State of the Science:

Spirituality and Palliative Care Research

Health Care Chaplaincy - Caring for the Human Spirit

Orlando, 2015

National Palliative Care Research Center

Sponsor

September 30-October 1, 2014

Participants

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- Elizabeth J. Taylor RN, PhD
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Why Research?

- Can't put mystery in a box
- Systematic Discovery – The 4 questions

What do you do?
Taxonomy and Measurement

What effect does it have?
Outcomes

Who is in spiritual distress?
What is the plan of care?
Screening and Assessment

How would you intervene?
Interventional

Are you at peace?

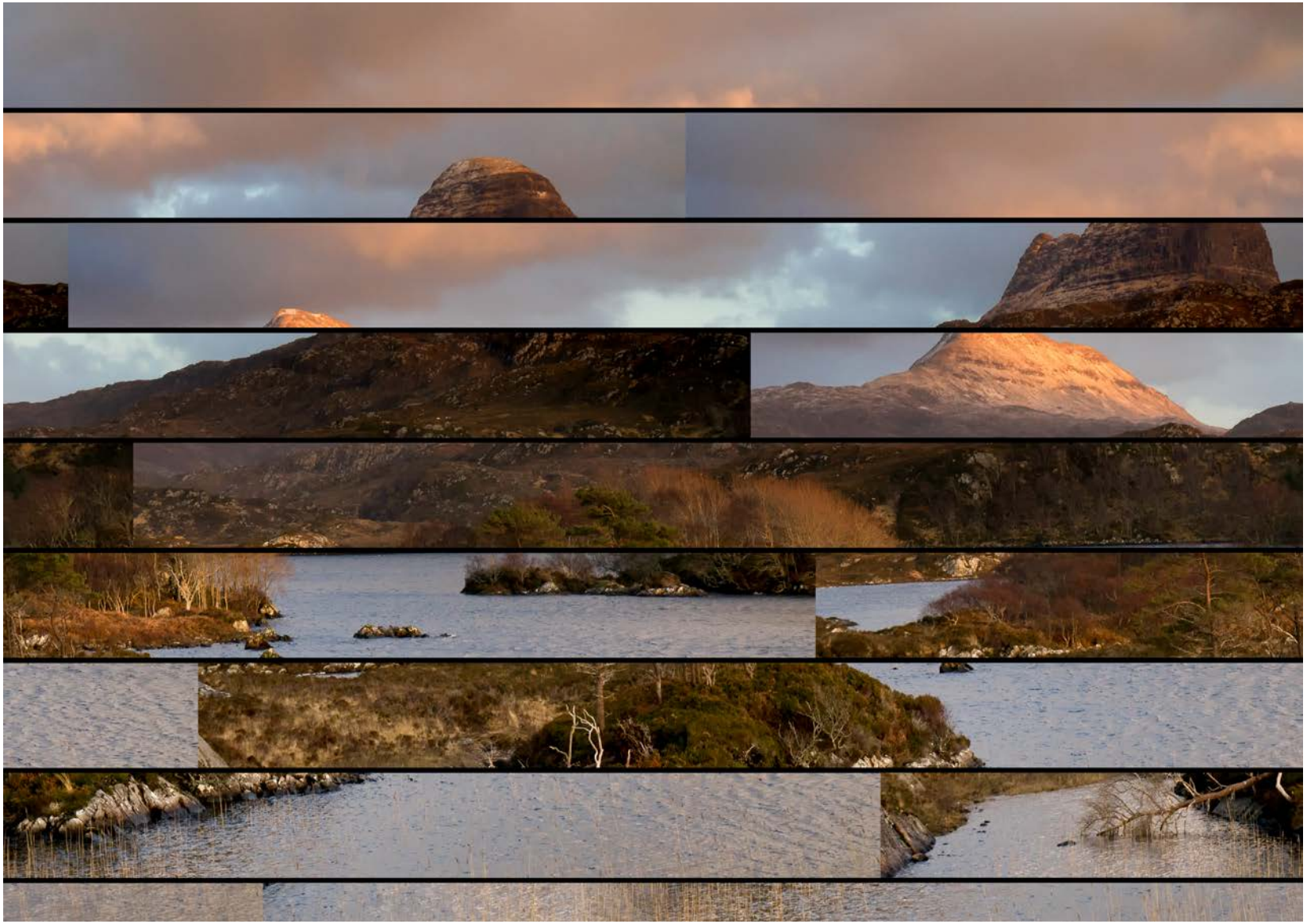
"100%. If I pass, I'm not worried. During this sickness, hope has changed me. Given me a different look on life. Two-three years ago, I might not have said these things."

"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."

Research has shown

- Religion and spirituality integral to lives of Americans
- Patients in acute health care situations have spiritual and religious needs
- Religion and spirituality are central to coping
- Negative coping associated with poorer outcomes
- Satisfaction and QOL are higher when spiritual care attended.
- Religious and spiritual beliefs influences decision-making and utilization



The landscape

- Demonstrated
  - Central and complex role of spirituality in patient/family experience of serious illness
- Lacking:
  - Rigorous approach to
    - Taxonomy
    - Measurement and methods
  - Assessment of the 'landscape' of research in spirituality and palliative care
    - Outcomes
    - Screening and Assessment
    - Interventions (Chaplaincy and other team members)
    - Clinician Education
- Goal: Review challenges and identify priorities

Taxonomy

What is spirituality?

The Current Challenges and Opportunities

Challenge of the Current Taxonomy- The Melting Pot

What do we know?

- Use religion and spirituality as a catch-all
- Large variation in definition of both R/S and dimensions of interest
- Clinical vs. research use – often not specified
- Within chaplaincy – practice and terms not standardized
- Lack of taxonomy results in
  - Unclear or mixed dimensions
  - Unclear or mixed goals
  - Measures not clearly linked to design
  - Unclear mechanisms
  - Confounding results – in some designs.
  - Difficult to compare studies and settings

Why a taxonomy?

- Definition
  - statement of the exact meaning of a word
- Taxonomy
  - process or system of describing the way in which different living things are related, by putting them into groups.
    - Greek – taxis – arrangement

      nomia – distribution
- Spirituality-
  - a collection of things that relate to one another.

What we know - Definition - 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.

- U.S. Consensus committee (JPM, 2009)

"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. Spirituality is expressed through beliefs, values, traditions, and practices."

- International Consensus conference.

A search for the sacred. - Pargament

What we know - Definition - Religion

- A system of beliefs or practices based in the belief in, or acknowledgement of, some super human power or powers.
- Beliefs, practices and rituals related to the Transcendent or the Divine. (Koenig, 2011)
- Painstaking observation of rites (Cicero)
- “The search for significance that occurs within the context of established institutions that are designed to facilitate spirituality” (from Hill et al. 2000; Pargament, 1999).

What these definitions share?

- Plurality - multiple dimensions
- R/S – Intertwined
- Clinical and causal research applications
- Substance and function
  - Substantive approaches –emphasize components necessary for consideration as R/S
  - Functional - how people use it as orienting way people live
  - What's in the syringe?
- Evaluation without reductionism
- The role of sacred qualities

Recommendations - Taxonomy

1. Define broadly and inclusively – (clinical)
   - Begin with the broad (possibly modified) international consensus definition
2. Measure particularly (research)
   - acknowledge the dimensions of spirituality that lie within (including religious beliefs and practices).
3. Specify dimension
   - Name which dimension they seek to observe, assess, or intervene upon.

Measurement and Methods

An approach for research in spirituality and palliative care

Measurement - A general approach

- Select Purpose
  - Clinical Assessment
  - Research
  - QI
  - Accountability
- Specify a conceptual model
- Define Content – What domains are we assessing?
- Choose Measures that match construct
- Examine measures psychometric properties
  - Is it valid and reliable

What is the Purpose?

