Choosing Patient-Reported Outcomes and Measurement Methods for Team Based Health Care

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Integrated Health Care Conference
Arizona State University Doctor of Behavioral Health Program
Scottsdale, AZ - March 5-7, 2018
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.”

Background

- Proven value of patient-reported outcome (PRO) measures (even short-forms) in prediction and monitoring health care
- Increased understanding of functional health and well-being has led to much better PRO tools
- Standardization (concepts represented, range measured, underlying metrics) is progressing across applications
Approach

- More actionable integration of disease-specific and generic measures
- More practical Internet-based data capture
- Better-matching of measurement methods and applications
- Directly comparable metrics across methods
- Better single-item measures
What Are Some Distinct Applications?

- Population monitoring
- Group-level outcomes monitoring
- Patient-level screening and monitoring
Different Outcome Monitoring
Applications and Matching Methods

- Population
- Group-level
- Individual patient-level

Ceiling Effect

“Item Bank” (CAT Precision)
Quality of Life (QoL)

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

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 Can Be Measured Using Different Operational Definitions:

- **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 General Health Measures

X-ray of Arthritic Hip

Clinical Markers

(1)

Specific Symptoms

(2)

Arthritis Symptoms

Have you had the following symptoms: Joint pain, swelling, burning sensation:
- Almost every day
- Several days a week
- A few days a month
- Not at all

Arthritis Impact

How often did your arthritis limit your physical activities such as walking or climbing stairs?
- Very often
- Often
- Sometimes
- Rarely
- Never

Disease-specific QOL Impact

Generic Health

How often did your health limit your physical activities such as walking or climbing stairs?
- Very often
- Often
- Sometimes
- Rarely
- Never

Generic QOL Impact

Attribution to arthritis

Attribution to health

Health-related QOL

Adapted from: Wilson and Cleary, JAMA, 1995
Ware, Annual Rev. Pub. Health, 1995
Generic QOL Measures Respond to 87% of Clinically Efficacious Treatments

In the first 17 years of well-controlled pharmaceutical RCTs, across 14 therapeutic areas, SF-36 summary measures responded significantly when primary clinical endpoints responded 87% of the time: 58% > MID

Generic and Disease-specific QOL Measures Are Among Our Best Predictors

Health-Related QOL

Disease-specific QOL Impact $\rightarrow$ General QOL Impact

Predictive Validity

(3)

(4)

Costs of health care
Job loss
Response to treatment
Return to work
Work productivity
Future health
Mortality
Measurement Validation & Interpretation

Clinical Criteria
- Diagnosis
- Disease severity
- Clinical endpoint
- Treatment

Gold Standard

HR-QOL

Other Measures & Methods

Economic & Social Consequences
- Costs of care
- Job loss
- Work productivity
- Mortality

### 40-year Trends in Health Domains Represented in Widely-used Surveys

<table>
<thead>
<tr>
<th>Concepts/Domains</th>
<th>Psychometric</th>
<th>Utility</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SIP</td>
<td>HIE</td>
</tr>
<tr>
<td>Physical functioning (¬)</td>
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<td>Social functioning (¬)</td>
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<tr>
<td>Role functioning (¬)</td>
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<td>Psychological distress (¬)</td>
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<td>Health perception (general)</td>
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<tr>
<td>Pain (¬)</td>
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<td>Fatigue (¬)</td>
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<td>Energy</td>
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<td>Psychological well-being</td>
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<td>Sleep</td>
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<tr>
<td>Cognitive functioning (¬)</td>
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<td>Quality of life</td>
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<tr>
<td>Evaluated health outcome</td>
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</tbody>
</table>

### Psychometric
- **SIP** = Sickness Impact Profile (1976)
- **HIE** = Health Insurance Experiment (1979)
- **NHP** = Nottingham Health Profile (1980)
- **COOP** = Dartmouth Function Charts (1987)
- **DUKE** = Duke Health Profile (1990)
- **MOS FWBP** = MOS Functioning & Well-Being Profile (1992)
- **MOS SF-36** = 36-Item Short-Form Health Survey (1992)
- **EORTC QLQ-C30** = European Organization for Research & Treatment of Cancer (1993)
- **PROMIS** = Patient Reported Outcomes Measurement Information System (2004-on)

### Utility
- **QWB** = Quality of Well-Being Scale (1973)
- **EQ-5D** = European Quality of Life Index (1990)
- **HUI** = Health Utility Index (1996)
- **SF-6D** = SF-36 Utility Index (2002)

