What is Quality Care in Serious Illness?

NQF Expert Panel Measure Incubator Hospice and Palliative Care Strategy Session

John Cagle, PhD, MSW
SWHPN Boston, March 2018
Why care about measures?

- Without good measures:
  - How do we know that we’re have a beneficial impact?
  - How do we monitor quality of care/services?
  - How do we identify opportunities for improvement?
  - How do we demonstrate value?

_Evidence is powerful!_
Concerns about measures

- Measures have limitations/challenges:
  - Validity/reliability
  - Reductionism
  - Burden
  - Interpretation
  - Unintended consequences
My measurement background

  - Informed 6 of the top 10 *Measuring What Matters* measures
- Quality of Dying-Hospice Scale
- Correlates of a Good Death and the impact of hospice
- Hospice and person-centered care items on the HRS
My measurement background

• 10 years of clinical work in hospice

• One noteworthy clinical vignette...
Types of Measures

- Research measures
- Clinical measures
- Quality measures
Types of Measures

- Research measures
- Clinical measures
- Quality measures
Quality assessment of care

- **Structures:**
  - Context of care – facilities, equipment, staffing, funding

- **Processes:**
  - Actions of care – assessments, interventions, treatments

- **Outcomes:**
  - Effects of care – symptoms, QoL, satisfaction

*Measurement of these domains is critical to ensuring that patients receive the best possible care.*
Quality assessment of care

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Contextual challenges

- Concerns about the hospice and palliative care population:
  - Declining function and cognition
  - Use of proxy report (are they accurate?)
  - Diverse care settings
  - Coping issues; psycho-affective extremes

- Current measures:
  - Generic measures are minimally informative
  - Multidimensional measures are long, burdensome
Measurement Gaps

- Major gaps in person-reported outcome measures for hospice/palliative care
  - e.g., no quality measures for distress
- Measures are needed that are:
  - Contextually appropriate for hospice/palliative care
  - Person-centered
  - Inclusive of both social and practical needs
  - Patient/family reported
Panel objective

**Goal:** Identify and prioritize a measure concept(s) that could be developed into a person-centered outcome measure to fill measurement gaps in hospice and palliative care.
NQF

- The National Quality Forum (NQF)
  - Non-profit
  - Nonpartisan
  - Membership-based
  - Works to catalyze improvements in healthcare
Person-centered Preferences to Guide Advanced Illness Care

Purpose and Connection

Peaceful Death and Dying
Physical Comfort

Financial Security
Emotional and Psychological Well-Being

Family and Caregiver Support

THE NORTH STAR: INDIVIDUAL PREFERENCES

Expert panel

- NQF Measure Incubator Strategy Session: Hospice and Palliative Care
- All day, Washington DC, summer 2017
- One step in a much larger process
Interdisciplinary Panel of Experts

- 5 MDs
- 2 SWs
- 2 Non-clinical researchers
- 1 Nurse
- 1 Chaplain
- 1 Lawyer
Panel results

- Panel identified gaps in four thematic areas:
  1. Distress and peacefulness
  2. Social and cultural needs
  3. Patient-reported and patient-prioritized QoL
  4. Communication and shared decision-making

- A 3 part proposed measure
Distress and peacefulness

- Recalibrate to focus on strengths:
  - Eliminating distress may not be an optimal objective; a more positive concept may be attaining peacefulness
Distress and peacefulness

- Good bedside manner ≠ good care

- These concepts are challenging to measure:
  - Differing opinions on how they are defined in practice
  - Measures need to be:
    - Actionable – providers need to be able to impact the outcomes on which they are being measured
Social and cultural needs

- Measuring social/cultural needs can lead to over-focused on differences
- Attention to patient/family priorities may be more productive
Pt-reported, Pt-prioritized QoL

- First step – have all providers collect, document, and share patient-reported QoL

- An innovative step would be for patients to prioritize the QoL domains of importance to them
Communication and Shared Decision Making

- Talk to patients!:
  - Clinician-patient communication to identify priorities and preferences is essential for high quality care
- Tailor care:
  - Understanding preferences/priorities can inform care
- Preferences/priorities change over
- Information sharing needed:
  - Data communicated across teams to reduce data collection burden and improve coordination
Proposed measure – Part 1

- **Description:** % patients with patient-reported and patient-prioritized QoL domains incorporated in the EHR and accessible to all interdisciplinary care team members across settings
Proposed measure – Part 2

**Description:** % patients who maintained or improved on QoL domains prioritized in Part 1
Proposed measure – Part 3

- **Description:** % patients who maintained or improved on QoL domains prioritized in Part 1...

- ...where there is evidence that clinician action can drive improvements (e.g., pain/sx management)
Moving forward

- The future of hospice/palliative care measurement will require:
  - EHRs to collect necessary data
  - Ability to transmit and share data
  - Operationalizing “complete” and “comprehensive” hospice/palliative care

- Tension:
  - Push for accountability vs. readiness
Next Steps

- Focus groups to identify core *patient-defined* QoL items
- Obtain broad multi-stakeholder feedback on the domains and problem list
Questions?