Religious affiliation	%
Christian	70.6
Non-Christian	5.9
Unaffiliated	22.8

- * Christian
 - * Protestant 46.5%
 - * Catholic 20.8%
 - * Other (Mormon, Jehovah Witness, Orthodox) 3.3%
- * Non-Christian: Jewish, Muslim, Buddhist, Hindu, other
- * Unaffiliated
 - * Religious 18%
 - * Spiritual but not religious 37%
 - * Neither 42%

Marin et al (2017)

Universal concerns

- * Meaning of life
- * Purpose
- * Accomplishments
- * Legacy
- * Afterlife



Concerns in illness

- * Making sense of illness and suffering (“Why me?”)
- * Losses
 - * Activities
 - * Identity
 - * Dignity
 - * Control
- * Regrets
- * Mortality



Spirituality and illness

- * Historically, physical and spiritual intertwined
- * Impacts health-related outcomes
- * Affects medical decision-making
- * Many spiritual concerns during illness or end of life
- * Most terminally ill patients rely on religion to cope
(Borneman et al)

Spirituality in older adults

- * Increases with age
- * Often rooted in community
- * Higher risk of spiritual distress



Spirituality as solace

- * Hope for healing
- * Sense of connectedness
 - * Community support
- * Comfort in familiar rituals
- * Belief in afterlife

Spiritual distress

- * Impaired ability to find meaning and purpose in life through spiritual means
- * Associated with
 - * Increased somatic symptoms
 - * Depression, anxiety
 - * Substance abuse and self-harm
 - * False hope
 - * Poorer outcomes

Spiritual distress

- * 73-96% of patients with advanced cancer (UNIPAC)
- * 40% of patients with new cancer diagnoses (Puchalski 2015)
- * 65% of older inpatients (Hughes et al 2017)

Spiritual distress

Category	Examples
Existential (meaning, purpose)	“Life is (I am) meaningless/worthless”
Loss/grief	Employment, activities, relationships, dignity
Abandonment	By other people, by the medical system, by God
Despair/loss of hope	“I have nothing left”
Anger	“How could God let this happen?” “They should have found it sooner”
Fear	Dying, afterlife, being forgotten

Spiritual distress

Category	Examples
Guilt/shame Need for reconciliation/ forgiveness	“I’m at fault for my illness” “I deserve to suffer” Past trauma
Struggles of faith	Questioning prior beliefs “Inadequacy” of faith Discouragement of questions Judgment from community
Religious	“I never made my pilgrimage” “I can’t pray anymore” Threat of hell Redemption through suffering

Spiritual distress in older adults

- * Illness/symptoms
- * Cognitive impairment
- * Repeated transitions
- * Functional dependence/loss of agency
- * Loss of privacy/dignity
- * Loss of loved ones, loneliness
- * Reduced ability to participate in spiritual or religious practices



Consequences



* Physical

- * Intractable pain
- * Agitation
- * Anxiety, insomnia
- * Depression

* Psychosocial

- * Guilt and anger
- * Poor coping
- * Strained relationships
- * Being “difficult”

Why should we care?

- * Fosters care of the whole patient and support system
- * Can provide insight into physical symptoms
- * Provides opportunities to relieve suffering
- * Higher levels of spiritual support from medical team associated with more hospice, less ICU care, lower costs (Balboni et al 2011, Marin et al)
- * Too few chaplains!



2018 National Consensus Project: Clinical Practice Guidelines for Quality Palliative Care

- * Basis of standards for Joint Commission certification
- * One of eight care domains – Spiritual, religious, and existential aspects
 - * Spiritual care should be integral part of care
 - * Spiritual care models should be interdisciplinary
 - * Every patient should be screened
 - * All members of the palliative care team should be trained in spiritual care (Puchalski et al 2009)

Patients want us to ask

- * Addressing spirituality improves satisfaction with care (Daaleman et al)
- * 41-94% of patients want their physicians to address spirituality (Borneman et al)
- * 71.6% of physicians and 85.1% of nurses think routine spiritual care has a positive impact on patients (Hughes et al 2017)

We're not so good at asking

- * 72% of patients reported minimal or no spiritual support from the medical team (Hall et al)
- * 10-20% of patients report that their physicians have done so (Anandarajah et al)
- * 16% of ICU family meetings include spiritual discussion + medical professionals changed the subject (Marin et al)

