



Geriatric Palliative Care: The Role of Measurement

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Overview

- Where are we?
- Measures 101
- Application
 - Evaluating complex interventions
 - The Liverpool pathway
 - Spirituality
- Consultancy





The landscape

- Palliative care needs are increasing
- Care and interventions becoming more complex – (e.g. more diseases, multi-morbidity)
- Integration of palliative care varies greatly
 - in-patient
 - out-patient
 - hospice
- Joan's point about accountability – OR
- Outcome measurement has a major role in improving the quality, efficiency and availability of palliative care.



Measurements Role in Palliative Care

- Increase awareness of the opportunity to improve
- Determine best practices or outcomes and improve quality of care
- Clinical assessment for targeting of services
- Justify existence of Palliative Care Consult Services
- My hope - measurement tools will serve as safety valve to preserve quality of care.



Where are we?

- Widely used in health research
 - describe patient populations
 - assess effectiveness of interventions
- Not yet used in routine clinical practice
- Increasing focus on patient autonomy, equitable service delivery, and transparent information
- Accountability to patients, funders, government to demonstrate efficiency and high quality care.



What is measurement?

- Assessment of change in outcome (patient's health status) overtime, beginning with baseline, including follow-ups, that evaluate a trajectory or change relative to that baseline.

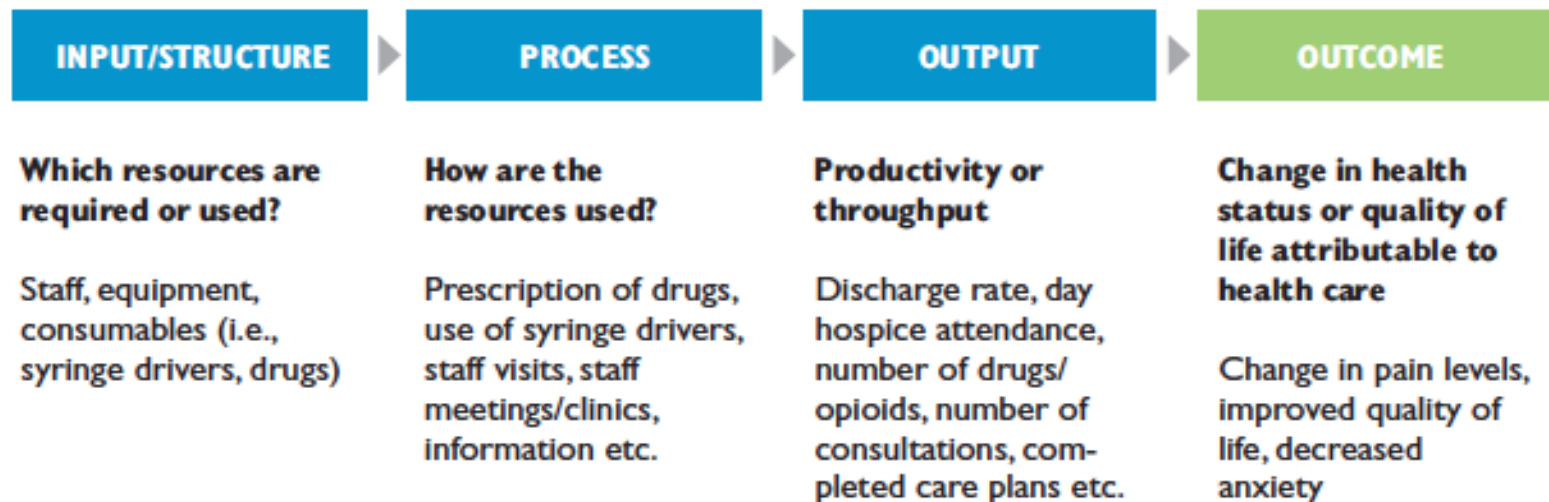


Figure 1.1 A palliative care example regarding the sequence involved in outcome measurement (adapted from Higginson and Harding 2007²)



Difference in Measurement Tools

	Clinical Assessment	Research	Improvement	Accountability
Audience	Clinical Staff	Science Comm.	QI team and Clinical staff	Purchasers And consumers
Focus	Status of Patient	Know- ledge	Understand Care process	Comparison
Evidence Base	Face validity	Building off and new knowledge	Building off and developing new knowledge	Domain ought to be under control of health care provider
Importance Psycho- metric Properties	To the individual provider	Extremely important	Important within setting	Ext. important - valid and responsive across settings of care



Evolution of Measurement Tools

- Distinctions between measurement tools are important –
 - some are interchangeable (e.g., adjustable wrench and pliers)
 - some are not (e.g., hammer and screw driver).
- Over time, a measurement tool may involve from one use to another.



Measuring the Quality of Care

- **Outcome** – end results measure - what happens?
 - Mortality rates, leading cause of death, site of death
 - Health care utilization and costs
 - Symptoms - % died in pain
 - Consumer perceptions of the quality of care

- **Process** - What we do for patients?
 - Pain as a 5th vital sign
 - Completed an advance directive
 - Hospice referral



Where are we? Where were we?

