Methodological Challenges of Publicly Reporting Patient and Family Experiences of Serious Illness Care

May 9, 2017

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Why is Public Reporting on the Rise?
Which characteristics must a measure have to be suitable for publicly reporting?

- Measures that “matter”
  - To patients and their families
  - To providers
    - Within providers’ control

- Measure properties
  - Validity (measure what they’re supposed to)
  - Reliability (distinguish between providers)
    - Not “topped out” (room for improvement)
What is patient-centered care?

- Care that is “respectful of and responsive to individual patient preferences, needs, and values” and “ensuring that patient values guide all clinical decisions”
- Cardinal feature of high-quality care, especially for those with serious illness

How do we measure patient-centered care?

Surveys with standardized administration and analytic procedures can produce:

Comparable data on experiences of care to

Enable objective and meaningful comparisons between providers

Utilizing domains that are important to consumers, and

Focusing on areas where the patient or family caregiver is the best or only source of information.
Are measures of patient-centeredness “measures that matter”?

- Patient-centeredness is inherently important, particularly for those with serious illness
- In addition, better care experiences are often associated with:
  - Better patient adherence to care recommendations
  - Better care processes
  - Better clinical outcomes


Can providers improve their patient-centeredness?

- Evidence that CAHPS scores can improve in response to public reporting
- Case studies suggest that individual quality improvement initiatives are associated with improvements in CAHPS measure scores

*Measures are within provider control*

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Can measures of patient-centeredness have strong measurement properties?

- **Validity**
  - Reported experiences are key drivers of overall ratings of care and willingness to recommend providers

- **Reliability**
  - Can distinguish between providers with a sufficient number of completed surveys
  - Not “topped out”
What are the unique challenges to **validity** of measures of patient-centeredness for the seriously ill?

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Proposed Solutions &amp; Future Research</th>
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| Proxy response  
- Needed more for some disease trajectories than others  
- Needed to assess end-of-life experiences |  
- Allow proxy responses  
- Make analytic adjustments to account for proxies  
- Study methods for identifying best proxies |
| Ensuring fair comparisons across providers  
- Considerable variation in types of patients/disease trajectories, settings of care |  
- Develop core measure set relevant to all patients, settings  
- Case mix adjustment |
What are the unique challenges to reliability of measures of patient-centeredness for the seriously ill?

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<tbody>
<tr>
<td>Small numbers</td>
<td>• Examine cost-effective strategies for boosting response rates</td>
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<tr>
<td>• May result in poor reliability</td>
<td>• Pool responses</td>
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<tr>
<td>• High levels of performance +</td>
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<tr>
<td>small numbers → topped-out</td>
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<td>measures</td>
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Priorities for Future Research

1. **Develop, field test, and gain national endorsement for a survey instrument** that assesses patient and family experiences of seriously ill care across the full range of patient trajectories and care settings in which this care is provided.

2. Refine strategies for:
   a) Identifying the most knowledgeable **proxy respondent**
   b) Achieving the highest possible **response rates**
   c) Calculating **reliable measure scores** for smaller providers

3. **Develop and test quality improvement approaches** to address key domains of patient- and family-centeredness