Barriers

- * Lack of time/prioritization
- * Lack of training
- * Uncertainty about whom to ask
- * Perceived patient reluctance
- * Different belief system
- * Varying attitudes towards spiritual care
- * Burnout



Levels of assessment

- * Screen (all of us, all patients) – triage
- * History (various disciplines) – more in-depth questions to better understand needs and resources
- * Assessment (chaplains) – most extensive process resulting in spiritual care plan

Where to start – spiritual screen

- * All patients should receive a spiritual screening – anyone can do this
- * Identify patients experiencing spiritual distress
- * Careful observation and listening
 - * “I really miss my daughter”
 - * “I just don’t understand why this happened to me”
 - * “I’m scared”

Screening questions

- * I imagine this is very difficult... how are you holding up?
- * Who/what helps you to cope?
- * What's most important to you?
- * Are you at peace?
- * Would you appreciate a chaplain visit?

Spiritual history

- * More in-depth, to better understand spiritual needs and resources
- * Screen and history can be done in the context of a routine visit
 - * Initial
 - * Breaking bad news
 - * Crisis point
 - * End of life discussion
- * Tools: FICA, HOPE, SPIRIT

History tools

- * **F**aith beliefs and meaning
- * **I**mportance and **I**nfluence of beliefs (including in health and illness)
- * **C**ommunity
- * **A**ddress in care

- * **S**piritual belief system
- * **P**ersonal spirituality
- * **I**ntegration with a spiritual community
- * **R**itualized practices and restrictions
- * **I**mplications for medical care
- * **T**erminal events planning

Spiritual assessment

Performed by chaplain; explores:

- * Sources of support
- * Existential concerns
- * Religious concerns
- * Struggles with faith
- * Cultural and spiritual preferences and practices
- * Hopes, values, fears
- * Fears about death/dying
- * Concerns about relationships
- * Life roles/tasks
- * Grief

Results in a spiritual care plan

What we can do

- * Provide optimal symptom management
- * Validate experience, affirm values, accomplishments, and relationships
- * Help the team understand sources of suffering
- * Facilitate spiritual practices, storytelling, mementos, life review, legacy activities
- * Refer to other team members

What we can do

- * Withhold judgment
- * Supportive presence
- * Reflective listening
- * Touch
- * Ask how we can help

- * Practice self-care



People with dementia

- * Involve family
 - * Facilitate contact
 - * Seek insights
- * Facilitate rituals
- * Support storytelling and life review
- * Music

Cognitively impaired people less likely to receive spiritual support (Daaleman et al)

What we can do - facilities

- * Support relationships
- * Get people outside
- * Provide opportunities for spiritual and religious fellowship
- * Community events
- * Music, art, pet therapy
- * Massage, Reiki, yoga, meditation, aromatherapy

Potential pitfalls



- * Requests for prayer
- * “What do you believe?”
- * Making assumptions
- * Leading the discussion
- * Proselytizing

Miracles

- * Explore: “Tell me more about that. What would a miracle look like/what are you hoping for?”
- * Affirm: “I wish for the same thing/I also hope you make a full recovery...”
- * Educate, using AND instead of BUT: “...And I want to acknowledge that the situation may be changing/we may be in a place where we should hope for the best and plan for the rest”
- * Reiterate support: “No matter what, you’ll have support through this journey”

When to involve a chaplain

- * Spiritual distress
- * Religious beliefs in conflict with recommendations
- * IDT and/or goals of care meetings
 - * Negotiation on behalf of the healthcare team
- * Connection with other resources
- * End of life care
- * Patient request
- * Routinely!

Take-home points



- * Spirituality goes beyond religion
- * Spiritual concerns are common and important for older adults
- * Spirituality can give solace or cause distress
 - * Spiritual concerns can manifest with physical symptoms
- * Patients want to discuss this!
- * Screen all patients to elicit areas of immediate concern
- * Spiritual care generalists can be quite helpful
- * Chaplains (and others) are invaluable resources