- **"I shall long remember the young patient who in dying commented that his final months (which had been characterized by relentless physical deterioration and considerable suffering) had been "the best year of my life". The day he made that comment this young athlete, scholar, and executive who had measured 10/10 on the [Spitzer] QL throughout his life, measured 2/10. Clearly he was referring to something not embraced by the scales measuring activities of daily living and not reflected in the Spitzer QL."**

Bal Mount and John Scott

Wither Hospice Evaluation

Choosing a Measure

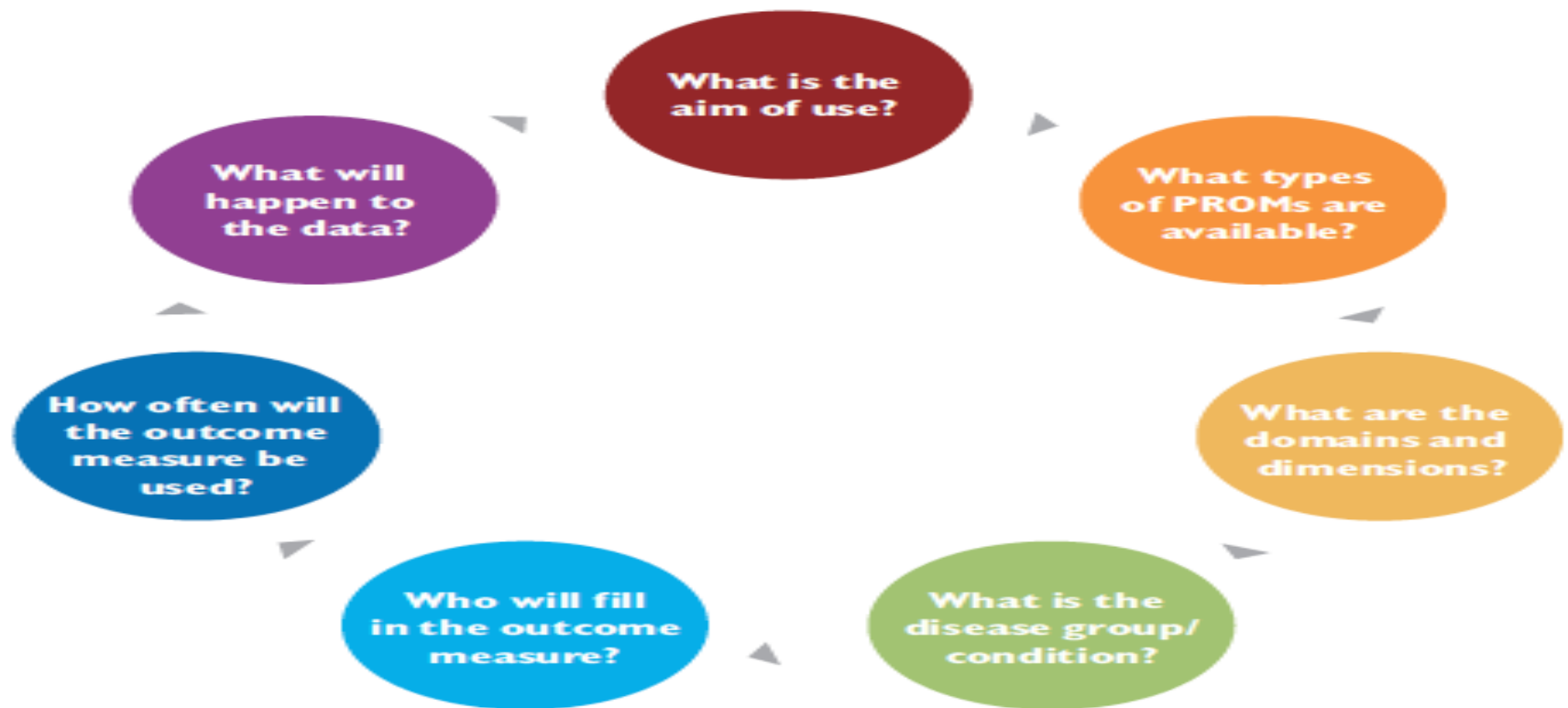


Figure 2.1 What to consider when choosing an outcome measure



If Aim is Research

- Screen for inclusion criteria for study
- Assess functional status
- Describe symptoms
- Monitor changes in health status
- Evaluate the effectiveness of an intervention.