- Clinical Assessment
  - Prioritize problems
  - Facilitate communication
  - Screen for problems
  - Identify preferences
  - Monitor changes in response to treatment
- Research
  - Make comparisons (within or between)
  - Evaluate response to intervention
- Quality Improvement
  - Evaluating a process to refine and revaluate
- Accountability
  - What would that mean in spiritual care?
    - Example, CMS
- Recommendation – Specify in advance purpose and acknowledge concomitant measurement needs

Define Content: What are dimensions of spirituality?

- Several outstanding working groups and literature reviews identify components
  - Within palliative care
    - Vachon
    - Puchalski
    - Selman
    - Alcorn
  - Outside palliative care
    - Fetzer – BMMRS
    - Koenig

Systematic Review of Measures and Domains Within Palliative Care: Selman

- Identify and categorize spiritual outcome measures, validated in advanced cancer, HIV or palliative care.
- Assess tools' cross cultural applicability
- Determine and categorize the concepts used to measure spirituality

Selman et al, 2011 JPSM, Vol 41 (4).

Background to systematic review

- Spirituality – Understood to include the existential beliefs and values, relating to meaning and purpose as well as religious beliefs and practices that may underpin the experience of advanced illness.
  - Coping
  - Discuss beliefs
  - Influence decision-making
  - Whole person – total pain
- Embedded in culture –
  - A system of ideas, rules, meanings and ways of thinking that are built, shared and expressed by a group with same background (ethnic)

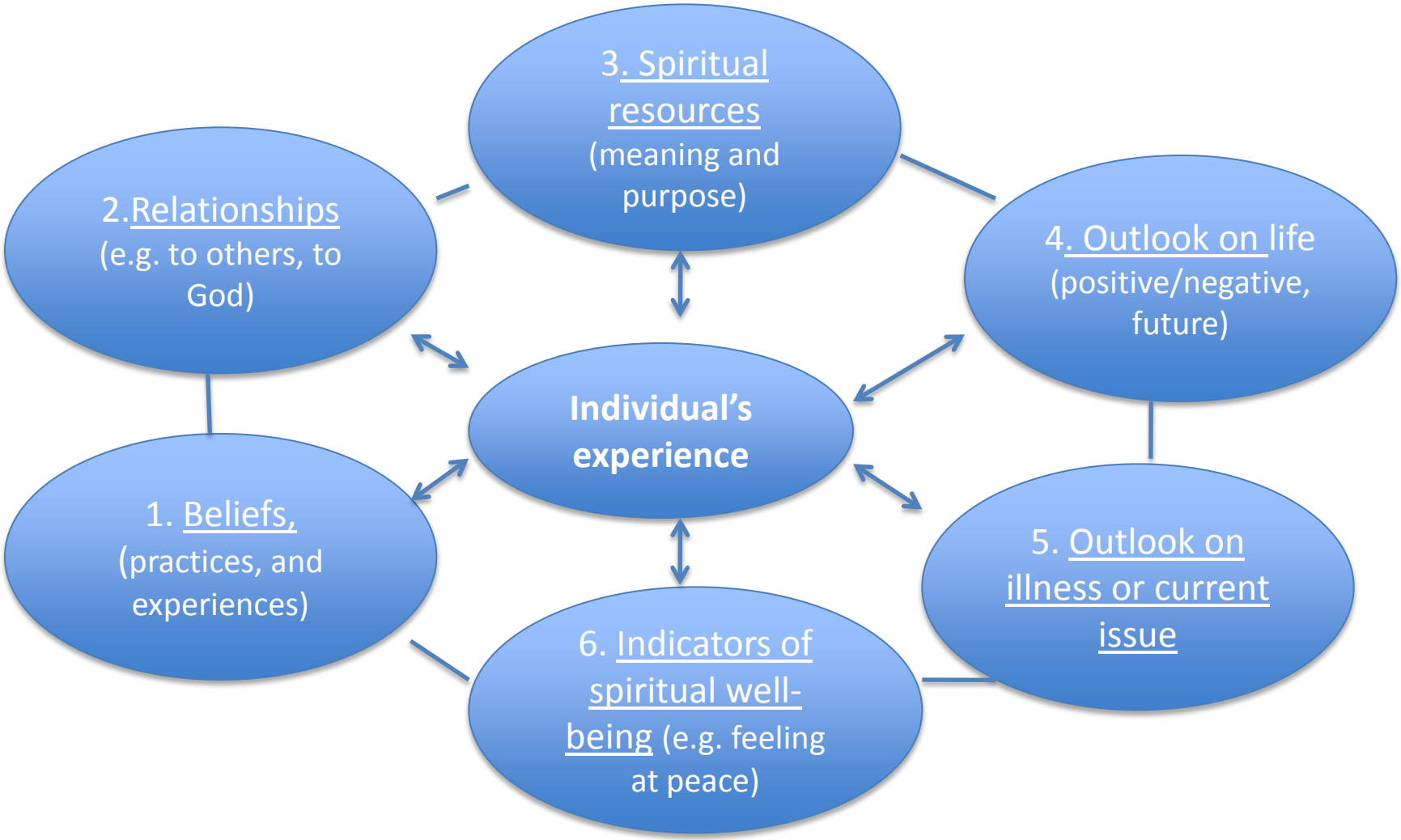
Methods

- 8 Databases
- Searching validation and research studies
- Search terms
  - Palliative care
  - Spirituality/religion- fill in.
  - Outcome measurement
- Search criteria
  1. Examined validation in advanced pall care setting
  2. Validation among ethnically diverse population

Results

- 191 articles
  - 85 tools (50 reported in research studies, 30 not validated in palliative care
  - 38 tools – Criterion 1
    - General multidimensional that include spirituality – n= 21
    - Functional, n=11
    - Substantive – n=6
  - 9 tools – Criterion 2

Dimensions of Spirituality in Palliative Care Measures



Selman et al JPSM Vol. 41 No. 4 April 2011

Gaps and Recommendations- (Selman)

1. Explore, compare evaluations of psychometric properties of instruments,
   - particularly when using translation.
2. Most multi-dimensional measures contain few spirituality items. So, validate other tools in palliative care populations.
   - FACIT – sp
   - SWBS
3. Focus on tools that are well validated, and include relevant (palliative) care populations
4. Evaluate cross-cultural applicability

Brief Multi-dimensional Measure of Religion and Spirituality

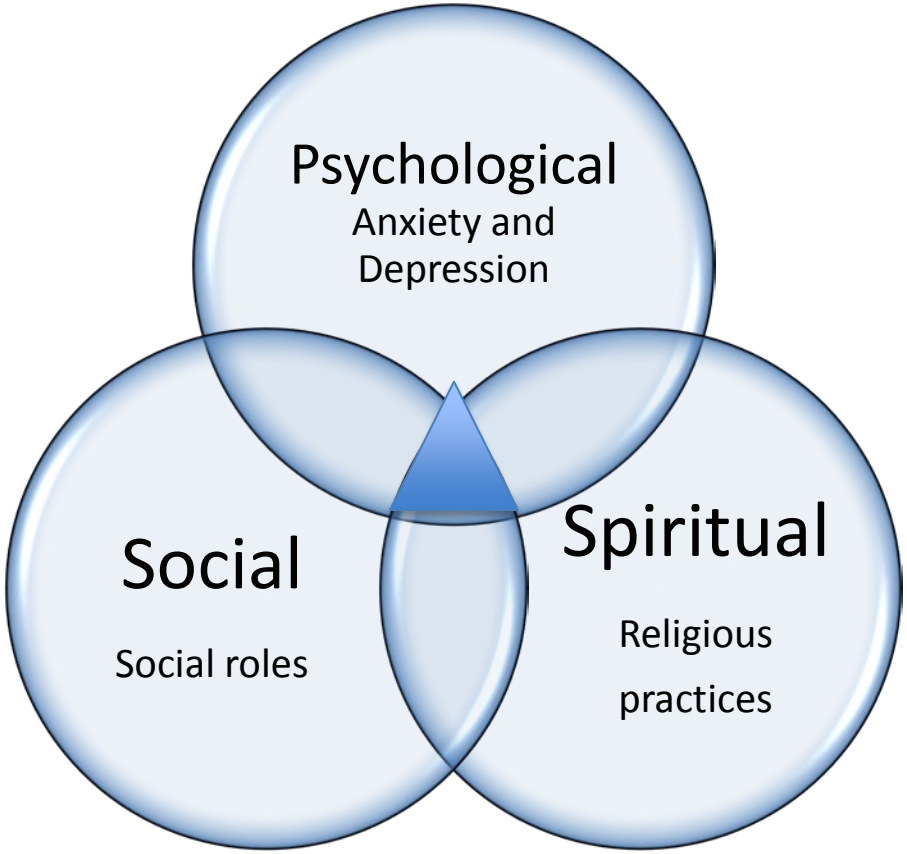
- Daily Spiritual Experience
- Meaning
- Values
- Beliefs
- Forgiveness
- Private Religious Practices
- Religious/Spiritual Coping
- Religious Support
- Religious/Spiritual History
- Commitment
- Organizational Religiousness
- Religious Preference

