Quality and Outcomes

"The best measure of quality is not how well or how frequently a medical service is given, but how closely the result approaches the fundamental objectives of prolonging life, relieving distress, restoring function, and preventing disability."

Lembcke, 1952


Quality of Life (QoL)

- Community
- Education
- Family Life
- Friendships
- Health
- Housing
- Marriage
- Nation
- Neighborhood
- Self
- Standard of Living
- Work

Source: Campbell, 1981

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World Health Organization
Definition of Health

“Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”

WHO, 1948

Health is Measured in Terms of:

- Bodily structure & function
- Specific symptoms
- What you do/are able to do – functioning
- How you feel – subjective ill- and well-being (+ and -)
- What you say it is – personal evaluation

Continuum of Disease-specific and Generic Health Measures - Arthritis

X-ray, Disease Progression
Arthritis Symptoms
Clinical Markers
Specific Symptoms
Impact of Disease-specific Problems
Generic Health
Arthritis Impact
Health-related QOL (HRQoL)

Adapted from: Wilson and Cleary, JAMA, 1995
Ware, Annual Rev. Pub. Health, 1995

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There is More to the Continuum

- Clinical Markers
- Specific Symptoms
- Impact of Disease-specific Problems
- Generic Functioning, Well-being and Evaluation

Predictive Validity:
HRQoL is One of the Best Predictors

- Future health
- Inpatient expenditures
- Outpatient expenditures
- Job loss
- Response to treatment
- Return to work
- Work productivity
- Mortality

Summary of Content/Concepts for Widely-Used Generic Health Surveys

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PROMIS Website
www.nihpromis.org

PROMIS References


Medical Outcomes Study
36-Item Health Survey (SF-36)

Generic Health Profiles: Before & After Medication

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Next Step: Integrate and Standardize Disease-specific and Generic Measures

Example: Osteoarthritis

Comparison of Content of Generic And Disease-Specific Measures

Content Areas*
QOL Disease Impact Scale (QDIS)
1. Global (“activity” and “QOL”)
2. Physical Functioning
3. Mobility
4. General Health
5. Fatigue
6. Cognitive
7. Emotional
8. Sleep
9. Role Functioning
10. Social Functioning

*Note: Bank of 49 items reduced to 25 items with attribution to specific condition

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Anatomy of a Survey Item:
QDIS Changes Attribution from Health to Specific Disease

During the past 4 weeks, how often did your arthritis limit your ability to do your everyday activities?

- Very often
- Often
- Sometimes
- Rarely
- Never


QDIS Reference: QOL Disease Impact Scale (QDIS); Ware JE, Guyer R, Harrington M, Boulanger R. Quality of Life Research, 2012.

Better Measures Are Being Constructed

- Standardized Metrics
- Adaptive survey administrations
- Norm-based scoring
- Internet and mobile data collection

Improving the Physical Function “Ruler”

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We Need the Health Equivalent of a Two-Sided Tape Measure

and Public-Private Partnerships Meeting the Needs of Research and Business

Short-Form Surveys and Ceiling Effects

Measuring Too Low - Ceiling Effect

Some Thermometers Focus on a Very Narrow Range

Cooking Thermometer

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Temperature

Example: Cross-Calibrating Celsius and Fahrenheit

Solution: Adaptive Survey Methods

CAT = Computerized Adaptive Testing

Adaptive Assessments of Disease Impact
Match Questions to Each Patient’s Level

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First Question
Noisy Score Estimate (+/- 15)

Score estimate, 1st response = 62 +/- 15

Higher is worse.
Mean = 50
SD = 10

Second Question: Standard Error
Reduced by One Third

Score estimate, 2 responses = 64 +/- 10

Higher is worse.
Mean = 50
SD = 10

Third Question: Standard Error
Cut in Half

Score estimate, 3 responses = 63 +/- 7

Higher is worse.
Mean = 50
SD = 10

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Fourth Question: Standard Error
Cut by Two Thirds

Score estimate, 4 responses = 62 +/- 5

Moderate

Mild

Higher is worse. Mean = 50
SD = 10

Practical Implications of CAT in Health Assessment

Reference:

A Promising Solution in 1999: CAT-Based Health Assessment

Reference:

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Performance of 5-item CAT Scores Confirmed in NIH-Sponsored Studies

- Mental Health: $r = 0.96$, N = 2,753
- Headache Disability: $r = 0.96$, N = 1,016
- Pediatric Disability: $r = 0.96$, N = 263
- Chronic Kidney Disease: $r = 0.96$, N = 1,000
- Diabetes Impact: $r = 0.96$, N = 100
- Post Acute Rehabilitation: $r = 0.96$, N = 485

What are the Advantages of Dynamic Assessments?

- More accurate risk screening
- Reliable enough to monitor individual outcomes
- Brevity of a short form – 90% reduction in respondent burden
- Elimination of “ceiling” & “floor” effects
- Can be administered using various data collection technologies
- Markedly reduced data collection costs
- Monitor data quality in real time

Matching Methods to Applications

Single-Item Scale, Multi-Item Scale, “Item Bank” (CAT Dynamic)

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Adaptive Survey Logic (ASLX®) Flow Chart

- Survey Content and User Interface (UI)
- Screen Health Assessments
- QOL Assessments (QOLIX®)
- Follow-Up Associated Modules

- Supplemental Domain Assessment (CAT/Static)*
- Repeat Cycle for Each Chronic Condition

**Adaptation:**
- Estimate Score & CI from Screen
- Repeat Cycle for Each Generic Domain
- Repeat Cycle for Each Chronic Condition

**Clinical Causes**
- Diagnosis
- Disease severity
- Clinical endpoint
- Treatment

**Gold Standard**
- HR-QOL

**Economic & Social Consequences**
- Work productivity
- Costs of care
- Mortality
- Self-evaluated health

**Other Measures & Methods**
- MOS Physical Component Summary (PCS)
  - Mean = 50, SD = 10

**Interpreting HRQoL Scores**

**HRQoL Validation Strategies**

**Gold Standard**
- HR-QOL

**Economic & Social Consequences**
- Work productivity
- Costs of care
- Mortality
- Self-evaluated health

**Other Measures & Methods**
- MOS Physical Component Summary (PCS)
  - Mean = 50, SD = 10

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Interpreting HRQoL Scores

- Content of questionnaire items
- Statistically significant change
- Important reduction in disease burden
- Reduction in subsequent expenditures
- Substantial increase in work productivity

MOS Physical Component Summary (PCS)
(Mean = 50, SD = 10)

Chronic Lung Disease
Average Adult

Diabetes Type II

Congestive Heart Failure

Asthma

Are Generic HRQoL Measures Responsive?

X-ray, Disease Progression

SF-36 agreed with primary endpoint (across Rx): - 219 of 253 RCTs - 86.6%

Clinical Markers

Specific Symptoms

Impact of Disease-specific Problems

Generic Functioning, Well-being and Evaluation

Reference:

Internet Sampling and Data Collection

Reference:

References – Asthma Control:

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Health Outcomes Research
Using Handhelds - Mobile Metrics

Final Comment

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