If Aim is Clinical

- Establish patient baseline
- Assess symptoms
- Screen for problems
- Prioritize problems
- Facilitate communication
- Identify preferences
- Monitor change in health
- Monitor changes in response to treatment
- Aid clinical decision-making

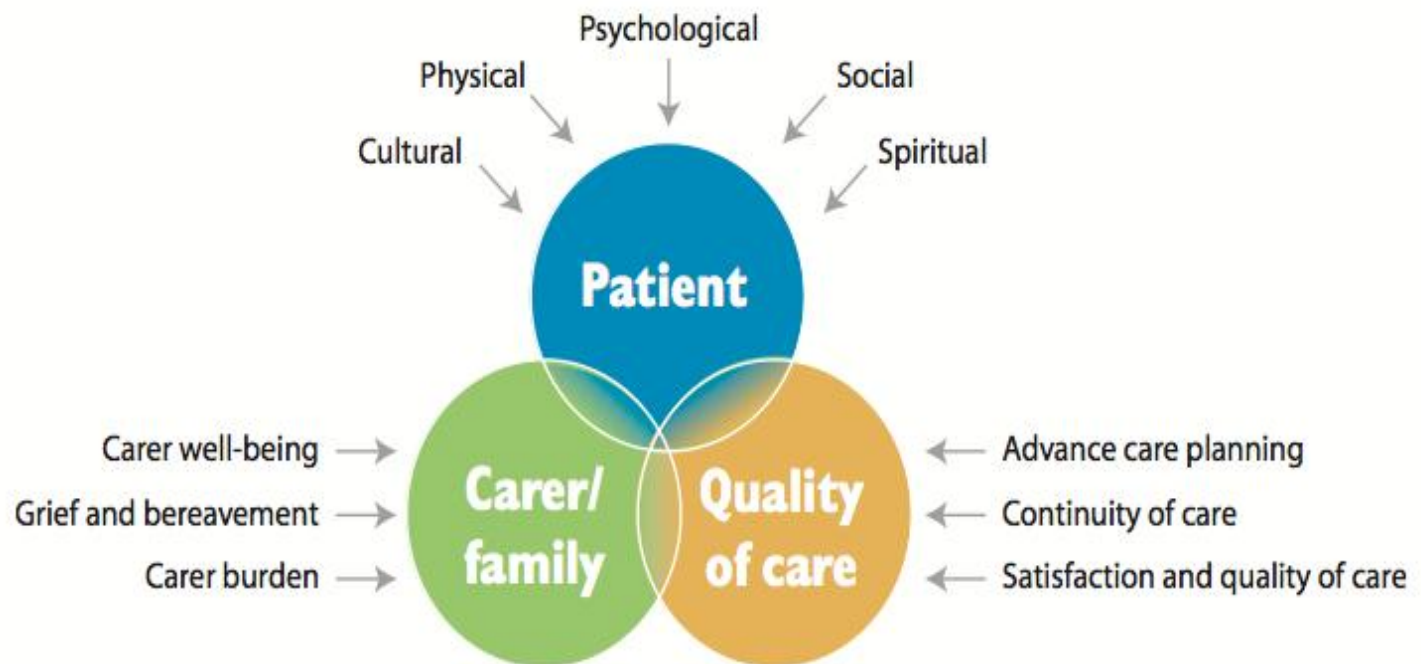


If Aim is Audit/QI?

- Establish standards of practice in particular departments, teams or organizations
- Assess care given established standards with view to improving the standard
- Determine uptake of services
- Benchmark or compare standards of practice in one organization with another (or unit or another)

Domains and Dimensions of Outcome Measurement

Example 2.3 Domains and dimensions of outcome measures in palliative care (adapted from Mularski et al 2007⁸)





Hendelomer

"I'd like to congratulate you on dying with a lot of dignity."

? Generic vs. Disease Specific?

Table 2.1 Type of outcome measures

(see Example 2.1). The actual value is then

	Generic measures	Specific measures
Advantages	<ul style="list-style-type: none">▶ applicable across a broad population for comparing different conditions;▶ large range of domains;▶ can compare palliative treatment with other treatments.	<ul style="list-style-type: none">▶ specifically developed to measure outcomes in palliative care;▶ for use in specific conditions or domains (for example, symptoms, function, palliative care needs);▶ more responsive to clinically meaningful changes.
Disadvantages	<ul style="list-style-type: none">▶ often lack responsiveness to change;▶ not validated in palliative care;▶ do not allow specific problems to be identified.	<ul style="list-style-type: none">▶ do not allow direct comparison with data collected from another patient group.
Examples	<ul style="list-style-type: none">▶ SF-36¹▶ EuroQol (EQ-5D)²▶ General Health Questionnaire (GHQ)³▶ Sickness Impact Profile⁴	<ul style="list-style-type: none">▶ Palliative care Outcome Scale (POS)⁵▶ Hospital Anxiety and Depression Scale (HADS)⁶▶ Edmonton Symptom Assessment Scale (ESAS)⁷



Other issues to consider (cont.)