- Keonig – 2012 – Spirituality in health: measures and methods

Test in Palliative Care Settings

- Select existing tools but modify content, and adapt to patients and caregivers in palliative care.
- Establish reliability and validity – in palliative population
- Test reliability and validity of tools in diverse cultural contexts.
- Establish responsiveness to change over time.
- Capture clinically important data
- Easy to administer
- Applicable across settings, or setting specific if needed
- Minimize problem of response shift.

Higginson et al. BMC Medicine 2013, 11:111; MoreCARE



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- Meaning
- Purpose
- Connection
- Peace
- Hope

How are these similar and distinct?

Concern of confounding

- Many definitions and elements called “psycho-spiritual”
  - E.g. guilt or loneliness, relate to psychological states
- Concern – tautological link between spirituality and positive mental states
- Counter
  - Only an issue of causal relationship
  - If goal is screening, service evaluation, QI, or testing intervention measures may still be appropriate.
  - Psychospiritual may more accurately reflect own views of spirituality

Methodological – Gaps and Recommendations

- Consider how distinct and similar from other psychosocial aspects.
- Conduct research to examine various dimensions and their relationship to psycho-social factors
- Like taxonomy, often do not show how spirituality dimensions are conceptually linked with outcomes
- Specify which dimensions of spirituality of interest.

Recommendations – Approach to Measurement

1. Researchers articulate definition of spirituality , purpose and dimensions of interest to guide measure selection.
2. Begin with existing validated tools, modify and test in palliative care populations.
   - Identify which tools available to test within domains
   - Examine content by user – patient and caregiver needs
3. Conduct research that includes multiple measures to understand the way that elements are similar and distinct and how they related to outcomes
4. Conduct research that allows understanding of which elements of spirituality active for individual *patients* and *families*. Assist with Tailoring intervention.

Spirituality and Outcomes in Palliative Care

What is being effected?

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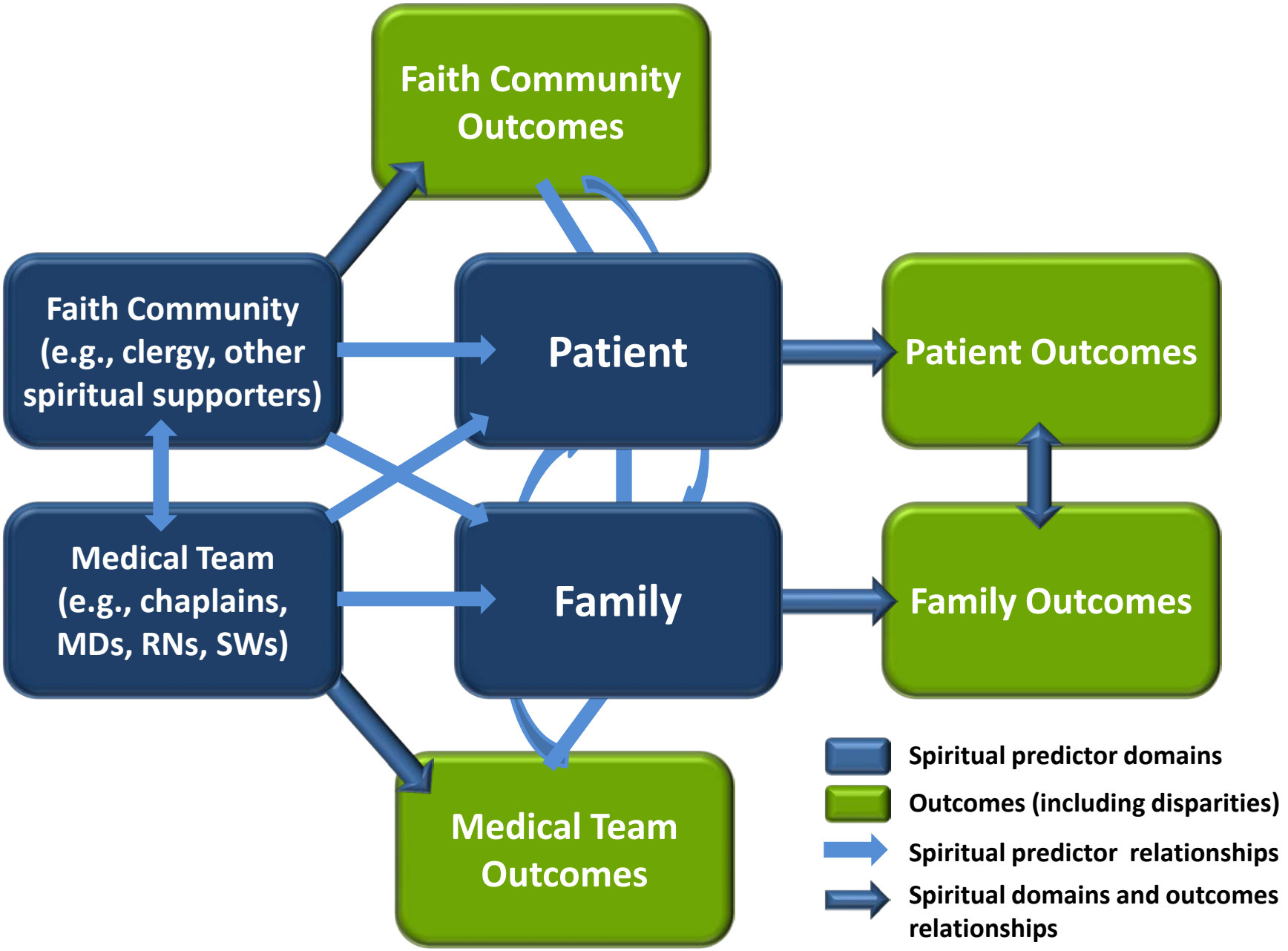
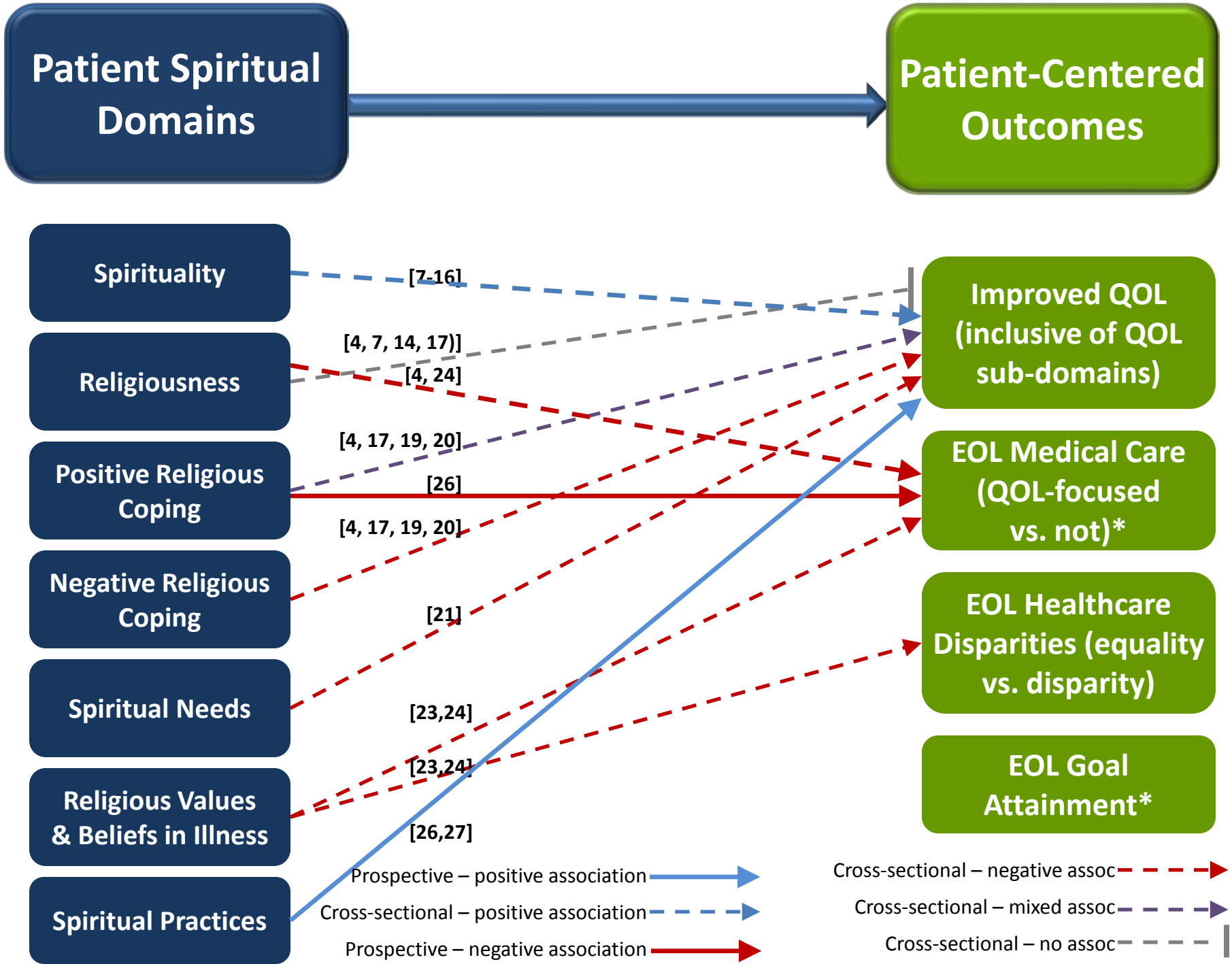
DukeMedicine
Duke Palliative Care

