Spiritual Assessment in Palliative Medicine and End-of-Life Care

Karen Pugliese, MA, BCC
Aoife Lee, D.Min, BCC
George Fitchett, D.Min, PhD, BCC

May 30, 2017

National Association of Catholic Chaplains

Workshop Objectives

1. Describe the limitations of current approaches to spiritual assessment.

2. Utilize a new model to quantitatively assess the unmet spiritual needs of a Palliative Medicine patient.

3. Evaluate the strengths and limitations of a quantifiable model for assessing unmet spiritual needs in patients receiving palliative care.
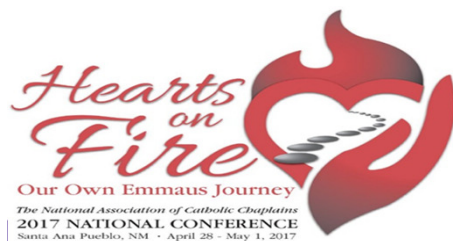
Current Approaches to Spiritual Assessment
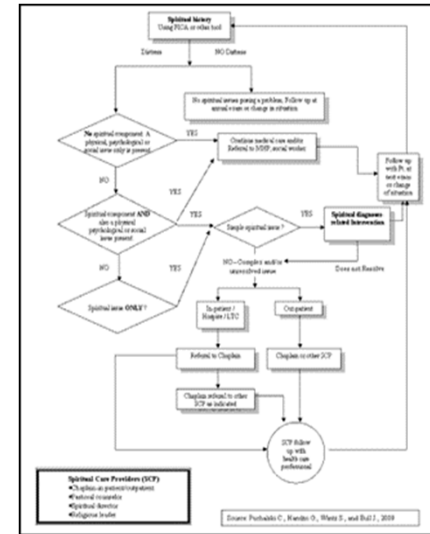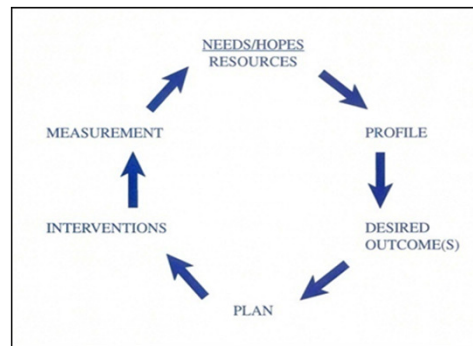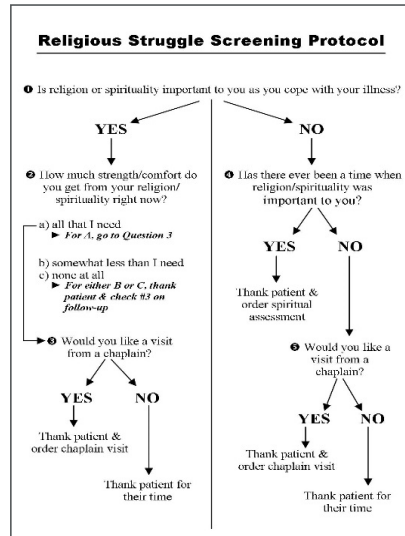
Limitations of Current Practice in Spiritual Assessment

Current Practice	Revised Practice	Rationale
One-size fits all	Multiple condition specific assessments	Recent research about R/S needs in specific clinical populations supports condition-specific assessment
Narrative	Quantifiable	Communication with colleagues is thwarted by narrative models whose assessments are too long and use chaplain jargon 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
Inefficient	Useful	Acceptable to patients Acceptable to chaplains: helpful guide to spiritual care; consistent with identity and education Provides information valued by other clinicians
Local	Universal	The same model is used by all chaplains working with patients with this condition

4

SDAT: Needs, Interview Questions & Scoring

Spiritual Needs Model	Patient Interview		Scoring
	Set of Questions for patient interview		
MEANING *NEED FOR LIFE BALANCE*	*Are you having difficulty with what is happening to you now (hospitalization, illness)?*		**Score = 0** No evidence of unmet need for life balance
TRANSCENDENCE *NEED FOR CONNECTION*	*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?*		**Score = 1** Some evidence of unmet need for life balance
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 feel you are participating in the decisions made about your care?*		**Score = 2** Substantial evidence of unmet need for life balance
PSYCHO-SOCIAL IDENTITY NEED TO MAINTAIN IDENTITY	*Do you have any worries or difficulties regarding your family or other persons close to you?* *Do you feel lonely?* *Could you tell me about the image you have of yourself in your current situation (illness, hospitalization)?*		**Score = 3** Evidence of severe unmet need for life balance