- Disease group and conditions
 - Where was tool developed
 - Does it apply?
- Completing the outcome measure
 - Functional limitations
 - Proxies
 - Professional
 - informal



Other issues to consider

- How often to use
 - Based on aim
 - Symptoms – frequently
 - Intervention – fixed points
- What to do with the data
 - Clinical notes
 - QI – establish a process for use



Measurement is Science

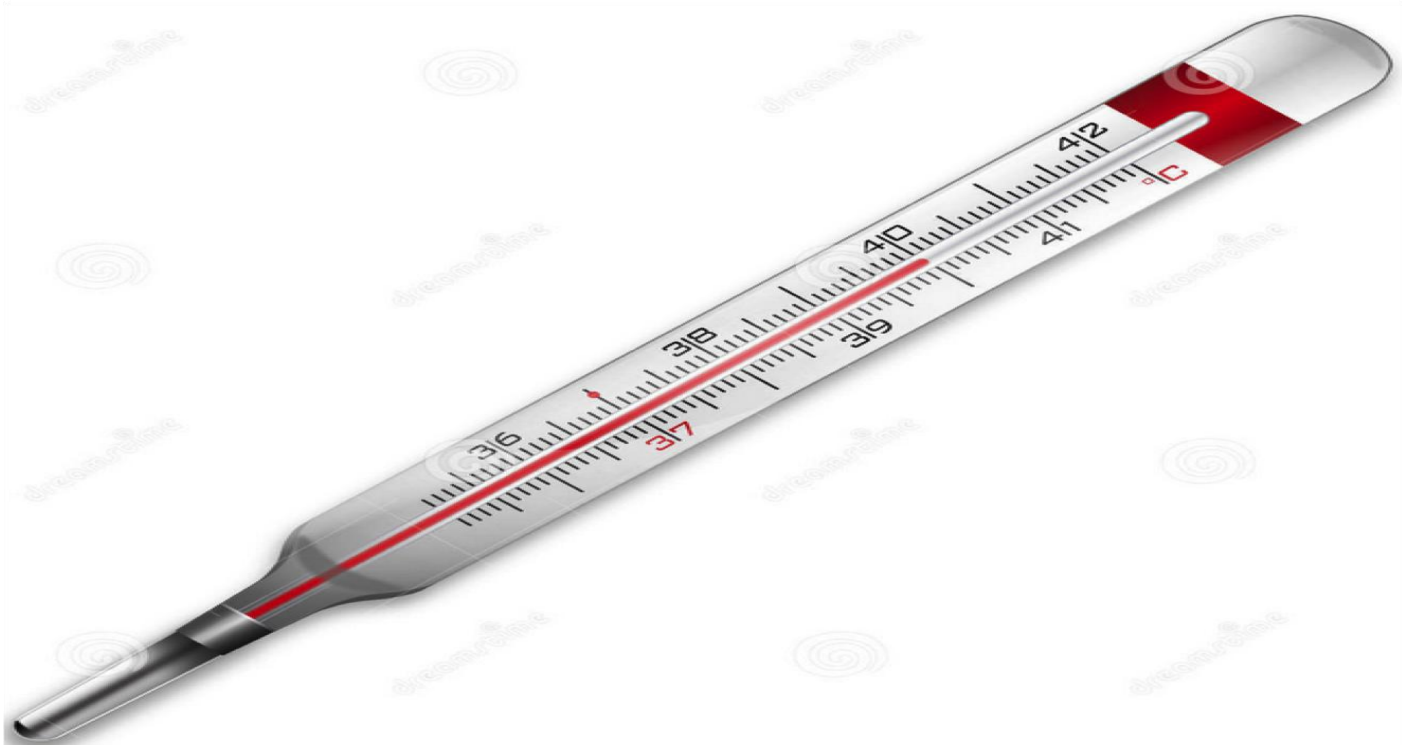
- The assumption that if you can type or talk, you can create a survey is WRONG.
- Conceptual Model
 - How does a particular process related to a particular outcome?
 - What is the magnitude of that relationship of that process to outcome?
 - What is the proportion of the patient population to whom it is applicable?
- Psychometric properties



What makes a good measure?

- Validity
 - Face and content
 - Criterion and construct validity
- Reliability
 - Inter-rater
 - Test-re-test
- Acceptability
- Responsiveness to change
- Interpretability

Q and A





Evaluating complex interventions

- Applying 101 to complexity



What is Quality of Medical Care?

- Institute of Medicine defined quality medical care as the “degree to which health services for individuals and populations increased the likelihood of *desired* health outcomes and are consistent with professional knowledge.”
- Donavedian noted that “achieving and producing health and satisfaction, as defined for its individual members by a particular society or subculture, is the ultimate validator of the quality of care.”

Patient Focused, Family Centered Medical Care



- Key is medical care is Competent, Coordinated and Compassionate
 - Competent care – understands disease trajectory, treatment options, and works with the patient to arrive at medical care the meets the patient goals and expectations (within the constraints that society imposes)
 - Coordinated - ensures care is seamless with transitions
 - Compassionate – treat with respect, provide holistic care

Patient Focused, Family Centered Medical Care



Provide the desired level of physical comfort and emotional support

- **Unmet needs in pain, dyspnea, and emotional support**
- **Promote shared decision-making**
- **Treat with respect and dignity**
- **Attend to the needs of caregivers for information and skills in providing care for the patient.**
- **Physician communication about disease treatment and prognosis**
- **Degree to which the patient was treated with dignity and respect**
- **Whether the family was informed about what to expect**
- **Emotional support to the family prior to and after the patient's death**

What is so different about end-of-life care?