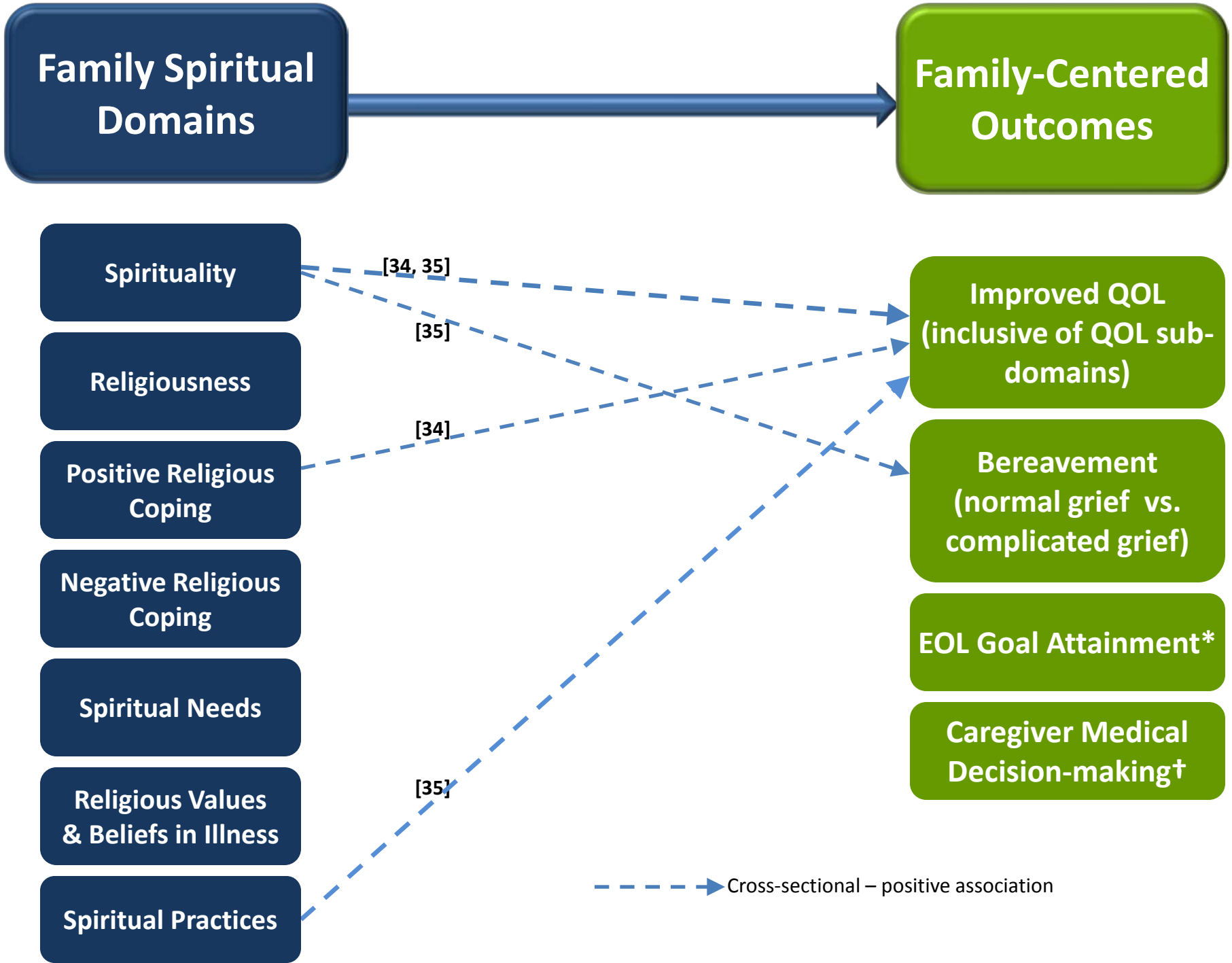
DANA-FARBER/BRIGHAM AND WOMEN'S CANCER CENTER

