Patient-Reported Outcomes: How They Influence the Care We Provide to Our Patients

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Disclosure – Judith Baumhauer MD MPH

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   a = research/institutional support, b = misc. non-income support, 
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   f = Journal reviewer

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Dessert Before The Meal

1. Patient is King
2. Patient Reported Outcomes, Patient Generated data is CRITICAL
   1. Preventative Health Strategies
   2. Maximize Healthy Behavior
   3. Assess Treatment Response
   4. Appropriately Allocate Healthcare Resources
3. University of Rochester is leading the field

Leeds UK: Double Hand Transplant
Health Care Quality

• Process Measures
  – Provider productivity; adherence to standards

• Patient Experience Measures
  – Focus on healthcare delivery (ie. Communication)
  – “Patient Engagement”

• Patient Reported Outcome Measures (PROs)
  – Services provided improve patient health and well-being
“Of the 1958 quality indicators in the National Quality Measures Clearinghouse...only 139 (7%) are actual outcomes and only 32 (<2%) are patient-reported outcomes”

Porter et al, Standardizing Patient Outcome Measurement, NEJM, 2/11/16
"Achieving **good patient health outcomes** is the **fundamental purpose** of health care.

...thus, **outcome measurement** is perhaps the **single most powerful tool** in revamping the **health care system**. Yet systematic and rigorous outcome measurement remains rare or nonexistent in most settings."
A Patient-Reported Outcome (PRO) is a health outcome **directly reported by the patient** who experienced it... 

*NOT the doctor, not the nurse, not the tech....THE PATIENT.*

Patient-Reported Outcome – Wikipedia
En.Wikipedia.org/wiki/Patient-reported_outcome
Patient Is King!

**FIGURE 3: Top Three Goals and Concerns for Breast Cancer Decisions**

<table>
<thead>
<tr>
<th>Condition: Goal</th>
<th>Pat</th>
<th>Prov</th>
<th>p</th>
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<tr>
<td>Keep your breast?</td>
<td>7%</td>
<td>71%</td>
<td>P&lt;0.01</td>
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<tr>
<td>Live as long as possible?</td>
<td>59%</td>
<td>96%</td>
<td>P=0.01</td>
</tr>
<tr>
<td>Look natural without clothes</td>
<td>33%</td>
<td>80%</td>
<td>P=0.05</td>
</tr>
<tr>
<td>Avoid using prosthesis</td>
<td>33%</td>
<td>0%</td>
<td>P&lt;0.01</td>
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If you want to know how your patients are doing..... Just ask them
Must Have’s

• Validated Instrument
• Quick
• “Not on the backs of the Clinician”
• Not costly
• Generalizable and Flexible
• Viewed in Erecord
• Searchable
Validated Outcomes In Clinical Experience

UR VOICE

Every Patient, Every Clinic, Every Visit
NOW....Delivery Windows...Ask at the right time when it matters
PROMIS
Patient Reported Outcome Measurement Information System

- 11-year, $100 million effort by NIH
- Domain specific not disease specific
- Standardized across domains
  - 1-100 with 50=mean score for US population
  - t-score (10pts = 1 standard deviation)
- Follow patients throughout Health Care System
- Produces validated data quickly “Smart Testing”
  - Computer Adapted Technology
  - Item Response Theory
Are you able to get in and out of bed? 
Are you able to stand without losing your balance for 1 minute? 
Are you able to walk from one room to another? 
Are you able to walk a block on flat ground? 
Are you able to run or jog for two miles? 
Are you able to run five miles?
Link the Patient-Reported Outcomes Measurement Information System (PROMIS) with other related instruments.
PROMIS vs SF-36PF
Total, Sept 2019
2.4 million scores
252K unique patients
12 million questions

2.4 minutes
Median time to complete assessment

12 questions
98.2% completed
MIPS
Merit-based Incentive Payment System

- **60%** Quality
- **15%** Improvement Activities
- **25%** Advancing Care Information

**Cost**

- Replaces PQRS
- New Category
- Replaces MU
- Replaces Value-Based Modifier

**Most participants**: Attest that you completed up to 4 improvement activities for a minimum of 90 days.

Participation in a QCDR, demonstrating performance of activities for promoting use of patient-reported outcome (PRO) tools and corresponding collection of PRO data (e.g., use of PQH-2 or PHQ-9 and PROMIS instruments).
Recommendations for PRO-PMs

• CMS Comprehensive Care for Joint Replacement
  – Bundled payment for total hip/knee arthroplasty
  – Voluntary collection of PROs results in reduced discount
  – Final Nov 2015 – PROMIS Global or VR-12, HOOS or KOOS
Clinical Outcome Assessment Compendium

Welcome to the Pilot Phase of the Clinical Outcome Assessment Compendium (COA Compendium) Web Site!

WHAT IS THE PURPOSE OF THE COA COMPRENDIUM?