While one is dying, life takes on a new shape – values change. Things once ignored become more important.

What is more important to this women?

Mammogram rates or being treated by the same provider with compassion.



Quality of Medical Care for

- 45 y/o AMI with chest pain
 - presumption to preserve function
 - evidence base on treatment 5,319 papers on treatment just in the last two years. Of these, 519 are RCTs
- 79 y/o lung Ca with dyspnea
 - presumption to preserve function does not necessarily hold
 - evidence base is 13 articles with only one RCT



Definitions of Palliative Care

- Palliate = “to cloak”
- WHO - “the active total care of patients whose disease is not responsive to curative treatment” “Control of pain, other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment.”



Definitions of Palliative Care

(2)

- Oxford Textbook of Palliative Medicine
“the study and management of patients with active, progressive, far advance disease for whom the prognosis is limited and the focus of care is the quality of life.”



Definitions of Palliative Care

(3)

- “..Palliative care is comprehensive, interdisciplinary care, focusing primarily on promoting quality of life for patients living with a terminal illness and for their families. Key elements for helping the patient and family live as well as possible in the face of life-threatening illness include assuring physical comfort, psychosocial, and spiritual support, and provision of coordinated services across various sites of care” Billings, Journal of Palliative Medicine

Adaptation of the Key Elements of the National Consensus Project and National Quality Forum, “A

National Framework and Preferred Practices for Palliative and Hospice Care Quality”

- Plan of care is based on the **goals, values, and needs of the patient and family**. This is regularly reviewed, shared with the family, and other health care providers. (NQF preferred practice 6,10,33,34,36)
- An **interdisciplinary team** provides services to the patient and family that is available, 24 hours, 7 days a week. Disciplines should include medical, nursing, social work, and spiritual care professionals who hold certification in palliative care (NQF preferred practice 1,2, 21, 22, 23)
- Assessment, plan of care, and treatment are **evidence-based and include the following domains: a) physical symptoms; b) emotional distress; c) grief and bereavement; d) spiritual, religious, and existential concerns** (NQF practices 12-18,20)
- **Care coordination** should occur across the disease trajectory and the health care institutions and providers involved in the care of the patient and family. Palliative care teams should have relationships with one or more institutions to provide high quality continuity care throughout the disease trajectory. **This includes hospice.** (NQF 7,8)
- **Social, practical, and legal aspects** of the patient and family are addressed as part of the social care plan. (NQF preferred practice 19)
- Care is **culturally sensitive** to the spiritual and social values and customs of the patient and family. (NQF preferred practice 24)
- Recognizes and appropriately manages the actively **dying patient**. (NQF preferred practices 26, 27)
- The palliative care team strives for excellence through **quality improvement** and management. (Domain 1 of NQF report)

eTable. Defining and Measuring High-Quality Medical Care at the Close of Life in Terms of Goals, Structure, Process, and Outcomes

