Why Patient-Reported Outcomes Are Important: Growing Implications and Applications for Rheumatologists

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Disclosures

No financial relationships related to this presentation.

Evidence-based Medicine

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U.S. Health Care Issues

• Access to care

 $- \sim 50$ million people without health insurance

• Costs of care

– Expenditures ~ \$ 2.7 Trillion

• Effectiveness (quality) of care

How Do We Know If Care Is Effective?

- Effective care maximizes probability of desired health outcomes
 - Health outcome measures indicate whether care is effective

Cost ↓

Effectiveness ↑

Health Outcomes Measures

- Traditional clinical endpoints

 Survival
 - Clinical/biological indicators
 - Rheumatoid factor
 - Blood pressure
 - Hematocrit



Patient-Reported Measures (PRMs)

Mediators

- Health behaviors (adherence)

- Health Care Process
 - Reports about care (e.g., communication)
- Outcomes (PROs)
 - Patient satisfaction with care
 - Health-Related Quality of Life (HRQOL)

HRQOL in SEER-Medicare Health Outcomes Study (n = 126,366)

SF-6D (0-1 possible range) by Condition



Controlling for age, gender, race/ethnicity, education, income, and marital status.

http://www.ukmi.nhs.uk/Research/pharma_res.asp



Health-Related Quality of Life (HRQOL)

How the person FEELs (well-being)

- Emotional well-being
- Pain
- Energy

What the person can DO (functioning)

- Self-care
- Role
- Social



Does your health now limit you in walking more than a mile?

(If so, how much?)

Yes, limited a lot Yes, limited a little No, not limited at all



HRQOL is Not

Quality of environment Type of housing Level of income Social Support



HRQOL is Reliable and Predictive of (5-year) Mortality



Ware et al. (1994). SF-36 Physical and Mental Health Summary Scales: A User's Manual.

Does your health limit you in vigorous activities?



Does your health limit you in walking one block?



Item Responses and Trait Levels



www.nihpromis.org

Computer Adaptive Testing (CAT)







Response Burden Reduced

- Paper and pencil rules of thumb
 - 3-5 items per minute
- PROMIS computer administration to general population
 - 8-12 items per minute

- Scleroderma patients at UCLA
 - 6 items per minute

Reliability Target for Use of Measures with Individuals

- Reliability ranges from 0-1
 0.90 or above is goal
- Reliability = 0.90 when SE = 3.2
 - T-scores (mean = 50, SD = 10)
 - Reliability = $1 (SE/10)^2$

T = 50 + (z * 10)

PROMIS Physical Functioning vs. "Legacy" Measures



I was grouchy [1st question]

- Never	[39]
- Rarely	[48]
- Sometimes	[56]
- Often	[64]
- Always	[72]

Estimated Anger = 56.1 SE = 5.7 (rel. = 0.68)

I felt like I was ready to explode

[2nd question]

- Never
- Rarely
- Sometimes
- Often
- Always

Estimated Anger = 51.9 SE = 4.8 (rel. = 0.77)

- I felt angry [3rd question]
 - Never
 - Rarely
 - Sometimes
 - Often
 - Always

Estimated Anger = 50.5 SE = 3.9 (rel. = 0.85)

I felt angrier than I thought I should [4th question]

- Never
- Rarely
- Sometimes
- Often
- Always

Estimated Anger = 48.8 SE = 3.6 (rel. = 0.87)

- I felt annoyed [5th question]
 - Never
 - Rarely
 - Sometimes
 - Often
 - Always

Estimated Anger = 50.1 SE = 3.2 (rel. = 0.90)

I made myself angry about something just by thinking about it. [6th question]

- Never
- Rarely
- Sometimes
- Often
- Always

Estimated Anger = 50.2SE = 2.8 (rel = 0.92)

Defining a Responder: Reliable Change Index (RCI)



RCI >= 1.96 is statistically significant individual change..

Thank you!



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Powerpoint file available at: http://gim.med.ucla.edu/FacultyPages/Hays/