This pilot COA Compendium (PDF) is part of FDA's efforts to foster patient-focused drug development. The physical functioning in oncology is to be determined, and physical functioning for use in clinical trials in oncology is the Patient Reported Outcome Measurement System (PROMIS) – Physical Function item bank (patient-reported outcome). The Submitter: PROMIS Network Center. Visit “Clinical Outcome Assessment Qualification Program Submissions” Web site for additional information.
Does Patient-Generated Data Help?

• Creating, managing and reporting data has the potential to empower patients, engage and activate them.

• Patients who read their notes, collect personal health data, and maintain a record become more aware of their conditions and behaviors => felt more in control of their care and showed increased participation in their treatment recommendations.

• Leverage Patient experience in shared decision making.
Improving scores on Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) surveys is an important priority for hospitals today. HCAHPS patient satisfaction scores are shared publicly and can impact a hospital's reputation and standing in the community, as well as the bottom line; HCAHPS scores account for 35% of a hospital's value-based purchasing score and directly impact Medicare payments.

HCAHPS Scores will determine up to 2% of a hospital or health system’s Medicare payments by 2017, up from 1.5% in 2015
How Do We Use The Data?

The NEW ENGLAND JOURNAL of MEDICINE

Perspective

Patient-Reported Outcomes — Are They Living Up to Their Potential?

Judith F. Baumhauer, M.D., M.P.H.

July 6, 2017

DOI: 10.1056/NEJMp1702978
Individual Patient

1st Visit to ME
Achilles tendonitis
Referral to PT

Improved with PT
Consider Home PT Program

Family Doctor
Posterior Heel Pain
Referral

Unnecessary Visit(s)
Fractured Ankle treated with surgery

Improving with Healing and Physical Therapy

Depression Symptoms most Dramatically Improved at 4 months
"Will I Be More Physically Active With Surgery?"  t-score 47
Annual cost savings by applying the PROMIS threshold values for each procedure

<table>
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<tr>
<th>PROCEDURE</th>
<th># PT impacted/total</th>
<th>% impacted</th>
<th>Annual Cost savings</th>
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<tr>
<td>Spinal Injection</td>
<td>1,069/3,814</td>
<td>28.0%</td>
<td>$123K-718K</td>
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<tr>
<td>Discectomy</td>
<td>618/2,436</td>
<td>25.4%</td>
<td>$319K-415K</td>
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<tr>
<td>TKR and THR</td>
<td>304/3,289</td>
<td>9.2%</td>
<td>122K-164K</td>
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“There are several different procedures to treat my problem, how do I choose the best one?”
Different Surgeries for Recurrent Ankle Sprains

Figure 1: A) Overall trends in PF demonstrate a return to baseline at 8-12wk follow-up based on reconstruction type demonstrate nearly significant slower improvement at 2, 4-6, 8-12, and > 12 wk follow-up.

*p < 0.05
“There are several different Surgeons, who should I choose?”
Similar Outcomes; Similar Quality for Patients

Thanks to Owen Papuga PhD, Mike Maloney and Sports Division
When will I be able to go to the basement to do the laundry?
T-Score 42
Bunion Surgery Recovery Curve

PROMIS Physical Function Score

- Pre-op
- 1wk
- 3-4wk
- 6-12wk
- >13wk**
Patient’s Like You....
Predictive Modeling

Example: Factors influencing the need for rehab stay after TJA (PROMIS PF scores, co-morbidities, pharma, prior surgery etc.)
Patient Generated Health Data, EHR and Innovation

WHO Social Determinants of Health
SNF Placement Prediction

- **Goals**: Pre-operatively predict which TJR patients will end up going to a SNF
- **Benefits**:
  - Prehab interventions
  - Break preconceived notions
  - Allow SNFs and the hospital to allocate resources with more advanced notice
Application Workflow

- Pull data automatically from EHR
- Use python scripts to transform data for machine learning....
- Blahh, Blahh, Blahh
- Run model
- Output.....
<table>
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<tr>
<th>Name</th>
<th>Status</th>
<th>Notes</th>
<th>Provider</th>
<th>Referral Name</th>
<th>POC</th>
<th>Surgery Status</th>
<th>Lab Work</th>
<th>Patient Status</th>
<th>RTF</th>
<th>MRN</th>
<th>SNR</th>
<th>Start Time</th>
<th>End Time</th>
<th>Next Appt Date</th>
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**Mach Learning**
Barriers

- Other “Quality Measures” more important for compliance and reimbursement than PRO
- IT limitations at other institutions
- PRO available but might not be viewed or shared by provider with patient
  - Patients question the need to complete the PRO
- Importance of Data not understood by all Providers
- Lack of Behavioral Health Specialist Support
PROMIS in Clinical Practice

- Advance Patient Care
- Engage the Patients
- Educate patients
- Share Decision Making with Patients
- Access cost related to outcomes
- Allocate patient care resources appropriately (P4P)
- Common Research outcomes across medicine
- Assess Population Health
- UNITE a Health Care System!
Summary

1. Patient is King
2. Patient Reported Outcomes, Patient Generated and EHR data are CRITICAL
   1. Preventative Health Strategies
   2. Maximize Healthy Behavior
   3. Assess Treatment Response
   4. Appropriately Allocate Healthcare Resources
3. UR is leading the field
Thank You!!