Components of High-Quality Palliative Care					
1. Competent Care					
Goal	Domain and supporting evidence from 30 existing guidelines	Structure	Process	Outcome	Example of measure from Family Evaluation of Hospice Care Survey
Plan of care is based on goals, values, and needs of patient and family	<p>Patient- and family-centered care N = 21 (70%)¹⁻²⁸</p> <p>Shared decision making and advance care planning N = 24 (80%)^{1, 3-4, 8,10, 11, 14,26, 29,30}</p>	<p>Qualified interdisciplinary staff with appropriate certification and excellent knowledge and assessment skills</p> <p>Clear policy and procedures for documentation of goals of care</p>	<p>Interdisciplinary assessment and care incorporates the goals, and aligns the values and needs of patient and family</p> <p>Care plan is documented and updated</p> <p>Continuity of care plan with health care transitions</p>	<p>Patient preferences and goals of care honored</p> <p>Patient and family felt their concerns and needs addressed</p> <p>Regularly reviewed, shared with the family, and other health care providers</p>	<p>“At any time while [PATIENT] was under the care of hospice, did any hospice team member do anything with respect to end-of-life care that was inconsistent with [PATIENT’S] previously stated wishes?”</p>
Screening, assessment, care planning, and monitoring of physical and emotional symptoms is done with goal that patient receives desired amelioration and emotional support	<p>Physical well-being N = 30 (100%)¹⁻³⁰</p> <p>Psychological well-being N = 28 (93%)^{1, 3-26, 28, 29,30}</p> <p>Social well-being N = 20 (67%)^{1-4, 6-9, 19, 21-24, 30}</p> <p>Spirituality and transcendence N = 21 (70%)^{1-4, 6, 8-12, 14, 17, 19-22, 29,30}</p> <p>Grief N = 19 (63%)^{1-4, 5-8, 12-17, 21,25, 29,30}</p>	<p>Policy and procedures are in place for screening of symptoms and need for emotional support, appropriate assessment, care planning, and monitoring of treatment plan</p> <p>Qualified interdisciplinary team, including physician, nurse, social worker, pharmacist, spiritual counselor and others, that is available 24 hours a day, 7 days a week</p>	<p>Patient screened for needs</p> <p>Among those with a concern, an in-depth assessment is done utilizing standardized measurement tools</p> <p>An individualized plan of care</p> <p>Plan is monitored for whether it is achieving patient and family goals</p> <p>Relationship and involvement fostered with patients’ clergy and religious advisors</p>	<p>Patient receives their desired level of physical comfort and emotional support</p> <p>Family receives their desired emotional support prior to and after the death of their loved one</p> <p>Patient is able to connect with significant persons and bring closure to their life, if desired</p>	<p>“How much medicine did [PATIENT] receive for [HIS/HER] pain? Would you say less than was wanted, just the right amount, or more than [HE/SHE] wanted?”</p> <p>“How much emotional support did the hospice team provide to you after [PATIENT’S] death? Would you say less than was wanted, the right amount, or more attention than you wanted?”</p>
Practical and legal aspects of care are addressed	Financial and practical aspects of care (N = 16) (53%) ^{1-3,5,7,9,13-15,18,20,24,29,30}	<p>Appropriate staff and referral sources to address patient and family concerns</p> <p>Policy and procedure for screening for these concerns</p>	Screened, assessed, and provided with appropriate services.	Patient and family receives the needed support in the practical and legal aspects of the patient’s care	“Did staff provide too much, too little, or just enough support around practical issues of what might happen after [PATIENT’S] death?”
Family member is supported in role as caregiver	Caregiver well-being N = 16 (53%) ^{1, 5, 8-16, 18,23, 26, 29,30}	Staff with appropriate education in supporting care giver	Family handouts instructing in care	Family receives the needed support in their caregiving role	“How confident did you feel about doing what you needed to do in taking care of [PATIENT]? Would you say very confident, fairly confident, or not confident?”
Care is culturally sensitive to spiritual beliefs, values, and	Care is patient- and family-centered	Staff trained in diversity and culture	Sensitive communication that respects the patient and	Care is consistent with patient values and cultural customs	“Did any member of the hospice team talk with you

