

Spirituality in Serious Illness: Current Evidence and Future Priorities

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Are you at peace?

"100%. If I pass, I'm not worried. During this sickness, hope has changed me. Given me a different look on life. Two-three years ago, I might not have said these things."

"I'm not at peace with my life right now. I be so tired. I'm used to going and I can't go. I was at peace until now."

"When in the dark by myself, I'm scared to death. I usually leave the light on."



What We Know

- Integral to people's lives and important to patients and families in serious illness.
 - Patients and families in acute health care situations have spiritual and religious needs.
 - Beliefs and practices are central to coping.
 - Negative coping associated with poorer outcomes.
 - Beliefs influences decision-making and treatment choices.
- Measures of Spirituality (e.g. spiritual well-being) are associated with higher QOL
- Costs are lower when spiritual care addressed.
- Interventions are associated with Improved QOL in seriously-ill patients

Spiritual Care



Spiritual care is frequently desired by patients in serious illness as part of medical care, with estimates ranging from 50% to 96% of patients wanting spiritual care.



Spiritual needs are infrequently addressed in medical care of seriously ill patients, with patient-reported spiritual care from medical teams ranging from 9% to 51%.

Embrace Population and Cultural Diversity

- Definitions of Spirituality
 - Including the "nones"
- The Role of Beliefs and Practices
- Measurement
- Intervention Design
- Trial Participation



Encourage specificity:

- What is our conceptualization and definition of spirituality?
- What components of spirituality are of greatest interest?
- How are those components related to one another?
- How are they related to outcomes of interest?
- What are suitable outcomes?
- How might we intervene?
- Who should intervene?



Spirituality

“Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek **ultimate meaning, purpose, and transcendence**, and experience **relationship** to self, family, others, community, society, nature, and the significant or sacred.

International Consensus Definition.

Puchalski C, Ferrell B, Variani R, et al., Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. Journal of Palliative Medicine, 2009, 12 (10): 885-904)

Identify a Common Taxonomy

Spirituality Dimension	Description
Importance of Religion/Spirituality (R/S)	Overall importance and extent to which R/S is a central feature of general patient values and preferences, and specific importance during decision-making
Religiosity	Denominational affiliation and extent of organized participation
R/S Coping, Positive & Negative	Items that assess positive and negative aspects of religious coping including how R/S views influence current circumstances (e.g. God or the Divine is loving, punishing or judging)
Spiritual Needs	Sense of connection, peace, meaning, purpose, thoughts about illness experience, and transcendence
R/S Values and Beliefs in Illness	Patient framework for understanding illness experience, as well as beliefs about life-sustaining technologies, the role of physician and clinicians in healing, and place of miracles
R/S Practices	Attention to rituals that are particular to a patient's faith tradition or personal history



Refine – Design and Measurement

- **Specify domains** relationships to one another and outcomes
 - logic model
- **Choose Correct measure** for domain of interest
 - Address confounding
- **Identify Core Common measures**
- **Workgroup funding**

Specify Intervention Components

- Early studies, components poorly specified.
- Improved efforts to have a common taxonomy (e.g. of what chaplains do)
- Meaning-centered interventions are best specified in literature
- **Need well-specified trials**
 - **Testing various modes of delivery**
 - **Comparative effectiveness**



Benefits of a Focus on Meaning

- Inclusive
 - For those who are part of organized practices and the “None’s”
- De-mystifies beliefs
- Value-based
- Patient empowering
- Addresses spirituality as fundamentally relational.
- Provides model linking to physical symptoms

Connectedness

Self, Others, the Transcendent

- A vast social science literature on health and social support.
 - Sense of Coherence
- A model for linking spirituality and physiology
 - Neuro-psychology
 - Barbara Frederickson
- A model for understanding mechanisms



Understand Intervention Timing:



Need Longitudinal studies of spirituality



How do spiritual need evolve over the course of serious illnesses and life course?



Demonstrate - Is this the same in different illness trajectories (e.g., cancer, CHF)?



Understand - When are specific interventions best delivered?

Triage Spiritual Needs in Clinical Settings



Many studies include “all comers” to a clinic.



Screening for need/distress.



Assess resources



The right intervention at the right time

Support Inter- professional Teams



Generalist Spiritual Care



Specialist Spiritual Care



Implementation Science

Guiding Questions for Future Investigation

- How do we best identify needs and resources?
 - Specific and Inclusive
- How do those needs and beliefs impact care decisions?
- How do we intervene?
- When is the best time to intervene?
- Who intervenes?
- How do we best implement intervention in the stream of care?

