WHAT IS QUALITY IN SERIOUS ILLNESS? FORGING NEW MODELS FROM EVIDENCE-BASED OUTCOMES

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Session Objectives

• To discuss how quality measures can be applied to social work practice in hospice & palliative care
• To examine how patient & family voices can be included in the development of quality measurement
• To consider strategies for how, what & how frequently to measure aspects of quality care
Defining Serious Illness

“… A condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments or caregiver stress.”
What are quality measures?
CMS on Quality Measures

https://www.youtube.com/watch?v=4g914YgL6g
WHAT IS A PERFORMANCE MEASURE?
A healthcare performance measure is a way to calculate whether and how often the health and healthcare system does what it should.

Measures are based on scientific evidence about processes, outcomes, perceptions, or systems that relate to high-quality care.

The New Paradigm: Measuring quality (not quantity)
Different levels of quality assessment

**TYPES OF PERFORMANCE MEASURES**

**STRUCTURAL MEASURES**
- Assess healthcare infrastructure
- Example: The percentage of physicians in a practice who have systems to track and follow patients with diabetes.

**PROCESS MEASURES**
- Assess steps that should be followed to provide good care
- Example: The percentage of patients with diabetes who have had an annual eye exam in the last year.

**OUTCOME MEASURES**
- Assess the results of healthcare that are experienced by patients
- Example: The percentage of diabetes patients who are blind or have compromised vision.
Established in 1999, NQF is a non-profit, non-partisan, membership-based organization that brings together public & private sector stakeholders to reach consensus on healthcare performance measurement. The goal is to make healthcare in the U.S. better, safer, & more affordable.

Mission: To lead national collaboration to improve health and healthcare quality through measurement

- An Essential Forum
- Gold Standard for Quality Measurement
- Leadership in Quality
Measure Applications Partnership: Alignment Matters

Statutory Authority

The Affordable Care Act (ACA) requires HHS to contract with the consensus-based entity (i.e., NQF) to “convene multi-stakeholder groups to provide input on the selection of quality measures” for public reporting, payment, and other programs. (ACA Section 3014).
This project will evaluate measures related to Palliative & End-of-Life Care that can be used for accountability & public reporting for all populations & in all settings of care. This project will address topic areas including:

- Assessment & management of physical, psychological, & spiritual aspects of care
- Care planning
- Appropriateness of care

NQF solicits new measures for possible endorsement

NQF currently has 35 endorsed measures within the area of Palliative & End-of-Life Care. Endorsed measures undergo periodic evaluation to maintain endorsement – “maintenance”.
Measure Evaluation Criteria (abbreviated)

1. Importance to measure and report (must-pass)
   1a. Evidence to Support the Measure Focus (must-pass)
   1b. Performance Gap, including disparities (must-pass)
   1c. For composite measures: quality construct and rationale (must-pass)

2. Scientific acceptability of measure properties (must-pass)
   2a. Reliability [includes additional subcriteria] (must-pass)
   2b. Validity [includes additional subcriteria] (must-pass)
   2c. Disparities (addressed in 1b)
   2d. For composite measures: empirical analysis supporting composite construction (must-pass)

3. Feasibility
   3a. Required data elements routinely generated and used during care delivery
   3b. Availability in electronic health records or other electronic sources OR a credible, near-term path to electronic collection is specified
   3c. Data collection strategy can be implemented

4. Usability and Use
   4a. Accountability and Transparency
   4b. Improvement
   4c. The benefits to patients outweigh evidence of unintended negative consequences to patients

5. Comparison to Related or Competing Measures
   5a. Measure specifications are harmonized OR differences are justified
   5b. Superior measure is identified OR multiple measures are justified
NQF Algorithm for Measure Evaluation

Algorithm #1: Guidance for Evaluating the Clinical Evidence

1. Does the measure assess performance on a health outcome (e.g., mortality, functionality, health status, complications) or process (e.g., adherence, function, symptom, experience, health status, behavior)?
   - YES: PASS
   - NO: NO PASS

3. For measures that assess performance on an intermediate clinical outcome, process, or structure—Is it based on a systematic review and grading of the body of empirical evidence where the specific focus of the evidence matches what is being measured?
   - Evidence consists of empirical studies of any kind, the body of evidence constitutes a body of evidence that may be associated with a guideline?
   - YES: Rerate
   - NO: NO Rerate

5. Does the SR conclude:
   - High quality evidence that benefits clearly outweighs any risks or harms (e.g., USPSTF A)
   - Moderate certainty that the net benefit is substantial (e.g., USPSTF B)
   - Moderate certainty that the net benefit is moderate (e.g., USPSTF C)
   - Moderate certainty that the net benefit is small (e.g., USPSTF D)
   - No evidence to support a benefit (USPSTF E)

6. Does the SR conclude:
   - Consistent evidence, overwhelming advantages of the intervention (e.g., GRADE A)
   - Consistent evidence, advantages of the intervention (e.g., GRADE B)
   - Consistent evidence, advantages of the intervention (e.g., GRADE C)
   - No evidence to support a benefit (USPSTF E)

7. Does the empirical evidence that is summarized in the body of evidence include all studies?
   - YES: NO Rerate
   - NO: NO Rerate