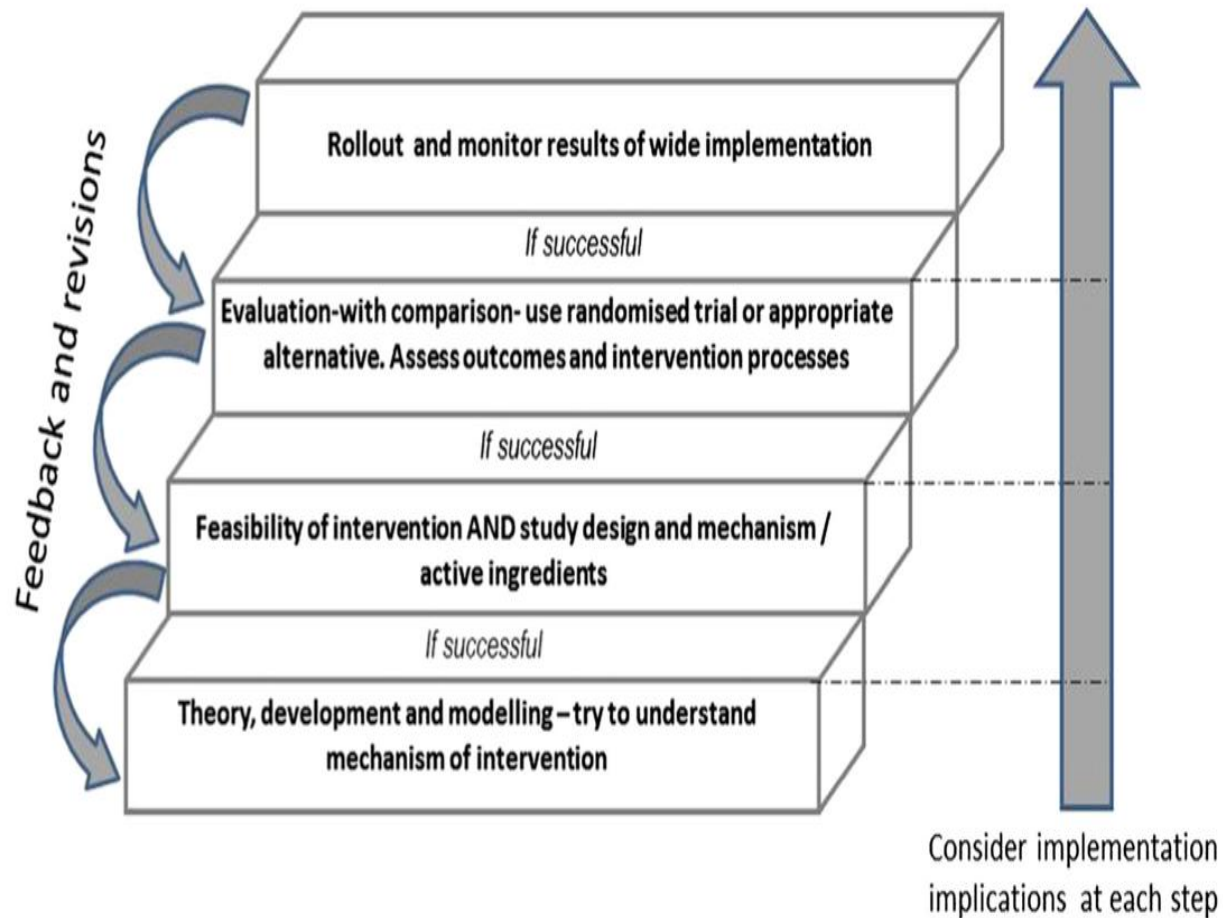


Figure 2 Key steps in developing and evaluating EoLC interventions. Although it is possible to begin at any step in the ladder it is important to progress development with successful interventions. EoLC, end of life care.



Methods of Researching End of Life Care (MORECare)

- Choose Outcome measures
 - Established validity and reliability in relevant populations
 - Responsive to change
 - Capture clinically important data
 - Easy to administer and interpret
 - Applicable across settings of care
 - Able to be integrated into clinical care
 - Use patient's experience of care, as this is central to many interventions



Methods of Researching End of Life Care (MORECare)

- Concerns

- Moving from feasibility and piloting to implementation without robust evaluation
- Failing to develop the feasibility of evaluation methods
- Lack of theoretical underpinning treatment/intervention
- Anticipate attrition

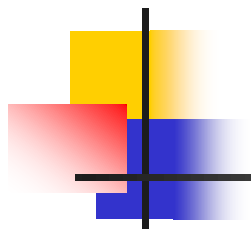


Liverpool Pathway



Spirituality stuff

- Not sure how this all fits in.



For this, expertise in symptom control is required, as well as group understanding, together with an ability to make sense of the inner concerns and values of the person. Above all, there is a need to engage with ‘the whole area of thought concerning moral values throughout life’ — ‘the spiritual’.

Cicely Saunders

Where a desolate sense of meaninglessness is encountered by the person at the end of life, here, one finds the essence of ‘spiritual pain’.

■ -

- Journal of Palliative Care, vol. 4, no. 3 (1988), pp. 29–32.



National Consensus Project Guideline 5.1

“Spiritual and existential dimensions are assessed and responded to based upon the best available evidence, which is skillfully and systematically applied.”



Why Conduct Spiritual Assessment

- **Joint Commission on Accreditation and Health Care**
 - Mandates a spiritual assessment to be directed to the patient and his/her family.
 - Settings affected include - Hospitals, home care organizations, long-term care facilities, and behavioral health settings that treat addiction.
 - Lists general content, does not mandate specific instrument to be used.
- Initial assessment may be brief but must
 - Identify the importance of spirituality and religion to the patient as it may affect care
 - Determine if follow-up with a more comprehensive assessment is warranted



Screening vs. Assessment

- *Screening* - a process for evaluating the possible presence or absence of a particular problem.

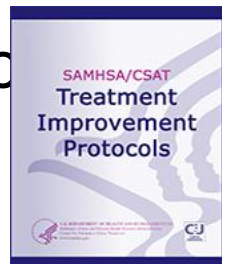
- Does a problem exist?
- Does person require care?

yes or no

Refer or not

- *Assessment* - a process for defining
 - the nature of that problem
 - determining a diagnosis
 - developing specific treatment recommendations for addressing the problem or diagnosis.

See: <http://www.ncbi.nlm.nih.gov/books/NBK85293/>





Spiritual Assessment

It is a systematic approach to care that will inform:

- Plan of care
- Interventions selected
- Outcomes assessed
- Communication between disciplines
 - What chaplaincy does
 - How an individual's care and well-being may be influenced by spiritual needs, beliefs, and traditions.

Is there Value in a Standardized Spiritual Assessment?



- Benefits of standardization?
 - Repeatable
 - Actionable
 - Objective
 - Minimizes Subjectivity
 - Communicates in, an evidence-based format, what you do
- Concerns about standardization
 - Reduces the richness of care
 - Can be alienating versus empathic
 - Focuses on outcomes versus process



History of Assessment in Chaplaincy

- Traditionally, chaplaincy has stayed away from standardized assessment.
- Pastoral care does not have a standard method.
- Field moving in direction of having a system that is standard.
- Internal and external accountability



