The Role of Patient-Reported Outcome Measures in Clinical Practice

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Outline

1. Definitions of PROMs
2. Rationale for Measuring Patient-reported Outcomes
3. Implementation
## Key Definitions

| **Patient-reported outcome (PRO)** | Any report of the status of a patient’s health condition that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else.  
| **PRO patient-level measure** | Tools to assess health condition (e.g., health status and status of physical, mental, and functioning) as perceived by the patient obtained by directly asking the patient to self-report (e.g., PHQ-9) |
| **Performance measure** | Numeric quantification of healthcare quality for a designated accountable healthcare entity, such as hospital, health plan, nursing home, clinician, etc. |
| **PRO-based performance measure** | A performance measure that is based on patient-reported outcome data aggregated for an accountable healthcare entity (e.g., percentage of patients in an accountable care organization whose depression score as measured by the PHQ-9 improved) |

https://www.qualityforum.org/Projects/n-r/Patient-Reported_Outcomes/Patient-Reported_Outcomes
Why Measure PROs?

“You can’t manage what you don’t measure.”

Source: Old management adage.

“The underlying reason for using PRO measures in clinical practice is to ensure that treatment plans and evaluations focus on the patient rather than the disease.”

How to Use PROMs?

• Clinical practice
• Program evaluation
• Quality improvement
Conceptual Model Uses/Effects of PROMs in Daily Clinical Practice

Completion of PROMs & sharing of results with clinicians and family members

Communication

- Clinician-Clinician
- Patient-Clinician
- Patient-Relative
- Clinician-Relative

Patient Engagement

- Clinician Satisfaction
- Decision Making
- Patient Adherence
- Patient Satisfaction

Patient Outcomes

- Patient Management

What Has Been Done in Diverse Healthcare Settings?

- Lung Transplant program, University of Alberta Hospital, Edmonton, Alberta, Canada; Cancer Care Ontario, Toronto
- European experience
- USA experience
- New Zealand
Lung Transplantation Outpatient Clinic
University of Alberta Hospital

HRQL Results

Clinical Interpretation of Results

HUI
Single-attribute utility scores: differences of >=0.05 are important.

Overall utility score: differences of >=0.03 are important.

PH = Perfect Health
E2 = HUI2 Emotion
SC2 HUI2 Self-care
V3 = HUI3 Vision
H3 = HUI3 Hearing
S3 = HUI3 Speech
A3 = HUI3 Ambulation
D3 = HUI3 Dexterity
E3 = HUI3 Emotion
C3 = HUI3 Cognition
P3 = HUI3 Pain
O3 = HUI3 Overall

Legend:
- Green = Normal
- Yellow = Mild
- Blue = Moderate
- Red = Severe
HRQL Results

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Legend:
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- Severe
HRQL scores and FEV1% pred vs. transplant time

<table>
<thead>
<tr>
<th>Health Utilities Index</th>
<th>Pre-tx</th>
<th>4 months</th>
<th>6 months</th>
<th>16 months</th>
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<tr>
<td>Self-care</td>
<td>0.85</td>
<td>1</td>
<td>0.85</td>
<td>0.85</td>
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<tr>
<td>Ambulation</td>
<td>0.83</td>
<td>1</td>
<td>0.83</td>
<td>0.36</td>
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<tr>
<td>Emotion</td>
<td>0.73</td>
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<td>0.73</td>
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<tr>
<td>Pain</td>
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<tr>
<td>Overall</td>
<td>0.46</td>
<td>0.86</td>
<td>0.42</td>
<td>0.1</td>
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<tr>
<td>FEV1% pred</td>
<td>0.54</td>
<td>0.86</td>
<td>0.71</td>
<td>0.22</td>
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</tbody>
</table>
Emma Children Hospital, Amsterdam, Netherlands

Effectiveness of a Web-Based Application to Monitor Health-Related Quality of Life
Lotte Haverman, Marion A.J. van Rossum, Mira van Veenendaal, J. Merlijn van den Berg, Koert M. Dolman, Joost Swart, Taco W. Kuijpers and Martha A. Grootenhuis
Pediatrics; January 6, 2013 https://www.hetklikt.nu
USA Experience

1. Epic Systems Corporation (MyChart, EpicCare)
2. Cleveland Clinic (Knowledge Program)
3. Dartmouth Spine Center
4. Group Health Cooperative (Health Profile e-HRA)
5. Cincinnati Children’s Hospital
6. Kaiser Permanente Colorado (PATHWAAY)
7. Essentia Health (MN Community Measurement)
8. University of Pittsburgh Medical Center
9. Duke University (Patient Care Monitor)
10. UCLA/Michigan (My GI-Health)
11. University of Washington/ Centers for AIDS Research Networks of Clinical Systems
USA Experience

Information Systems (IS) for the Collection & Use of PRI Data in Clinical Practice

International Society for Quality of Life Research
17th Annual Conference
October 27-30, 2010
London, England

