Patient-reported outcomes in clinical care—are we ready?

Rachel Hess, MD, MS
OUTLINE

• Why patient-reported outcomes?
• How can patient-reported outcomes be leveraged in clinical care?
  – Resource use and cost
  – Identifying individuals for intervention
  – Assessing outcomes of care
• What impacts self-reported outcomes?
Why Patient-Reported Outcomes
\[ V = \frac{Q}{C} \]

- \( V \) (VALUE)
- \( Q \) (QUALITY)
- \( C \) (COST)
Q (QUALITY)

- Safe
- Effective
- Patient-centered
- Timely
- Efficient
- Equitable
PATIENT REPORTED OUTCOMES

...any report of the status of a patient's health condition that comes directly from the patient...

(i.e., without interpretation by a clinician or anyone else)
PATIENT REPORTED OUTCOMES ARE NOT NEW

• Dartmouth Cooperative Functional Assessment (COOP) Charts (1990s)
  – 7 domains, single question, illustrations
• RAND Medical Outcomes Study (1990s)
• Oncology use of PROs (2000s)
CHALLENGES MEASURING PATIENT REPORTED OUTCOMES

- Burden on the patient and the office – time, effort, and cost
- Collecting data can reduce clinical productivity
- Collecting unnecessary information
- Validation concerns
Bring out the Ice Cream Truck!

- Every Clinic gets the same two "flavors"
  - Clinic intervals can be determined within guidelines
  - Clinics are able to choose an additional "flavor"

- PROMIS Physical Function
- PROMIS Depression
CLINIC WORKFLOW

Patients check in with OSS

OSS finds patient encounter within mEVAL Portal

QR Code generated with MRN information embedded

OSS scans QR Code with tablet

Patient is handed tablet to complete all questionnaires

After completion, patient is instructed to return tablet

Note: There will be a minimum and maximum interval based on clinic which patients will complete the baseline health assessments
How can patient-reported outcomes be leveraged in clinical care?
THREE EXAMPLES...

- Resources use and cost
- Identifying individuals for intervention
- Assessing the outcomes of care
VALUE DRIVEN OUTCOMES

- Laboratory
- Supply
- Pharmacy
- Diagnostic Imaging
- Other
- Operating Room Utilization
- Accommodation

Cost Type Groupings
WE FIGURED OUT OUR COSTS

You Don’t Want to Know

$396

$47
### APPENDECTOMY

<table>
<thead>
<tr>
<th>Time</th>
<th>Emergency Department</th>
<th>Operating Room</th>
<th>Surgical ICU</th>
<th>Step down and Floor Units</th>
<th>Day 2</th>
<th>Day 3</th>
<th>Day 4 – 1:45pm</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:54am - Day 1</td>
<td>10:54am</td>
<td>9:46 to 10:48</td>
<td>2:16am</td>
<td>1:30pm</td>
<td>IMCU Intermediate Care Unit</td>
<td>SSTU Surgical Specialty &amp; Trans. Unit</td>
<td></td>
</tr>
<tr>
<td>IMCU Intermediate Care Unit</td>
<td>1:30pm</td>
<td></td>
<td>Surgical ICU</td>
<td>Step down and Floor Units</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1:30pm</td>
<td></td>
<td></td>
<td></td>
<td>Step down and Floor Units</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSTU Surgical Specialty &amp; Trans. Unit</td>
<td>3:25pm</td>
<td></td>
<td></td>
<td>Step down and Floor Units</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Emergency Department
  - Labor
  - Supplies
  - Imaging
  - Pharmacy
  - Lab
  - Other Services

- Operating Room
  - Labor
  - Supplies
  - Other Services

- Surgical ICU
  - Labor
  - Supplies
  - Pharmacy
  - Lab

- Step down and Floor Units
  - Labor
  - Supplies
  - Other Services

Total Cost of Providing Patient Care

**VALUE DRIVEN OUTCOMES – APPENDECTOMY**

- Emergency Department
- Operating Room
- Surgical ICU
- Step down and Floor Units

**TIMELINE**

- **10:54am - Day 1**
  - Emergency Department
- **Day 2**
  - IMCU Intermediate Care Unit
- **Day 3**
  - SSTU Surgical Specialty & Trans. Unit
- **Day 4 – 1:45pm**

**CLINICAL PATHWAY**

- **IMCU** (Intermediate Care Unit)
  - 1:30pm
- **OR** (Operating Room)
  - 9:46 to 10:48
- **SICU** (Surgical ICU)
  - 2:16am
- **Step down and Floor Units**