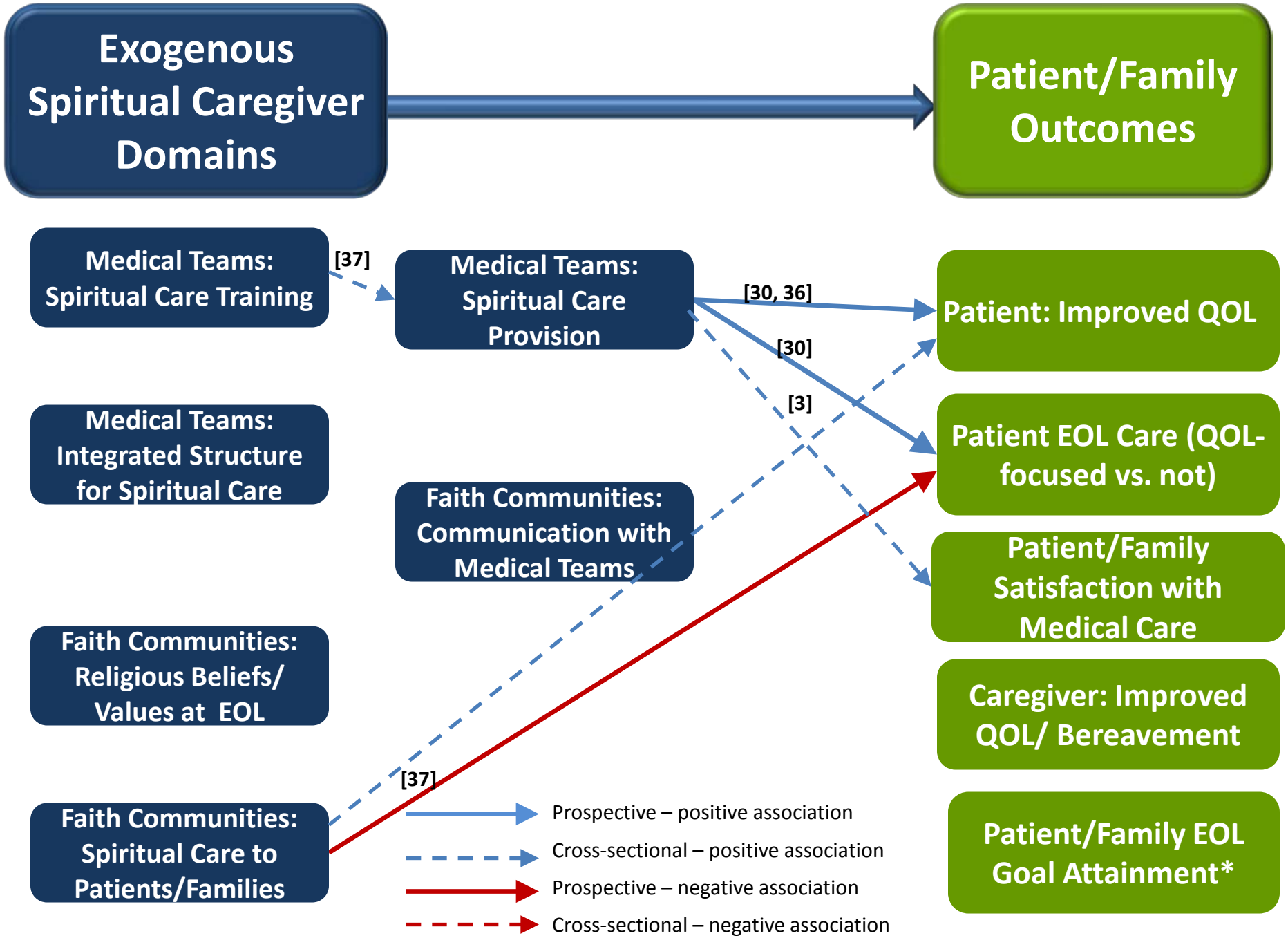
HARVARD MEDICAL SCHOOL

Conceptual Framework: Spirituality and Outcomes




Patient Spiritual Domains
Patient-Centered Outcomes
Spirituality
Religiousness
Positive Religious Coping
Negative Religious Coping
Spiritual Needs
Religious Values & Beliefs in Illness
Spiritual Practices
Improved QOL (inclusive of QOL sub-domains)
EOL Medical Care (QOL-focused vs. not)*
EOL Healthcare Disparities (equality vs. disparity)
EOL Goal Attainment*
[7-16]
[4, 7, 14, 17)]
[4, 24]
[4, 17, 19, 20]
[26]
[4, 17, 19, 20]
[21]
[23,24]
[23,24]
[26,27]
Prospective – positive association
Cross-sectional – positive association
Prospective – negative association
Cross-sectional – negative assoc
Cross-sectional – mixed assoc
Cross-sectional – no assoc


Family Spiritual Domains
Family-Centered Outcomes
Spirituality
Religiousness
Positive Religious Coping
Negative Religious Coping
Spiritual Needs
Religious Values & Beliefs in Illness
Spiritual Practices
[34, 35]
[35]
[34]
[35]
Improved QOL (inclusive of QOL sub-domains)
Bereavement (normal grief vs. complicated grief)
EOL Goal Attainment*
Caregiver Medical Decision-making†
Cross-sectional – positive association


Exogenous Spiritual Caregiver Domains
Patient/Family Outcomes
Medical Teams: Spiritual Care Training
[37]
Medical Teams: Spiritual Care Provision
[30, 36]
[30]
[3]
Patient: Improved QOL
Patient EOL Care (QOL-focused vs. not)
Patient/Family Satisfaction with Medical Care
Caregiver: Improved QOL/ Bereavement
Patient/Family EOL Goal Attainment*
Medical Teams: Integrated Structure for Spiritual Care
Faith Communities: Communication with Medical Teams
Faith Communities: Religious Beliefs/ Values at EOL
Faith Communities: Spiritual Care to Patients/Families
[37]
Prospective – positive association
Cross-sectional – positive association
Prospective – negative association
Cross-sectional – negative association

Research Priorities in Spirituality and Outcomes in Palliative Care

Patient/Family Multidimensional Spiritual Domains and Healthcare Outcomes

- Prospective studies
  - *Patient high priority areas: (a) mechanisms of the relationship of spirituality domains to QOL outcomes; (b) religious beliefs/values and medical decision-making, care and goal attainment; and (c) spiritual needs and QOL outcomes.*
  - *Family high priority areas: (a) mechanisms of the relationship of spirituality domains to QOL/bereavement outcomes; (b) spiritual needs and QOL/bereavement outcomes; and (c) religious beliefs/values and goal attainment.*

Faith Community Spiritual Care Domains and Patient/Family Outcomes*

- Prospective studies
  - examining relationships of *how* spiritual care from faith communities relates to patient healthcare outcomes.
  - *Faith community high priority areas: Spiritual beliefs/values and understanding of palliative/hospice care relate to spiritual care provision to ill congregants.*

Medical Team Spiritual Care Domains and Healthcare Outcomes

- Prospective studies
  - elements of spiritual care provision (e.g., structure, content) and their relationships to
    - patient/family outcomes (e.g., quality of life, medical care, goal attainment).
  - medical team outcomes (e.g., patient/family satisfaction with care, communication effectiveness)

Disparities in Healthcare Outcomes in Palliative Care

- Religion/spirituality plays important role for many patient groups in whom health disparities are seen
  - (e.g., African-American and Latino race/ethnicity, poor, rural)

- Disparities in palliative care outcomes,
  - e.g., African American/Latino patient populations *more* frequently receive aggressive medical interventions at EOL

- In contrast, African Americans often receive *less* medical care prior to life-limiting illness
  - disparity shifts from *less* medical interventions to *more* medical interventions)

- Pew Religious Landscape Survey
- Hanchate et al. Arch Int Med 2009

Disparities in Healthcare Outcomes in Palliative Care

- Some possible contributors include:
  - Patient/family trust in medical system/practitioners
  - Ineffective communication about illness/care decisions by medical practitioners
  - Other social/economic factors (e.g., literacy, lack of economic resources)
  - Patient/family religious beliefs/values about illness/EOL medical care (e.g., My belief in God relieves me of having to think about medical decisions, God will perform a miracle and cure me)

Disparities in Outcomes in Palliative Care

- Key outcomes in addition to medical care received at EOL:
  - EOL goal attainment (patient goal/value-oriented medical care)
  - QOL/bereavement outcomes for patient/families
- Others? Further qualitative exploration of what matters most, in particular among minority patient populations

Spirituality and Disparities in Palliative Care Outcomes

Research Priorities

Patient/Family Spiritual Domains and Disparities in Palliative Care Outcomes

- Prospective studies
  - employing multifaceted spiritual domain assessment (patient/family spiritual domains, and spiritual care, employing validated measurement tools), multiple time points of assessment, examining quality of life, medical team outcomes (e.g., trust, communication effectiveness) and disparities in medical care outcomes (types of care, goal attainment).
  - assessment of key confounding factors (e.g., demographic, economic factors, literacy), examining a variety of vulnerable populations (e.g., African American, Latino, rural) and illness settings.

