Patient Reported Outcome Measures in Research

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Objectives

• What are Patient Reported Outcome Measures?
• How are / could PROMs be used in evaluating treatments?
• How are we evaluating the use of PROMs as part of practice?
What are PROMs
What are Patient Reported Outcome Measures (PROMS)?

- Questions patient asked to gauge their own views on their own health
- Completed by the patient
- Represent patient’s view of their health
- May be paper, interview, electronic
- Thousands of varieties

Devlin and Appleby. Getting the most out of PROMS. The Kings Fund. 2010
Key Aspects of PROMs

Generic
• Measures overall health through general domains
• Typically able to compare to general population

Specific
• Measures health related to a particular disease or body part
• Typically perception of symptom severity or impact on life
PROMs in Evaluating Treatments
Patient Important Outcomes

• Events that affect the way patients function, feel or survive
Patient Important Research

• 5 of top 10 research priorities involve PROMs

• Modalities differ in quality of life?
• Treatment of itching?
• Diet for quality of life?
• Symptoms management?
• Treatment of depression?

Manns et al. CJASN. 2014.
• Final common outcomes being determined
• SONG HD valued outcomes measured by PROM
Considerations when using PROMs

- Interventions to improve quality of life likely to do so through specific pathways
  Treatment for uremic pruritus improves quality of life by reducing pruritus and effects of pruritus on other aspects of life
  Unlikely to improve quality of life not affected by pruritus

<table>
<thead>
<tr>
<th>Big Effect</th>
<th>Modest Effect</th>
<th>Little Effect</th>
</tr>
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<tbody>
<tr>
<td>Pruritus</td>
<td>Sleep</td>
<td>Physical Function</td>
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Direct Effects of Treatment

Influenced by Non Pruritus Health Issues

www.phri.ca
Consider how intervention affects QoL

- Anabolic steroid to reduce symptoms of ESKD
  Increase appetite
  Increase muscle → Increased strength
KDQoL – 36 Symptoms

1. Soreness in your muscles
2. Chest pain
3. Cramps
4. Itchy skin
5. Dry skin
6. Shortness of breath
7. Faintness or dizziness
8. Lack of appetite
9. Washed out drained
10. Numbness in hands or feet
11. Nausea
12. Problems with your access
Effect of Choosing Symptoms Unlikely to Change

- Measuring all symptoms:
  Mean score 36 → 32
  Sample Size 216

- Measuring only responsive symptoms:
  Mean score 6 → 2
  Sample Size 22
Minimal Important Difference

- The smallest change in the score that patients can reliably perceive

  Contextualizes changes in PROMs
Minimal Important Difference

• Treatment for COPD changes Chronic Respiratory Questionnaire score
  0.6 difference between groups for breathlessness
• What does that mean?
• Does everyone improve a little or some people improve a lot and some not at all?
• MID terms
  10% improved greater than MID in control
  34% improved greater than MID in treatment
  Therefore need to treat 4 patients for at least 1 to experience noticeably reduced dyspnea
PROMs as the Intervention
Potential Benefits of PROMs
PROMs in Cancer Care: Effect on Quality of Life

- 766 participants randomized
- Primary outcome change in overall HRQoL
- No difference in nursing calls between groups (about 13 calls per patient)
PROMs in Cancer Care: Effect on Survival

- Hazard Ratio 0.83 (95% CI 0.70 to 0.99; p=0.04)
- Reduction in emergency room use and hospitalizations
Evaluation of routinely Measured PATtient reported outcomes in Hemodialysis care (EMPATHY) Trial: A cluster randomized controlled trial

• Does routine measurement of PROMs improve patient-provider communication, for patients undergoing in-facility hemodialysis in Canada.
Conclusions

• PROMs measure important components of patient health relevant to assessing treatment effects and effects of disease and prognosis etc.

• Choose a PROM carefully when considering a research question.

• Results of PROMs should be reported in ways that help patients and clinicians interpret their relevance.

• PROMs may also improve experience and health but require evaluation.
Thanks!