**TOTAL COST**

- Providing Patient Care
CAN PROs HELP US UNDERSTAND COST VARIATION?
## Demographics

<table>
<thead>
<tr>
<th></th>
<th>Total (N=93,687)</th>
<th>High Physical Function (N=76,350)</th>
<th>Low Physical Function (N=16,033)</th>
<th>High Depression (N=4,241)</th>
<th>Low Depression (N=59,179)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age [Mean (median)]</strong></td>
<td>48 (48)</td>
<td>46.5 (46)</td>
<td>54.6 (56)</td>
<td>45.1 (44)</td>
<td>48.4 (48)</td>
</tr>
<tr>
<td><strong>Sex (Female)</strong></td>
<td>53755 (57%)</td>
<td>43548 (57%)</td>
<td>9505 (59%)</td>
<td>2771 (65%)</td>
<td>34962 (59%)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White or Caucasian</td>
<td>81225 (87%)</td>
<td>66219 (87%)</td>
<td>13898 (87%)</td>
<td>3559 (84%)</td>
<td>51373 (87%)</td>
</tr>
<tr>
<td>Asian</td>
<td>1927 (2%)</td>
<td>1700 (2%)</td>
<td>202 (1%)</td>
<td>64 (2%)</td>
<td>1356 (2%)</td>
</tr>
<tr>
<td>Black/African American</td>
<td>1249 (1%)</td>
<td>1000 (1%)</td>
<td>225 (1%)</td>
<td>80 (2%)</td>
<td>688 (1%)</td>
</tr>
<tr>
<td>Other</td>
<td>9268 (10%)</td>
<td>7431 (10%)</td>
<td>1708 (11%)</td>
<td>534 (12%)</td>
<td>5690 (10%)</td>
</tr>
<tr>
<td><strong>Ethnicity: Hispanic/Latino</strong></td>
<td>6582 (7%)</td>
<td>5262 (7%)</td>
<td>1216 (8%)</td>
<td>422 (10%)</td>
<td>4132 (7%)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>55948 (60%)</td>
<td>45415 (61%)</td>
<td>8777 (55%)</td>
<td>1975 (47%)</td>
<td>36800 (62%)</td>
</tr>
<tr>
<td>Single</td>
<td>26562 (28%)</td>
<td>22298 (29%)</td>
<td>3904 (24%)</td>
<td>1499 (35%)</td>
<td>15631 (26%)</td>
</tr>
<tr>
<td>Divorced/Other</td>
<td>11177 (12%)</td>
<td>7637 (10%)</td>
<td>3352 (21%)</td>
<td>763 (19%)</td>
<td>6676 (12%)</td>
</tr>
<tr>
<td><strong>Employed</strong></td>
<td>92406 (99%)</td>
<td>75272 (99%)</td>
<td>15843 (99%)</td>
<td>4164 (98%)</td>
<td>58271 (99%)</td>
</tr>
<tr>
<td>Anxiety diagnosis</td>
<td>26430 (28%)</td>
<td>19923 (26%)</td>
<td>6086 (38%)</td>
<td>2672 (63%)</td>
<td>16513 (28%)</td>
</tr>
<tr>
<td>Substance diagnosis</td>
<td>16117 (17%)</td>
<td>11520 (15%)</td>
<td>4325 (27%)</td>
<td>1393 (33%)</td>
<td>9693 (16%)</td>
</tr>
<tr>
<td>Mood diagnosis</td>
<td>29577 (32%)</td>
<td>21601 (28%)</td>
<td>7437 (46%)</td>
<td>3063 (72%)</td>
<td>17967 (30%)</td>
</tr>
<tr>
<td>Elixhauser Score Mean</td>
<td>0.4</td>
<td>0.4</td>
<td>0.6</td>
<td>0.1</td>
<td>0.6</td>
</tr>
<tr>
<td># of clinic visits Median (IQR)</td>
<td>2 (0, 5)</td>
<td>2 (0, 4)</td>
<td>2 (0, 6)</td>
<td>3 (0, 7)</td>
<td>2 (0, 5)</td>
</tr>
<tr>
<td><strong>Inpatient admissions</strong></td>
<td><strong>12049 (13%)</strong></td>
<td><strong>8096 (11%)</strong></td>
<td><strong>3813 (24%)</strong></td>
<td><strong>694 (16%)</strong></td>
<td><strong>6846 (12%)</strong></td>
</tr>
</tbody>
</table>
### Hospital Admissions and PROMS Physical Function and Depression