- *High priority areas among vulnerable populations:*
  - Role(s) of religious beliefs/values to medical decision-making, medical care and goal attainment.
  - Elements of medical team spiritual care and relationships to communication effectiveness, trust, medical care decision-making, types of medical care received, and goal attainment at the end of life.

Next Steps in Evidence-based Approaches to Spiritual Screening and Assessment

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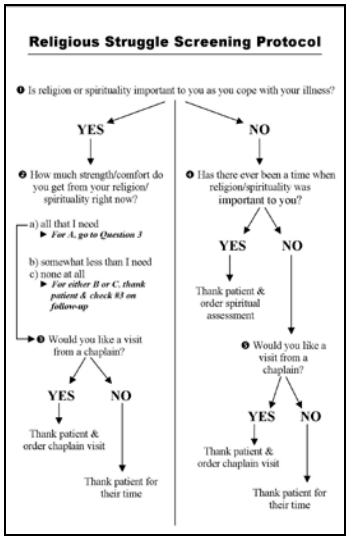

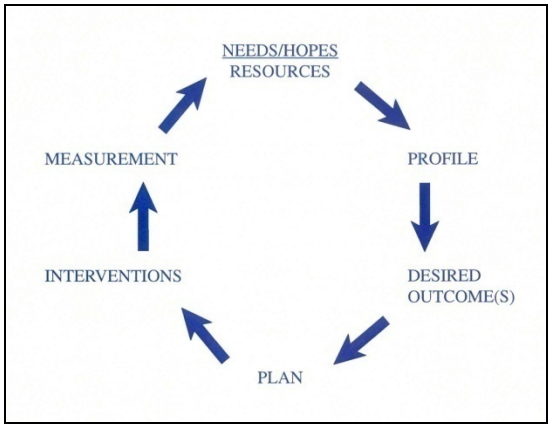

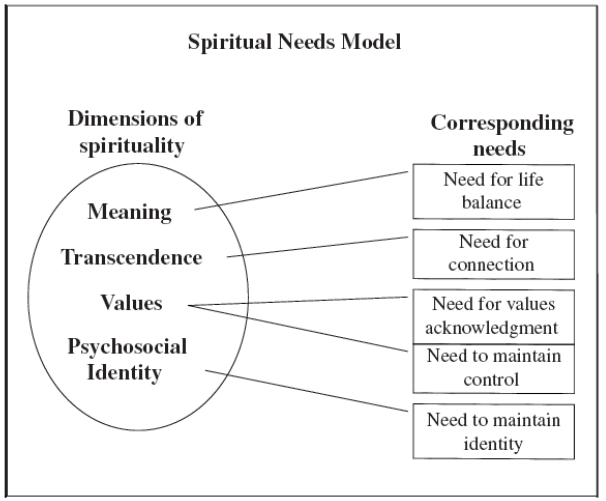

Three Levels of Clinical Inquiry about S/R

Level of Inquiry	Examples
SPIRITUAL SCREENING Context - Initial contact Length - Very brief Mode – Questions Clinician - Any trained clinician	• Rush Religious/Spiritual Struggle Screening Protocol (Fitchett and Risk, 2009) • "Are you at peace?" (Steinhauser et al., 2006) • "Do you have any spiritual pain?" (Make to al., 2006) • Spiritual Injury Scale (SIS, Berg, 1994, 1999)
SPIRITUAL HISTORY- TAKING Context - Initial contact Length - Brief Mode – Questions Clinician- Primary care provider	• FICA (Puchalski and Romer, 2000) • HOPE (Anandarajah and Hight, 2001) • SPIRIT (Maugans, 1996) • SPIR (Frick et al., 2005)
SPIRITUAL ASSESSMENT Context - Initial contact and on-going reassessment Length - Extensive Mode – Conceptual framework for interpretation and development of care plan Clinician- Board certified chaplain or other with equivalent training	• Pruyser (1976) • 7x7 (Fitchett, 1993) • Discipline for Spiritual Caregiving (Lucas, 2001) • Spiritual Pain (Millspaugh, 2005a, 2005b) • MD Anderson Model (Hui et al., 2011) • Spiritual AIM (Shields et al., 2014) • Spiritual Distress Assessment Tool (SDAT, Monod et al., 2010)

SCORECARD: Evidence-based spiritual screening & assessment

	Rush Screening Protocol	MD Anderson Spiritual Assessment	Spiritual Distress Assessment Tool	Spiritual Injury Scale
Reliable	Unknown	Unknown	Yes	Partial
Valid	Partial	Partial	Partial	Partial
Clinically Useful	Partial	Partial	Partial	Unknown

COSMIN: COnsensus-based Standards for the selection of health Measurement Instruments; http://www.cosmin.nl/

Properties of Two Approaches to Spiritual Screening

(follow-up survey of BMT recipients, SCCA, n=749)

	Total Sample N (percent)	Struggle (13.6%)	No Struggle (86.4%)	Se	Sp	PPV	NPV
Rush Screening Protocol							
Path 1 (R/S is currently important but issues with strength/comfort) (n=553)							
Yes	83 (15%)	33%	67%	39.7%	88.5%	32.5%	91.3%
No	470 (85%)	9%	91%				
[b]Path 2 (R/S not currently important was important in the past) (n= 171)							
Yes	70 (41%)	37%	63%	52.0%	61.3%	21.4%	86.1%
No	101 (59%)	24%	76%				
Possible struggle either Path 1 or Path 2 (n = 724)							
Yes	153 (21%)	55%	45%	43.3%	82.3%	27.5%	90.4%
No	571 (79%)	23%	77%				
Are you at peace? (n=748)							
Not at all/a little bit/ A moderate amount	170 (23%)	28%	75%	48.5%	81.2%	28.2%	91.2%
Quite a bit/ Completely	578 (77%)	9%	91%				

Se = sensitivity, Sp = specificity, PPV = positive predictive value, NPV = negative predictive value

SDAT: Needs, Interview Questions and Scoring

	PATIENT INTERVIEW	
SPIRITUAL NEEDS MODEL	**Set of questions for patient interview**	**Scoring**
MEANING ***NEED FOR LIFE BALANCE***	Does your hospitalisation have any repercussions on the way you live usually? Is your overall life balance disturbed by what is happening to you now (hospitalisation, illness)? Are you having difficulties coping with what is happening to you now (hospitalisation, illness)?	Score = 0 No evidence of unmet need for life balance Score = 1 Some evidence of unmet need for life balance Score = 2 Substantial evidence of unmet need for life balance Score = 3 Evidence of severe unmet need for life balance
TRANSCENDENCE ***NEED FOR CONNECTION***	Do you have a religion, a particular faith or spirituality? Does what is happening to you now change your relationship to God /or to your spirituality? (closer to God, more distant, no change) Is your religion / spirituality / faith challenged by what is happening to you now? Does what is happening to you now change or disturb the way you live or express your faith / spirituality / religion?	
VALUES ***NEED FOR VALUES ACKNOWLEDGEMENT***	Do you think that the health professionals caring for you know you well enough?	
NEED TO MAINTAIN CONTROL	Do you have enough information about your health problem, and on the goals of your hospitalisation and treatment? Do you feel that you are participating in the decisions made about your care? How would you describe your relationship with the doctors and other health professionals?	
PSYCHO-SOCIAL IDENTITY ***NEED TO MAINTAIN IDENTITY***	Do you have any worries or difficulties regarding your family or other persons close to you? How do people close to behave with you now? Does it correspond with what you expected from them? Do you feel lonely? Could you tell me about the image you have of yourself in your current situation (illness, hospitalisation)? Do you have any links with your faith community?	