### Source
Adapted from Ware 1987; Ware, 1995
MOS* Measurement Model, Operational Definitions and SF-36 Survey Items

*Medical Outcomes Study (MOS) surveys spawned the SF-36, SF-12, SF-8 health surveys

Activity Limitations (-)

Evaluations (+ and -)

Subjective well-being (+)

Subjective ill-being (-)

**Items**
- 3a. Vigorous Activities
- 3b. Moderate Activities
- 3c. Lift, Carry Groceries
- 3d. Climb Several Flights
- 3e. Climb One Flight
- 3f. Bend, Kneel
- 3g. Walk Mile
- 3h. Walk Several Blocks
- 3i. Walk One Block
- 3j. Bathe, Dress

**Scales**
- Physical Functioning (PF)
- Role-Physical (RP)
- Bodily Pain (BP)
- General Health (GH)*
- Vitality (VT)*
- Social Function
- Role-Emotional (RE)
- Mental Health (MH)

**Summary Measures**
- Physical
- Mental
Worst to Best (0-100) Scoring Simplified Health Profile Interpretation: Asthma RCT

Source: Okamoto et al., Medical Outcomes Study Short-Form 36 (SF-36), *Annals of Allergy, Asthma & Immunology*, 1996
**Norm-based Scoring of Profiles Makes Interpretation Easier: Asthma RCT**

Source: Norm-based scoring of Okamoto et al., MOS Short-Form 36 (SF-36), *Annals of Allergy, Asthma & Immunology*, 1996
Standardized Summary Measures Link Disease Burden to Population Health

Chronic Disease Registry

Population Health Surveys

SF-36 Physical Component Summary (PCS)
(Mean = 50, SD = 10)

Chronic Lung Disease
Congestive Heart Failure
Chronic Kidney Disease
Diabetes Type II
Asthma
Average Adult
Average Well Adult
Advantage of Standardization: Linking Treatment Outcomes to Population Health

SF-36 Physical Component Summary (PCS)
(Mean = 50, SD = 10)
SF-12 Enabled Two-thirds Reduction in Respondent Burden

**Items**

- 3a. Vigorous Activities
- 3b. Moderate Activities
- 3c. Lift, Carry Groceries
- 3d. Climb Several Flights
- 3e. Climb One Flight
- 3f. Bend, Kneel
- 3g. Walk Mile
- 3h. Walk Several Blocks
- 3i. Walk One Block
- 3j. Bathe, Dress
- 4a. Cut Down Time
- 4b. Accomplished Less
- 4c. Limited in Kind
- 4d. Had Difficulty
- 7. Pain-Magnitude
- 8. Pain-Interfere
- 1. EVGFP Rating
- 11a. Sick Easier
- 11b. As Healthy
- 11c. Health To Get Worse
- 11d. Health Excellent
- 9a. Pep/Life
- 9b. Energy
- 9c. Worn Out
- 9d. Tired
- 6. Social-Extent
- 10. Social-Time
- 5a. Cut Down Time
- 5b. Accomplished Less
- 5c. Not Careful
- 9e. Nervous
- 9f. Down in Dumps
- 9g. Peaceful
- 9h. Blue/Sad
- 9i. Happy

**Domain scales**

- Physical Functioning (PF)
- Role-Physical (RP)
- Bodily Pain (BP)
- General Health (GH)*
- Vitality (VT)*
- Social Functioning (SF)*
- Role-Emotional (RE)
- Mental Health (MH)

**Summary Measures**

- Physical
- Mental

* Significant correlation with other summary measure.
Ceiling Effects

Measuring Only Low

Reliability = 0.90

Ceiling Effect
“Ceiling Effect” Example: Measuring Only High Temperatures

130–190 °F
54–88 °C

Cooking Thermometer
Brief History of Raising a Ceiling: Physical Function “Ruler”

1980 “Ruler” > 75% @ Ceiling

1990: MOS “Ruler” > 30% @ Ceiling

2008, 2013 PROMIS < 3% @ Ceiling

Mean = 50, SD = 10

Vigorous Activities, Not limited

Climbing several flights of stairs

Walk one hundred yards

Bathing or dressing, Limited a little

Norm
Item Response Theory (IRT) Models

Locate Marks on PF “Ruler”