<table>
<thead>
<tr>
<th></th>
<th>Hazard Ratio</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Function (Continuous)</td>
<td>1.05</td>
<td>1.042 – 1.047</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Physical Function (1.5 SD below population average)</td>
<td>2.03</td>
<td>1.93 – 2.15</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Depression (Continuous)</td>
<td>1.005</td>
<td>1.002 – 1.008</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Depression (1.5 SD over population average)</td>
<td>1.12</td>
<td>1.034 – 1.218</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>
## Median Hospital Costs and PROMIS Physical Function and Depression

<table>
<thead>
<tr>
<th></th>
<th>Estimate</th>
<th>Standard Error</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Function (Continuous)</td>
<td>$98.63</td>
<td>$7.64</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Physical Function (1.5 SD below population average)</td>
<td>$2787.54</td>
<td>$381.54</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Depression (Continuous)</td>
<td>$31.27</td>
<td>$10.20</td>
<td>0.002</td>
</tr>
<tr>
<td>Depression (1.5 SD over population average)</td>
<td>$636.58</td>
<td>$455.64</td>
<td>0.16</td>
</tr>
</tbody>
</table>
SCREENING FOR DEPRESSION

• Depression screening has traditionally been ad hoc
• So what does standardized screening add?
SOME DEFINITIONS

• Above threshold for depression:
  – PROMIS Depression ≥65
  – PHQ-9 ≥15

• Diagnosed with depression: ICD-10 for depression in problem list, billing diagnosis, or encounter diagnosis

• Treated for depression: Anti-depressant medications on active medication list
# Completed | # Above Threshold | % Above threshold |
---|---|---
3,846 | 1,635 | 42.51%
501 | 191 | 38.12%
2,889 | 877 | 30.36%

**mEVAL RESULTS (PROMIS)**

| Unique Patients | Primary Care | Psychiatry | Specialty |
---|---|---|---|
# Completed | 7,833 | 1,127 | 33,355 |
# Above Threshold | 530 | 371 | 2,013 |
% Above threshold | 6.77% | 32.92% | 6.04% |
<table>
<thead>
<tr>
<th>Category</th>
<th>Category Total</th>
<th>mEVAL (%)</th>
<th>PHQ-9 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Above threshold but not diagnosed</td>
<td>1,641</td>
<td>1,244 (75.81%)</td>
<td>397 (24.19%)</td>
</tr>
<tr>
<td>Above threshold but not being treated with medications</td>
<td>1,848</td>
<td>1,322 (71.54%)</td>
<td>526 (28.46%)</td>
</tr>
<tr>
<td>Identified above threshold, not on meds, not diagnosed</td>
<td>962</td>
<td>820 (85.24%)</td>
<td>142 (14.76%)</td>
</tr>
</tbody>
</table>

*All data is from September 2016 through July 2017*
18 year old female presented for a Total Body Skin Examination

No Family History of Skin Cancer reported

A few very benign looking moles on her abdomen were noted on examination

Patient was reassured and asked to monitor the moles for new eruptions or any changes; Isotretinoin prescribed for Acne

Figure 1*
SAME-DAY GENERIC PROS BY AFSS GROUP

P<0.001 for each trend vs. AFSS

<table>
<thead>
<tr>
<th>PRO Score (mean)</th>
<th>AFSS Quartile 1 (mean 0.8)</th>
<th>AFSS Quartile 2 (mean 4.9)</th>
<th>AFSS Quartile 3 (mean 10.2)</th>
<th>AFSS Quartile 4 (mean 19.7)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>VAS (n=1281)</td>
<td>PROMIS Phys Fn (n=1293)</td>
<td>PROMIS Depression (n=1280)</td>
<td></td>
</tr>
<tr>
<td>76</td>
<td>65</td>
<td>67</td>
<td>60</td>
<td>49</td>
</tr>
<tr>
<td>49</td>
<td>46</td>
<td>45</td>
<td>49</td>
<td>49</td>
</tr>
<tr>
<td>57</td>
<td>57</td>
<td>49</td>
<td>49</td>
<td>50</td>
</tr>
<tr>
<td>67</td>
<td>67</td>
<td>60</td>
<td>49</td>
<td>49</td>
</tr>
<tr>
<td>60</td>
<td>60</td>
<td>50</td>
<td>49</td>
<td>54</td>
</tr>
<tr>
<td>49</td>
<td>49</td>
<td>50</td>
<td>49</td>
<td></td>
</tr>
<tr>
<td>46</td>
<td>46</td>
<td>42</td>
<td>49</td>
<td></td>
</tr>
<tr>
<td>45</td>
<td>45</td>
<td>49</td>
<td>49</td>
<td></td>
</tr>
<tr>
<td>42</td>
<td>42</td>
<td>49</td>
<td>49</td>
<td></td>
</tr>
<tr>
<td>49</td>
<td>49</td>
<td>50</td>
<td>49</td>
<td></td>
</tr>
<tr>
<td>38</td>
<td>38</td>
<td>50</td>
<td>54</td>
<td></td>
</tr>
<tr>
<td>37</td>
<td>37</td>
<td>50</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# PROS IN HF & AF