Reliability & Validity of SDAT

1. Factor analysis & reliability (internal consistency and item correlations)

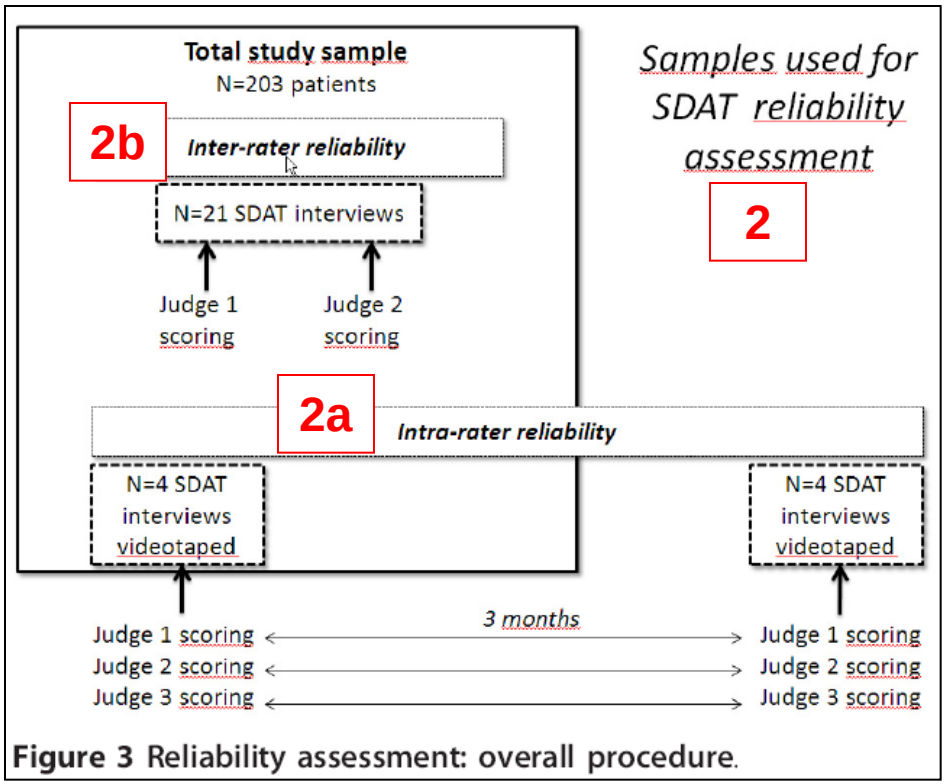

Figure 3 Reliability assessment: overall procedure.

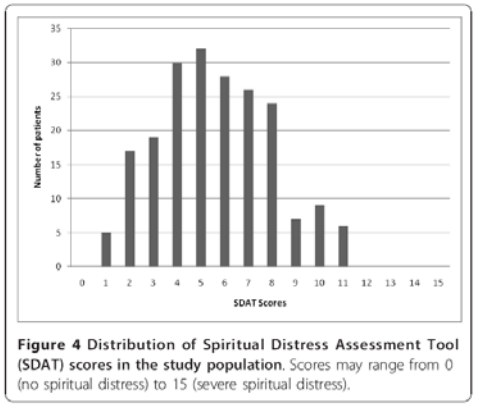

Figure 4 Distribution of Spiritual Distress Assessment Tool (SDAT) scores in the study population. Scores may range from 0 (no spiritual distress) to 15 (severe spiritual distress).

3. Validity

A. Criterion (correlation with related measures)

- FACIT-SP
- "Are you at peace?"

B. Concurrent

correlation with:

- Geriatric Depression Scale
- Need for family d/c meeting

C. Predictive (association with rehab outcomes)

- LOS
- D/C to NH

Monod et al 2012

Spiritual Assessment for Palliative Care

(Patient Needs Regarding Preparation and Completion)

Dimensions of Preparation and Completion	Examples	Scoring of unmet needs
Need for Meaning	The patient questions the meaning of their life. The patient has trouble accepting their illness.	0 no evidence of unmet need 1 some evidence of unmet need 2 substantial evidence of unmet need 3 evidence of severe unmet need
Concerns about Family	The patient has unfinished business with significant others (need to overcome estrangement, need to express forgiveness, need for reconciliation). The patient has concern about their family's ability to cope without them. The patient has concern that they are a burden to their family.	
Need for a Legacy	The patient questions whether they have made a contribution to others.	
Fear about Dying	The patient has fear about dying or about the future.	
Religious/Spiritual Struggle	The patient wondered whether they are being abandoned or punished by God. The patient questions God's love for them. The patient is angry with God. The patient is alienated from formerly meaningful connections with religious institutions or leaders.	

Based on Steinhauser et al and Pargament et al

Next Steps for evidence-based spiritual screening, history-taking & assessment

- What are current practices?
  - Interviews & survey of chaplains and clinicians
- Test clinimetrics of existing instruments
  - Including general screening instruments
- Test Spiritual Assessment for Palliative Care

The Challenges of Evidence-based Spiritual Assessment*

Characteristics (Alternative)	**Rationale**
Quantifiable (Narrative)	Identify degrees of R/S distress and R/S resources in order to inform care plan
	Describe change in R/S distress or other sx in response to chaplain spiritual care
Valid (Invalid)	Psychometric validity of instrument as measure of R/S issues relevant to patients with this diagnosis
Useful (Waste of time)	Acceptable to patients
	Acceptable to chaplains: helpful guide to spiritual care; consistent with identity and education
	Provides information valued by other clinicians
Inclusive (Pathologizes)	Inclusive and respectful of diverse R/S beliefs and practices
Universal (Local)	The same model is used by all chaplains working with patients with this condition

***assume condition-specific models for spiritual assessment, e.g., PTSD, not one-size-fits-all**

Spiritual Interventions in Palliative Care

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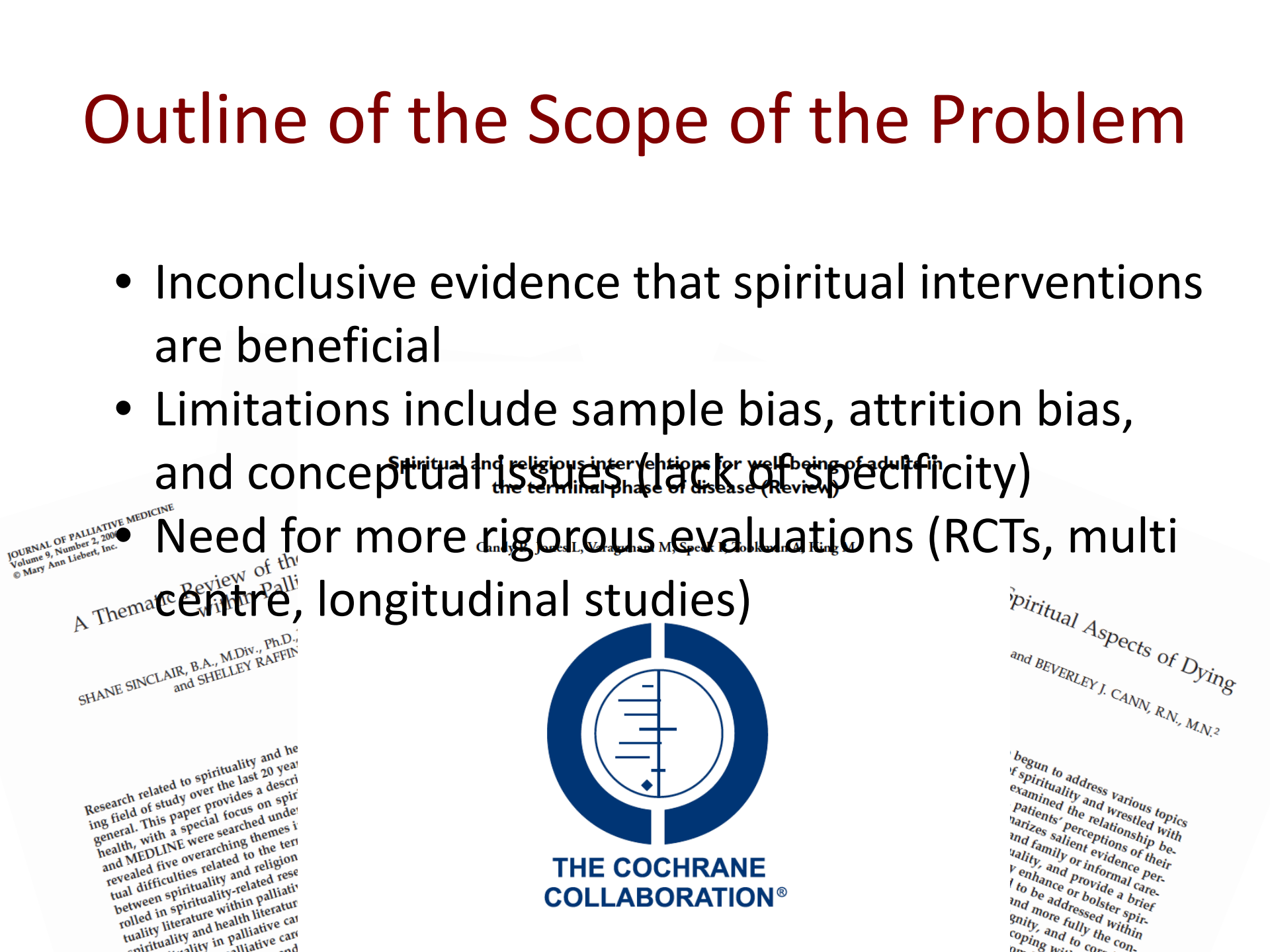
Loma Linda College