Characteristics of Assessment

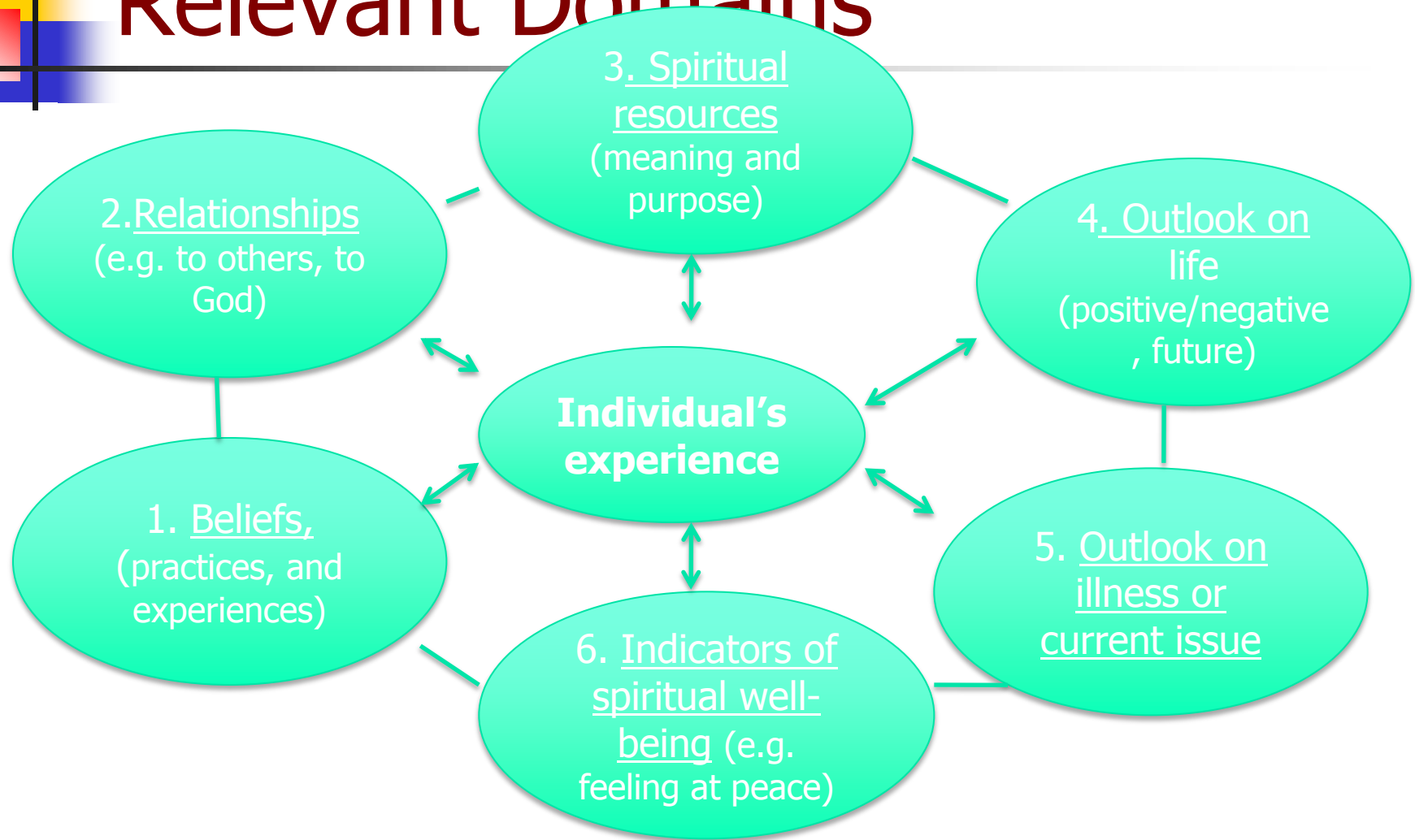
Valid	Content reflects that which is salient to population. Does it measure what it's supposed to measure?
Reliable	Degree to which something produces stable and consistent results
Quantifiable	Versus narrative only; the property of magnitude involving comparability with other magnitudes
Useful/Efficient	Practical, supplies a common need, advantageous.
Inclusive	Content (conceptual and language) is acceptable to and applicable to range of users.
Universal	Applicable and used in all cases, versus locally only
Multi-dimensional	Able to capture the range and depth of needs, and specific to diagnosis, condition, or setting

Characteristics 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, Efficient (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

Evidence-based Model of Relevant Domains






3 Levels of Spiritual Inquiry

Level of Inquiry	Delivery	Goal
Spiritual screening	Non-chaplain	Determine who needs to see a chaplain.
Spiritual history-taking	Non-chaplain	Understand religion and spiritual history, participation, past and present, and religious or spiritual community resources (may reveal negative experiences)
Spiritual assessment	Chaplain or theologically trained person	Gather information that serves as a foundation for evaluating needs, guiding care, communication with colleagues

3 Levels of Spiritual Inquire (cont.)



Level of Inquiry	Context	Length	Mode	Examples
Spiritual screening	Initial contact	Very brief	Questions	Fitchett and Risk, Hui, Peace
Spiritual history-taking	Initial contact and periodic reassessment	Brief	Questions	FICA HOPE Stoll
Spiritual assessment	Initial contact and on-going reassessment	Extensive	Conceptual framework for interpretation	Pruyser 7x7 Brun Berg Monod Morh



Consultancy