**Mean** = 50
**SD** = 10

<table>
<thead>
<tr>
<th>Physical Function (PF)</th>
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</thead>
<tbody>
<tr>
<td>70</td>
</tr>
<tr>
<td>60</td>
</tr>
<tr>
<td>50</td>
</tr>
<tr>
<td>40</td>
</tr>
<tr>
<td>30</td>
</tr>
<tr>
<td>20</td>
</tr>
</tbody>
</table>

**Reference Items**

- **Very easy to do** strenuous activities, running, sports
- **Able to sit on edge of bed** with some difficulty

**SF-36v2:** How limited are you in climbing several flights of stairs

- **Not limited/A little**
- **Limited a little/A lot**

**Item Response Theory (IRT) Models**

Locate Marks on PF “Ruler”

- **Limited a lot**
- **Limited a little**
- **Not Limited**

**Mean** = 50
**SD** = 10
Typical Single-item Response Categories Restrict Range of Physical Function Measurement (SF-36)

**Mean** = 50  
**SD** = 10

- **Ceiling effect (70%)**
- **Not limited/A little**
- **Limited a little/A lot**

**Reference Items**
- **SF-36v2: How limited are you in climbing several flights of stairs**
- **Very easy to do strenuous activities, running, sports**
- **Able to sit on edge of bed with some difficulty**
Extending Response Category Range Improves Physical Function Measurement

Mean = 50
SD = 10

Ceiling effect (70%)
SF-36v1 and v2
Not limited/A little
Limited a little/A lot
Climbing several flights of stairs

Ceiling effect (25%)
Very easy/Easy
Easy/Slightly difficult
Slightly difficult/difficult
Difficult/very difficult
Impossible

Very easy to do strenuous activities, running, sports
New item: How easy is it for you to climb several flights of stairs
Able to sit on edge of bed with some difficulty

References:
Liegl G, Gandek B, Fischer FH, Bjorner JB, Ware JE, Rose N, Fries JF, and Nolte S. Varying the item format improved the range of measurement in patient-reported outcome measures assessing physical function, Arthritis Research & Therapy 2017;19:66.
Next Step is One Item Per Domain: However, These Items Aren’t the Best Measures of Their Respective Domains

* Significant correlation with other summary measure.
Why Improve Single-item Measures?

• All surveys begin with the first questionnaire item

• The first item may be the only item per domain in the shortest short-form

• Also, because the first item determines what happens next in adaptive surveys, finding the best item is crucial in improving efficiency

• Systematic comparisons of item characteristics by domain show that the best items are not included in the most widely-used multiple-item scales
Improved Single-item Measures

Improvements over MOS, PROMIS and utility surveys include single-item measures with the following characteristics:

• Broader content representation,
• Response categories that cover a wider range,
• Directly measure a higher-order concept, and
• Better match between the essence of the domain and the operational definition.
New Approach to Standardized Disease-specific QOL Impact Measurement

Attribution to specific disease

X-ray of Arthritic Hip

Clinical Markers

(1)

Specific Symptoms

(2)

Arthritis Symptoms

Have you had the following symptoms: Joint pain, swelling, burning sensation:
• Almost every day
• Several days a week
• A few days a month
• Not at all

Arthritis Impact

How often did your arthritis limit your physical activities such as walking or climbing stairs?
• Very often
• Often
• Sometimes
• Rarely
• Never

Disease-specific QOL Impact

Generic Health

Generic QOL Impact

How often did your health limit your physical activities such as walking or climbing stairs?
• Very often
• Often
• Sometimes
• Rarely
• Never
What is the QOL Disease Impact Scale (QDIS®)

- A suite of disease-specific measures that are standardized across chronic conditions, including:
  - Comprehensive item bank for use in adaptive testing
  - 7-item fixed-length short form (QDIS-7)
  - Global QOL impact item

- Expands disease-specific item content to be on a par with the most comprehensive generic QOL measures

- Uses disease-specific attributions to increase responsiveness to one condition or disease

- All measures scored using the same underlying metric and normed in the US chronically-ill population

Source: Ware JE, Gandek B, Guyer R and Deng N. Standardizing Disease-specific Quality of Life Measures Across Multiple Chronic Conditions: Development and Initial Evaluation of the QOL Disease Impact Scale (QDIS®), Health and Quality of Life Outcomes, 2016; 14: 84.
## Content and Respondent Burden for General and Disease-Specific Measures