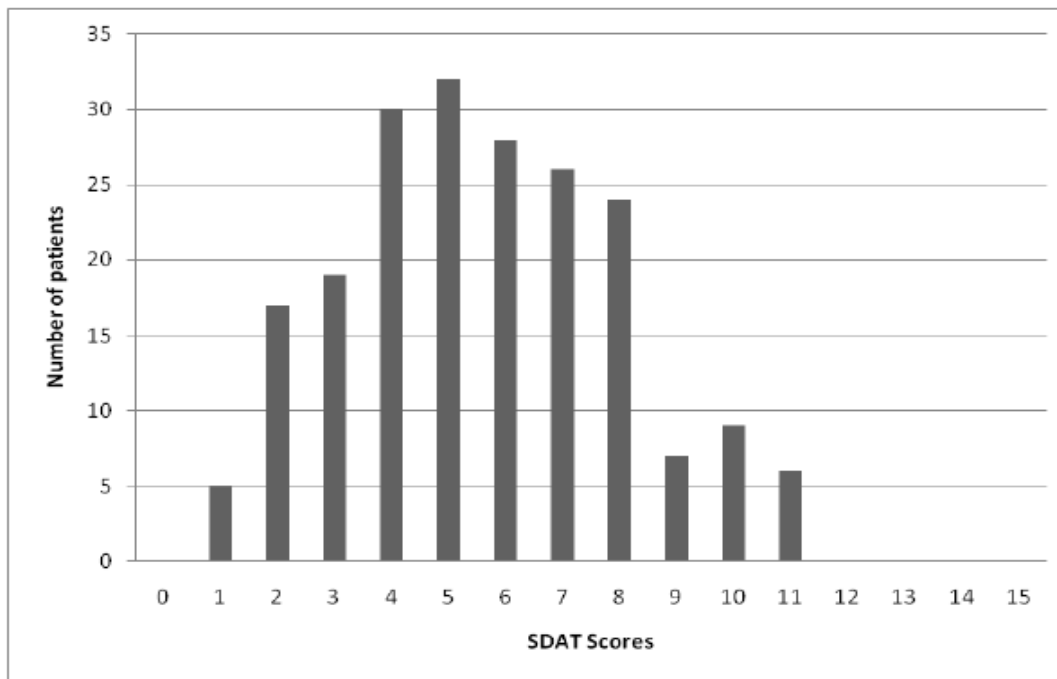# Spiritual Distress in Older Medical Rehab Patients

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).

65% some distress

27% some distress in all 5 dimensions

22% severe distress in at least one dimension

60% of severe unmet needs were for Life Balance

From Monod et al., 2012; n=203 geriatric patients in medical rehabilitation, Switzerland

Advancing EB Screening & Assessment
Reliability & Validity of SDAT

1. Factor Analysis & Reliability
(internal consistency and item correlations)

Total study sample
N=203 patients

2b Inter-rater reliability

N=21 SDAT interviews

Judge 1 scoring   Judge 2 scoring

Samples used for SDAT reliability assessment

2.

2a Intra-rater reliability

N=4 SDAT interviews videotaped

N=4 SDAT interviews videotaped

Judge 1 scoring ← 3 months → Judge 1 scoring
Judge 2 scoring ← → Judge 2 scoring
Judge 3 scoring ← → Judge 3 scoring
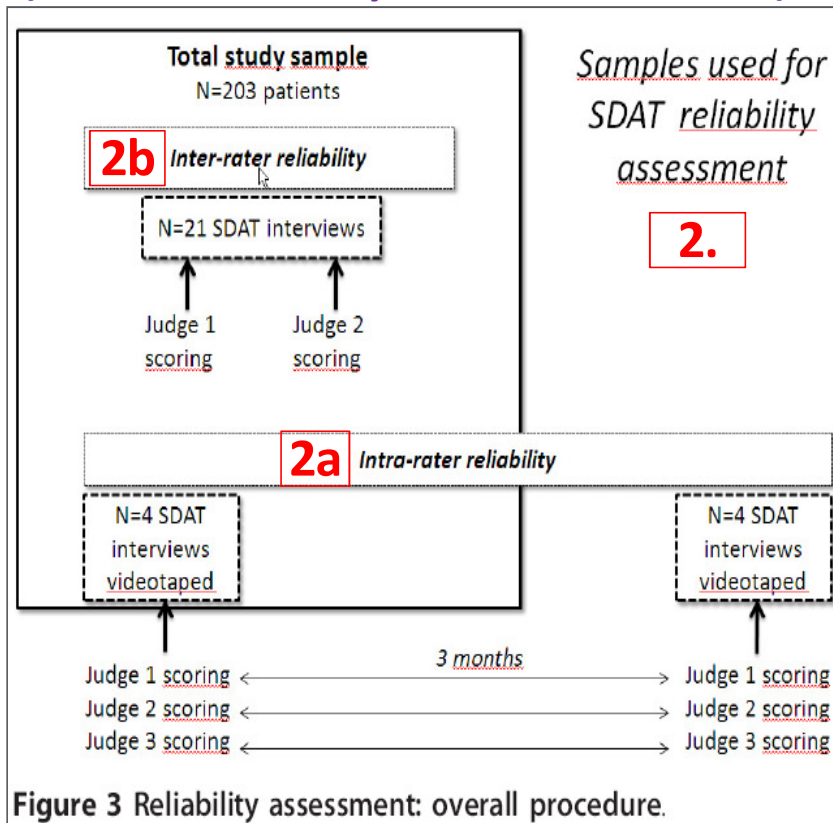
Figure 3 Reliability assessment: overall procedure.