References

- * Ambuel B. Taking a spiritual history. Fast Facts and Concepts. 2019 Jan; 19. Available at: <https://www.mypcnow.org>
- * Anandarajah G and Hight E. Spirituality and medical practice: using the HOPE questions as a practical tool for spiritual assessment. *Am Fam Physician* 2001;63:81-8.
- * Balboni T, Balboni M, Paulk ME, Phelps A, Wright A, Peteet J, Block S, Lathan C, Vanderweele T, Prigerson H. Support of cancer patients' spiritual needs and associations with medical care costs at the end of life. *Cancer*. 2011 Dec 1;117(23):5383-91.
- * Balboni TA, Fitchett G, Handzo GF, Johnson KS, Koenig HG, Pargament KI, Puchalski CM, Sinclair S, Taylor EJ, Steinhauser KE. State of the Science of Spirituality and Palliative Care Research Part II: Screening, Assessment, and Interventions. *J Pain Symptom Manage*. 2017 Sep;54(3):441-453.
- * Balboni TA, VanderWeele TJ, Doan-Soares SD, Long KNG, Ferrell BR, Fitchett G, Koenig HG, Bain PA, Puchalski C, Steinhauser KE, Sulmasy DP, Koh HK. Spirituality in Serious Illness and Health. *JAMA*. 2022 Jul 12;328(2):184-197.
- * Borneman T, Ferrell B, Puchalski CM. Evaluation of the FICA tool for spiritual assessment. *J Pain Symptom Manage* 2010;40:163-73.
- * Daaleman TP, William CS, Hamilton VL, et al. Spiritual care at the end of life in long-term care. *Med Care* 2008;46:85-91.
- * Byrne-Martell S, Rosenberg L. Communication strategies when patient utilize spiritual language to hope for a miracle. Fast Facts and Concepts. 2021 Nov; 433. Available at: <https://www.mypcnow.org>

References

- * Cooper RS, Ferguson A, Bodurtha JN, Smith TJ. AMEN in challenging conversations: bridging the gaps between faith, hope, and medicine. *J Oncol Pract*. 2014 Jul;10(4):e191-5.
- * Ferrell BR, Handzo G, Picchi T, Puchalski C, Rosa WE. The Urgency of Spiritual Care: COVID-19 and the Critical Need for Whole-Person Palliation. *J Pain Symptom Manage*. 2020 Sep;60(3):e7-e11.
- * Grech T, Marks A. Existential Suffering – Part 2: Clinical Response and Management. *Fast Facts and Concepts*. 2019 Dec; 320. Available at: <https://www.mypcnow.org>
- * Hall EJ, Hughes BP, Handzo GH. Spiritual care: what it means, why it matters in health care. *HealthCare Chaplaincy Network* 2016.
- * Hughes BP, DeGregory C, Elk R, et al. Spiritual care and nursing: a nurse's contribution and practice [White paper]. *HealthCare Chaplaincy Network* 2017.
- * Hughes B, Wintz S, Carbonell EL, et al. Spiritual care and social work: integration into practice [White paper]. *HealthCare Chaplaincy Network* 2018.
- * Long CO. Cultural and spiritual considerations in palliative care. *J Pediatr Hematol Oncol* 2011;33:S96-S101.
- * Jackson D, Doyle C, Capon H, et al. Spirituality, spiritual need, and spiritual care in aged care: what the literature says. *Journal of Religion, Spirituality & Aging*, 28:4, 281-295.
- * Marin DB, Sharma V, Powers RE, et al. Spiritual care and physicians: understanding spirituality in medical practice [White paper]. *HealthCare Chaplaincy Network* 2017.

References

- * Meraviglia M, Sutter R, Gaskamp CD. Providing spiritual care to terminally ill older adults. *J Gerontol Nurs* 2008;34:8-14.
- * National consensus project for quality palliative care. Clinical practice guidelines for quality palliative care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018.
<https://www.nationalcoalitionhpc.org/ncp> (Accessed March 18, 2019).
- * Puchalski CM, Ferrell B, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the consensus conference. *J Palliat Med* 2009;12:885-904.
- * Puchalski, C. Integrating spirituality into palliative care: a whole person model of care. University of Rochester Palliative Care Conference 2015.
- * Puchalski CM. Spirituality in geriatric palliative care. *Clin Geriatr Med*. 2015 May;31(2):245-52.
- * Primer of Palliative Care. 5th ed. Quill TE, Holloway RG, Shah MS, et al. Glenview, IL. American Academy of Hospice and Palliative Medicine; 2010.
- * Schmidt R. The Role of Chaplaincy in Caring for the Seriously Ill. *Fast Facts and Concepts*. 2019 Mar; 347. Available at: <https://www.mypcnow.org>
- * Wallace M and O'Shea E. Perceptions of spirituality and spiritual care among older nursing home residents at the end of life. *Holist Nurs Pract* 2007;21(6):285-9.
- * Weissman DE and Meier DE. Operational features for hospital palliative care programs: consensus recommendations. *J Palliat Med* 2008;11:1189-94.