<table>
<thead>
<tr>
<th></th>
<th>HF without AF N=1334</th>
<th>HF with AF N=704</th>
</tr>
</thead>
<tbody>
<tr>
<td>KCCQ-12</td>
<td>54</td>
<td>51</td>
</tr>
<tr>
<td>VAS General Health</td>
<td>54</td>
<td>54</td>
</tr>
<tr>
<td>PROMIS Physical Function</td>
<td>40</td>
<td>38</td>
</tr>
<tr>
<td>PROMIS Depression</td>
<td>51</td>
<td>51</td>
</tr>
</tbody>
</table>

\[ p = 0.003 \]

\[ p = 0.938 \]

\[ p < 0.001 \]

\[ p = 0.323 \]

---

**Patients with HF & AF**

<table>
<thead>
<tr>
<th></th>
<th>Not in AF at index visit</th>
<th>In AF at index visit</th>
</tr>
</thead>
<tbody>
<tr>
<td>KCCQ-12</td>
<td>56</td>
<td>66</td>
</tr>
<tr>
<td>VAS General Health</td>
<td>44</td>
<td>50</td>
</tr>
<tr>
<td>PROMIS Physical Function</td>
<td>39</td>
<td>36</td>
</tr>
<tr>
<td>PROMIS Depression</td>
<td>51</td>
<td>52</td>
</tr>
</tbody>
</table>

\[ p < 0.001 \]

\[ p < 0.001 \]

\[ p < 0.001 \]

\[ p = 0.513 \]

\[ p = 0.055 \]

\[ p = 0.055 \]

---

ASSESSING THE OUTCOMES OF CARE
Data from 5,659 Measures in 870 Lumbar Spine Surgery Patients before and after treatment

MCID = 4 points
403 ACL PATIENTS; 6 SURGEONS
16 year old female presented for **Acne follow-up**

Significant improvement was noted with residual scattered pustules on her cheeks

**Treatment plan before PROs** –
Taper/stop the 3 month Oral Antibiotics regimen (Tretinoin, QHS), and switch to topical

**Treatment plan after PROs** –
Continue the aggressive regimen for 2 months and reassess
What impacts self-reported outcomes?

Funding: R01 AT007262 (Hess PI)
METHODS: STUDY DESIGN

• Sampling strategy
  – Age ≥ 50 years
  – 50% men/50% women
  – 70% White/30% Black
  – 50% high/ 50% low subjective well-being

• Enrollment
  – Primary care clinics
  – Community and senior centers
  – Barber shops
METHODS: QUESTIONNAIRES

• Annually for 3 years
• Subjective well-being (Diener temporal subjective well-being)
  – Participants reported past, present, and future subjective well-being annually
• Sociodemographic characteristics
• Life transitions
DEFINING TRANSITIONS: ECONOMIC

• Change in difficulty paying for basics
• Change in employment status
• Change in partner’s employment status
DEFINING TRANSITIONS: SOCIAL

• Marriage/cohabitation
• Divorce/Separation
• Death of spouse/partner/close friend/loved one
• Assumption or loss of caregiving
• Children leaving or returning
DEFINING TRANSITIONS: HEALTH

• Self-reported development or worsening of:
  – Arthritis
  – Visual Impairment
  – Hearing Impairment
  – Hypertension
  – Ischemic Heart Disease
  – COPD
  – Diabetes
  – Cancer
RATING TRANSITIONS AS POSITIVE OR NEGATIVE

• Participants self-rated social and economic transitions as positive or negative

• Health transitions were assumed to be negative
METHODS: ANALYSIS

• Longitudinal, multivariate models—triplicate outcomes of past, present and future subjective well-being
• Additional models adjusted for race and gender including the interactions with transition
• Separate models fit for each transition
OVERALL BURDEN FOR AN INDIVIDUAL