Monod et al 2012

3. Validity

Criterion
(correlation with related measures)
*FACIT-SP
*"Are you at peace?"

Concurrent
correlation with:
*Geriatric Depression Scale
*Need for family d/c meeting

Predictive
(association with rehab outcomes)
*LOS
*D/C to NH

Developing Palliative Care Spiritual Assessment

Outgrowth of Coleman Palliative Education Project

❖ **Used SDAT framework**

❖ **Spiritual Concerns from**
   * **Steinhauser et al QUAL-E (preparation & completion)**
   * **Pargament – R/s Struggles**

❖ **Revisions based on monthly case discussions**

The **Coleman Palliative Medicine**
TRAINING PROGRAM

Spiritual Concerns in Palliative Care

Theme	Descriptions	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.)[2] • (The focus here is on coming to terms with illness, loss, diminishment. If the issue is about the meaning of their life then score under Legacy.)	
Need for Integrity, a Legacy, Generativity[1]	• 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 (If the regret is about a relationship where reconciliation is possible it is OK to score this concern here as well as under Concerns about Family and/or Significant Others.) • The patient questions whether they have made a positive contribution to loved ones, others, or society. • The patient has tasks they must complete before they are ready to die (If tasks are interpersonal score under Concerns about Family and/or Significant Others.) • Reminiscing about their life is painful for the patient. • Patient is distressed about having lived an imperfect life. (If the regret, conflict or discomfort focuses on current illness, code under Need for Meaning in the Face of Suffering.)	
Concerns about 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 of others). (Regrets about relationships where reconciliation is unlikely should only be scored under Legacy). • The patient has concerns about their family's ability to cope without them. • The patient has concern that they are a burden to their family. • The patient expresses unwanted isolation, loneliness.	

Spiritual Concerns in Palliative Care

Theme	Descriptions	Score
Concern or Fear about Dying or Death	• The patient has concerns about dying: unready for death, impatient for death. • The patient is concerned to participate in important events before death; the patient is concerned illness or death will prevent participation in important events. • The patient is torn between letting go and fighting on. • The patient has uncertainty or fear about life after death (afraid of damnation; concerned about reunion with loved ones.) • 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. • The patient has not expressed wishes about end-of-life treatment.	
Religious/ Spiritual Struggle	• The patient wonders whether they are being abandoned or punished by God. • The patient is concerned about God's judgment, forgiveness, and/or love. • The patient questions God's love for them. • The patient feel God is not answering their prayers (e.g. asking to die soon.) • The patient expresses anger with 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.	
Scoring spiritual concerns: 0 = no evidence of spiritual concern; 0* = no evidence of spiritual concern, further assessment to be sure; 1 = some evidence of spiritual concern; 2 = substantial evidence of spiritual concern; 3 = evidence of severe spiritual concerns		

Spiritual Concerns in Palliative Care

This assessment focuses on the patient as an individual and *is not meant to:*

   * aid in assessment of a family or

   * to be a comprehensive assessment of interpersonal issues that are

   sometimes the focus of attention for chaplains working in palliative care

This assessment *is meant to*:

   * assess <u>explicit</u> spiritual concern; and can note areas for future inquiry

   * focus on <u>unmet</u> spiritual need; need <u>minus</u> resources

Spiritual Concerns in Palliative Care

Scoring spiritual concerns:

0 = no evidence of spiritual concern;

0* = no evidence of spiritual concern, further assessment to be sure;

1 = some evidence of spiritual concern;

2 = substantial evidence of spiritual concern;

3 = evidence of severe spiritual concerns.

Case Study Process

Hear the case: Patient = "Barb"   Chaplain = "Lee"

Use the template to assess (score) the case

Report out on each of the 7 categories of spiritual concerns by a show of hands

Discuss:

Consensus on Scoring

Absence of consensus on scoring

Rationale for differences in scoring

Next Steps?

Test validity, reliability & clinical usefulness of this palliative care assessment

Form teams to develop similar assessment templates for other clinical contexts