8. Does the empirical evidence that is summarized in the body of evidence include all studies?
   - YES: NO Rerate
   - NO: NO Rerate
Continuum of Care – Palliative and End-of-Life Care

Disease progression

Disease-modifying treatment

Palliative care

Death

End of life care

Bereavement support

Adapted from NQF, 2006
Measure Development Framework—*a work in progress*
Goals:

- Reduce emergency room visits
- Prevent unnecessary hospitalizations
- Reduce hospital readmissions
- Improve patient/family
Social Work Skills

- Ensuring basic needs are met
- Provide meaningful caring relationship
- Complete organization tasks
- Help make informed decisions
- Prepare end-of-life care
- Tackle problems
- Monitor well-being
- Address grief & bereavement

- Emotional support
- Facilitate transitions
- Facilitate independence
- Care management
- Family communication
- Prepare for future/death

Conlisk & Casiano, 2016; Kramer, 2013
Goals of the Project

• Collaboration between The Pew Charitable Trusts and the Gordon and Betty Moore Foundation to:
  • Identify a small number of setting-specific measures applicable to serious illness care that can be implemented in the short-term by Medicare
  • Lay the ground work for future measure development in key gap areas, to be supported by public and private investments
  • Build on the work of previous measurement initiatives such as ACOVE, ASSIST, and Measuring What Matters
The Current State of Quality

- Difficult to determine the quality of care at the setting, community, or health system level
- Measures are not relevant for end-of-life care
- Lack of focus on patient-and family-centered care
- Lack of accountability measures for the care
- Cannot compare programs and models
What Does this Mean for Hospice and Palliative Care?

Challenges
• Serious illness measures will not be easy to develop
  • Difficult to capture/measure patient and family-centered nature of serious illness
  • Reliance on proxy reporting
  • No clear definition of who is seriously ill
• Metrics fatigue

Opportunities
• Move from volume to value
  – Medicare Care Choices Model
• Regulatory advances in quality metrics
  – New Hospice Item Set and CAHPS
  – Coming soon – Hospice Compare!
• National Quality Forum
Clinical Practice Guidelines for Quality Palliative Care

Domain 1: Structure and Processes of Care

Domain 2: Physical Aspects of Care

Domain 3: Psychological and Psychiatric Aspects of Care

Domain 4: Social Aspects of Care

Domain 5: Spiritual, Religious and Existential Aspects of Care

Domain 6: Cultural Aspects of Care

Domain 7: Care of the Patient at the End of Life

Domain 8: Ethical and Legal Aspects of Care
From Federal Policy to Best Practices: Quality Care at Life’s End
What is quality in the experience of dying?

The human encounter with dying is fraught with distress...

• **Is quality...**
  • Having psychosocial, spiritual, existential distress in people managed?
  • Experiencing minimized symptoms of pain, dyspnea, incontinence, delirium, anxiety, grief?
  • Expressing wishes for specific care?
  • Preparing for bereavement?

*Or, all of this & more?*

Dying is uniquely personal, intimate & profound; for each it is different.
Performance Measurement in Hospice

A quantifiable measure of care that indicates whether or not a hospice organization, a department or an individual provider/employee is providing quality care. Quality also includes the patient-family experience.

- What is quality end-of-life care?
- Why is the measure of quality important in end of life care?
- How can alignment be measured across settings?
- What are the gaps in measurement?
- Why is consistency needed in measurement of quality? And difficult?
- How do we advocate for person- & family-centered measurement?
Not every measure will fit every individual, but at its core, how do we identify the central, important elements of the dying experience?
Stakeholders in quality hospice & palliative care are: Clinicians, family members, volunteers, community partners, other providers

- Influence can be low—high
- Interest can be low—high

The combination—seriously—influences the quality of the interaction

Source: Kahootz: http://cloud-collaboration.kahootz.com/how-to-create-an-effective-stakeholder-engagement-strategy
Applying quality measurement to individual agencies & programs: Bringing it home

Paradigm shift: Moving from **quality is punitive** to **team quality**.

- What are the gaps? What issues do you hear about from staff in different units?
- What story does your data tell you?
- How can all departments contribute?
- How can issues that are identified at intake be “pulled through” the entire experience?

Examples (thank you to Mary Pruski, RN at Hospice Buffalo!)

- Patients who live alone; Families who decline PC; Including volunteers; On-call teams;
Resources

- NHPCO Quality Partners: https://www.nhpco.org/qualitypartners
- PEACE Hospice & Palliative Care Quality Measures: https://www.med.unc.edu/pcare/resources/PEACE-Quality-Measures
- California Health Care Foundation Measure Menu: http://www.chcf.org/publications/2016/02/palliative-care-measures-tool
- Cancer Quality-ASSIST Supportive Oncology Quality Indicator Set: http://effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?productid=444&pageaction=displayproduct
- Health Affairs Blog: Building Additional Serious Illness Measures into Medicare Programs: http://healthaffairs.org/blog/2017/05/25/building-additional-serious-illness-measures-into-medicare-programs/
Questions…

• What problematic issues do you face?
• What is quality in social work?
• How to measure?
• How frequently should we measure?
• Measure fatigue?
• Do you involve patients/families in stakeholder groups?
• How to do all of this when 30% die within 7 days of admission?