- Pick two people (A and B)—one has a transition and one does not. Otherwise they are the same.
- Each has an average subjective well-being score over 3 years
- We compare A’s average subjective well-being to B’s average subjective well-being
DIFFERENCES BETWEEN THOSE WITH AND WITHOUT TRANSITIONS IN A GIVEN YEAR:

- Pick up 2 people (A and B)—one has transition in that year, one does not. Otherwise they are the same.
- We subtract A’s subjective well-being at time-t from A’s average subjective well-being and do the same with B’s
- We compare the difference in A’s subjective well-being to the difference in B’s subjective well-being
RESULTS: POPULATION

634 (80%) of enrollees completed baseline questionnaires

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean)</td>
<td>63 years</td>
</tr>
<tr>
<td>Female</td>
<td>60%</td>
</tr>
<tr>
<td>Married</td>
<td>42%</td>
</tr>
<tr>
<td>Black</td>
<td>30%</td>
</tr>
<tr>
<td>Economic transition (≥1)</td>
<td>54%</td>
</tr>
<tr>
<td>Social transition (≥1)</td>
<td>68%</td>
</tr>
<tr>
<td>Health transition (≥1)</td>
<td>64%</td>
</tr>
</tbody>
</table>
RESULTS: OVERALL BURDEN FOR AN INDIVIDUAL (AVERAGE OF PERSON A vs. AVERAGE OF PERSON B)

<table>
<thead>
<tr>
<th>Subjective Well-Being Temporal Perspective</th>
<th>Transition</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Economic</td>
</tr>
<tr>
<td></td>
<td>Coefficient (p-value)</td>
</tr>
<tr>
<td>Past</td>
<td>-4.68 (&lt;0.001)</td>
</tr>
<tr>
<td>Present</td>
<td>-7.75 (&lt;0.001)</td>
</tr>
<tr>
<td>Future</td>
<td>-5.24 (&lt;0.001)</td>
</tr>
</tbody>
</table>
RESULTS: DIFFERENCES BETWEEN THOSE WITH AND WITHOUT TRANSITIONS IN A GIVEN YEAR (DIFFERENCE OF PERSON A vs. DIFFERENCE OF PERSON B)

<table>
<thead>
<tr>
<th>Subjective Well-Being Temporal Perspective</th>
<th>Transition</th>
<th>Economic</th>
<th>Social</th>
<th>Health</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Coefficient (p-value)</td>
<td>Coefficient (p-value)</td>
<td>Coefficient (p-value)</td>
</tr>
<tr>
<td>Past</td>
<td></td>
<td>-0.80 (0.03)</td>
<td>-0.17 (0.56)</td>
<td>-0.16 (0.61)</td>
</tr>
<tr>
<td>Present</td>
<td></td>
<td>-0.92 (0.01)</td>
<td>-0.48 (0.08)</td>
<td>-0.12 (0.70)</td>
</tr>
<tr>
<td>Future</td>
<td></td>
<td>-0.70 (0.03)</td>
<td>-0.14 (0.57)</td>
<td>-0.34 (0.20)</td>
</tr>
</tbody>
</table>
CONCLUSIONS

• Economic, social, or health transitions were associated with decreased subjective well-being

• Compared to subjects without transitions in that year:
  – Social or health transitions were not associated with change in subjective well-being
  – Economic transitions were associated with a decline in subjective well-being
So where does that leave us

• PROs can help us:
  – Understand variation
  – Identify individuals for intervention
  – Evaluate change after intervention
  – But... Respond to economic and social change as well as health change
Unable to do

- Step up and down curbs
- Carry laundry basket up flight of stairs
- Run errands and shop

Somewhat able to do

- Vacuuming and yardwork
- Vigorous activities like running and lifting
- Strenuous activities like backpacking
- Jog 5 miles

Fully able to do

- Walk at normal speed
- Walk more than one mile
- Hike a couple of miles (3 km)
- Two hours of physical labor
- Jog for 2 miles
- Run fast pace for 2 miles
- Run 5 miles
- Run 10 miles

PROMIS PHYSICAL FUNCTION

- Jog 5 miles
- Active sports like swimming, basketball
- Exercise for an hour
- Eight hours of physical labor

- Vacationing and yardwork
- Step up and down curbs
- Get out of bed to chair and back

- Run 5 miles
- Run 2 miles
- Step up and down curbs
- Go errands and shop
“We’re ready to begin the next phase of keeping things exactly the way they are.”
Let’s Talk!