"There's no easy way I can tell you this, so I'm sending you to someone who can."

Outline of the Scope of the Problem

- Inconclusive evidence that spiritual interventions are beneficial
- Limitations include sample bias, attrition bias, and conceptual issues (lack of specificity)
- Need for more rigorous evaluations (RCTs, multi centre, longitudinal studies)



Search Strategy

- Replicated and extended the search strategy of the 2012 Cochrane Review (as of July 31, 2014)
  - MEDLINE, PSYCHINFO, EMBASE, AMED, CINAHL, ATLA, ASSIA, Anthropology Plus, Social Services Abstract, Sociological Abstracts
- Secondary iterative manual search of reference lists
  - Allowed for broader psychospiritual interventions excluded from Cochrane Review
- Excluded articles that did not involve a health care provider (ex. personal prayer, intercessory prayer, personal spiritual practices)

What we know – Summary of the Current Evidence

Types of Spiritual Interventions:

1. Psychotherapeutic Interventions
2. Life Review Interventions
3. Multidisciplinary Team Interventions
4. Mind-Body Interventions

Summary of the Current Evidence

Types of Spiritual Interventions:

1. Psychotherapeutic Interventions
   - Logotherapy/meaning based psychoeducation and psychotherapy - ↑ SWB, QOL, symptom burden/distress
   - Religious Cognitive Behavioral Therapy - ↑ optimism, purpose, no relationship with depression
2. Life Review Interventions
   - Life Review - ↑SWB, preparation and completion
   - Outlook – in hospice patients ↑preparation, anx. Dep, func.
   - Dignity Therapy - ↑ high patient sat. and dignity

Summary of the Current Evidence

Types of Spiritual Interventions:

3. Multidisciplinary Team Interventions
   - Generalized Palliative Care Consults (including chaplain)
     - ↑ SWB
     - Oncologist assess SC, ↑ depression, QOL, sense of caring, relative to control
   - Targeted Spiritual Interventions by Multidisciplinary team members
     - Unclear components
     - Some influence on QOL and less aggressive care

4. Mind-Body Interventions
   - Mindful Based Stress Reduction (MBSR) – weak or no effects in RCTs
   - Spiritual Focused Meditation (SpM) – ↓ depression ↑ positive affect

Research Priorities

- Define and determine the key components of spiritual interventions
- Conduct construct-based programmatic research
- Patient-centered research investigating the key elements of an effective spiritual intervention
- Diagnostic indicators of spiritual distress in order to develop evidence based screening tools, providing the basis for future intervention studies
- Actively incorporate knowledge translation plans within the research process and develop knowledge translation studies
- Develop multidisciplinary, multi-centred, cross-cultural emerging team grants to support the creation of collaborative spirituality and health research teams

Spiritual Care Practice: Research Opportunities in Education

Christina Puchalski MD, MS

George Washington Institute for Spirituality & Health

Education for Clinicians

- Hospital based-training programs
  - Based on NCC model and guidelines
  - Piloted in 9 sites
- Other
  - Online Courses
  - Curie Spiritual and Religious Competencies
- Outcomes
  - Pre-post knowledge
  - No systematic patient care outcomes
  - Some anecdotal evidence in patient care

Challenges in Research to Date

- Spirituality courses are integrated into larger courses, hard to get data
- Deans do not know specifics of what is offered
- Questions about definitions – some score only religious or cultural topics
- Overlap with humanities and other issues
- Patient outcomes challenging to assess in clinical setting
  - Not all programs open to research
  - Changes in QI measure - hard to define course as only variable open to change

Recommendations of Global Consensus Conference (JPM 2014)

- Assess current body of knowledge
- Conduct needs assessment to identify best training practices
- Focus assessment on training practices
- Develop evaluation tools to match standards
- Outcomes of curriculae
  - Process – (are MDs charting on spiritual issues)
  - Clinical outcomes – (communication, documentation, referrals to chaplains, resources to patients and families, visibility of programs)

Chaplaincy Research in Palliative Care

Rev. George Handzo, BCC, CSSBB
Director, Health Services Research & Quality
HealthCare Chaplaincy Network

What do you do?

- Taxonomy –
  - Practices and terms not standardized
  - Few descriptions of what chaplains do- and dated, now have a taxonomy to test
- Focus on EOL, grief, emotional support
- R/S needs are broad- love and belonging
- Remind of God's presence
- Wide scope of practice – Emory
- Chaplains are well received

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Taxonomy of Chaplaincy Care

Pargament - (Massey, Summerfelt, Barnes)

- Distinctively spiritual kind of care
  - Blessing for care team member(s)
  - Perform a religious rite
  - Share a written prayer
- Generic care
  - Communicate patient's needs/concerns to others
  - Provide compassionate touch
  - Facilitate communication between patient, family, and care team

What do We Mean by Spiritual Care?

- Care by a religiously/spiritually legitimated provider
- Care that addresses religious/spiritual issues
  - How do we define a religious/spiritual issue?
    - Is the topic of end-of-life inherently religious/spiritual?
    - Is the topic of virtues (e.g., forgiveness, gratitude, meaning) inherently religious/spiritual?
- Care to a particular religious/spiritual context
- A particular kind of care
  - A particular kind of spiritual caring relationship

Sacred Moments in Health Care

- Transcendent
- Ultimacy
- Boundlessness
- Spiritual Emotions
- Deep Connectedness

Gap Analysis

R/S needs and resources

- *In various care settings*
- *Family caregivers*
- *By age & culture- especially the elderly*
- Natural course of spiritual distress
- *Loneliness and despair*

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Process and Outcomes

- **Spiritual Care Outcomes**
  - Linking Chaplaincy with relevant outcomes
  - Community ministry
- **Chaplain competency & training**
  - What competencies are required for each spiritual care role?

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Research Agenda

How helpful or harmful are particular healthcare chaplaincy activities delivered by particular chaplains on behalf of particular people dealing with particular problems in particular social contexts according to particular criteria of helpfulness and harmfulness? (Pargament, 2014)

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Why Research?

Systematic Discovery

- What do you do?
- What effect does it have?
- Who is in distress?
- How should we intervene?

Whose goal is to:

- Share
- Disseminate
- Improve care for patients and families in palliative care