Dale Collins Vidal, MD, MS
Chief of Plastic Surgery, Professor of Surgery, Dartmouth Medical School
Director of the Center for Informed Choice,
The Dartmouth Institute (TDI) for Health Policy and Clinical Practice

Dartmouth-Hitchcock Medical Center
Dartmouth Medical School

WHERE KNOWLEDGE INFORMS CHANGE

Dana Faber Cancer Institute, Boston  http://www.youtube.com/watch?v=6rWtA66Q7OY
Dartmouth Medical Centre

Improve Quality and Efficiency of the clinical encounter by incorporating

• Patient-reported information systems

Reports:
• Web accessible at home or clinics
• Incorporated to the EMRs
Integrating ISS into Breast Care

Auto-queue survey
Patient completes survey
Clinician reviews summary report
Social Worker processes referral
Auto-trigger follow-up surveys
Monitor patients at home

1. Auto-email sent with survey instructions
2. Patient signs onto Web to complete survey from home OR
3. Patient sent reminder to come for appointment to complete survey
Breast History
- Left breast cancer dx: 2004
- Right breast cancer dx: 2003
- Palpable lump: Left
- 1st degree relatives with breast cancer: 2
- 2nd degree relatives with breast cancer: 1
- Bra Size: 44DD

Gyn History
- History of ovarian cancer?: Yes
- Last menstrual period: within last month
- Post Menopausal?: No
- Hx of HRT?: Yes
- Current HRT?: No
- 1st degree relatives with ovarian ca: 1

ROS and Comorbidities per Charlson index*
(Score 3/23)
- Current smoker: 2 packs/day x 30 yrs
- Drinks: 15/week CAGE Score: 1/4
- Positive For
  - Incur BP
  - Breast cancer
  - Admission for mental health
- Negative For
  - Asthma/meds
  - PILD

Surgical History
- Positive For
  - Appendectomy
  - Knee Surgery
  - Tubal Ligation
- Negative For
  - C-section
  - Tonsillectomy

Breast Symptom Questionnaire
- PSC = 17
- All or Most of the Time
  - Physical: Lower back pain, Painful strap grooves
  - Psychosocial: Difficulty finding clothes, Difficulty with sports, Difficulty running, Unwanted attention

Surgeon:
- Smith, William / 2/17/2005
- Jones, Kim / (appt date N/A)
- Height: 5'5
- Weight (lbs): 205
- BMI: 34.1
- BSA: 2.0

Mean = 50, standard dev = 10

BB Level:
- Date: 7/0/10
- Ral to a breast care coordinator has been made. A referral for familial counseling has been made.

Decision Making
- Option toward: Mastectomy
- About choice: No

Left:
- Stands:
- Survival rates:
- Recurrence rates:

- Keep breast:
- Minimize chance of recurrence:
- Avoid radiation:
- Did everything possible:
- Minimize length of tx:
- Aid breast reconstruction:
- Think what the doctor thinks best:
- We breast (peace of mind):

Less important Very important
Patient View

Patient Logs In

Patient Selects and Begins Survey

Johns Hopkins Hospital
http://www.youtube.com/watch?v=S-r4ykaUhfU
New Zealand National IT/IS Strategy
New Zealand National IT/IS Strategy

“Enabling an integrated healthcare model”

Phase 1 (2 Years)

- Clinical Data Repository
- Patient Vitals
- E-events
- Care Plans
- Decision Support
- PROMs

Phase 2 (5 years)

- Continuum of Care - Referral
- Transfer of Care - Discharge
- Medicine Reconciliation
- E-Prescribing
- GP2GP

Dr Sharon L Kletchko
Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations

Claire F. Snyder · Neil K. Aaronson · Ali K. Choucair · Thomas E. Elliott · Joanne Greenhalgh · Michele Y. Halyard · Rachel Hess · Deborah M. Miller · Bryce B. Reeve · Maria Santana

Accepted: 18 October 2011
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Implementation: A Review of the Options and Considerations

- Identifying the goals for collecting PROs in clinical practice

- Selecting the patients, setting, and timing of assessments

- Determining which measure(s) to use

- Choosing a mode for administering and scoring the questionnaire
Implementation: A Review of the Options and Considerations

- Designing processes for reporting results
- Developing strategies for responding to issues identified by the questionnaires
- Evaluating the impact of the PRO intervention on the practice
User’s Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice

Version: November 11, 2011

Produced on behalf of the International Society for Quality of Life Research by (in alphabetical order):

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Available at: http://www.isoqol.org/
Need I Say More?

“...we have the instruments and we have the technologies to collect, store, and transmit the data. What is needed now is the will to measure output (outcomes) and not just inputs.”

D. Feeny / Journal of Clinical Epidemiology 66 (2013) 706-709
Summary

• PROMs are health measurements elicited from the patients

• PROs can be used in clinical practice

• PROMs are here to stay