<table>
<thead>
<tr>
<th>Health Domains*</th>
<th>Comprehensive Generic</th>
<th>Disease-Specific</th>
<th>QOL Disease Impact Scale (QDIS)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>SIP</td>
<td>MOS SF-36</td>
<td>PROMIS 29-57</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Social functioning</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Role functioning</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Psychological distress</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Health perceptions</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Pain (bodily)</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Energy/fatigue</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>●</td>
<td>●</td>
<td>●</td>
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<tr>
<td>Sleep</td>
<td>●</td>
<td>●</td>
<td>●</td>
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<tr>
<td>Cognitive functioning</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Quality of life</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Health transition (B/S/W)</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>Sexual functioning</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
</tbody>
</table>

*Specific symptoms
Specific treatments

**SIP**=Sickness Impact Profile (1976); **MOS FWBP**=MOS Functioning and Well-Being Profile, 149 items (1992); **PROMIS®**=Patient Reported Outcomes Measurement Information System (2004-on); **KDQOL**=Diabetes Quality of Life Measure; **MLHQ**=Kidney Disease Quality of Life Instrument; **MLHFQ**=Minnesota Living with Heart Failure® Questionnaire; **SAQ**=Seattle Angina Questionnaire; **St George**=St George’s Respiratory Questionnaire; **WOMAC®**=Western Ontario and McMaster Universities Osteoarthritis Index; **QDIS®**=QOL Disease Impact Scale (Ware et al, 2016). **Source for comparison**: Adapted from Ware 1987; Ware, 1995.
Anatomy of a Survey Item: What Makes it Generic or Disease-specific?

During the past 4 weeks, how often did your heart problem limit your ability to do your everyday activities such as work, school or chores?

Very often
Often
Sometimes
Rarely
Never

References:

In Contrast to Generic Health, the Model for Disease-Specific Attributions is 1-Factor

Confirming unidimensionality, out of 7,056 residual correlations across five disease groups, only one residual correlation, $r=0.202$, exceeded 0.20.

QOL Disease-specific Impact Scale (QDIS) (unidimensional model)

References:
QDIS Scores Increase with Disease Severity, US General Chronically-ill Population (N=5351)

Plot of QDIS Scores Across Groups Differing in Disease Severity, US General Chronically Ill Population (N=5351)

Source: Ware JE, Gandek B, Guyer R and Deng N. Standardizing Disease-specific Quality of Life Measures Across Multiple Chronic Conditions: Development and Initial Evaluation of the QOL Disease Impact Scale (QDIS®), Health and Quality of Life Outcomes, 2016; 14: 84.
Solution to the Practical vs Precise Measurement Problem: Computerized Adaptive Test (CAT) Assessments

Individual scores here; CAT algorithms match items to that level.

CAT = Computerized Adaptive Testing
Practical Implications of CAT-Based Assessment Demonstrated in 2000

Static 5-Item Headache Pain Measure

Adaptive 5-Item Headache Pain Measure

“Ceiling Effect”

References:
Logic of Computerized Adaptive Testing (CAT)

1. Begin with initial score estimate

2. Select & present optimal survey item

3. Score response

4. Re-estimate health score and confidence interval

5. Is stopping rule satisfied

6. End scale assessment

7. End of battery?

8. Administer next scale

9. Stop

Adaptive Software Can Substantially Improve Measurement Efficiency
1st Item Yields Noisy Score Estimate

- Extremely:
- A lot:
- Some:
- A little:
- Not at all:

1st item
Score = 62
+/- 15

Mean = 50
SD = 10
2nd Item Reduces CI by 1/3

2nd item
Score = 64
+/- 10

Mean = 50
SD = 10
3rd Item Cuts CI by 1/2

3rd item
Score = 63
+/- 7

Mean = 50
SD = 10
4th Item Cuts CI by 2/3

4th item
Score = 62
 +/- 5

Mean = 50
SD = 10
Advantages of Computerized Adaptive Test (CAT) Assessments

- More accurate individual risk screening and outcomes monitoring
- Brevity of a short form – 70%+ reduction in response burden
- Elimination of “ceiling” effects, with improved items
- Can be administered using various electronic data collection technologies
- Monitor data quality in real time

However, because of the number of generic domains and comorbid conditions, routine CAT’s won’t solve the respondent burden problem.
Alternate Forms of QDIS

- 1 global impact item
- 7-item static form
- MCC form
- CAT

In the past 4 weeks, how much did your asthma limit your everyday activities or your quality of life?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little</th>
<th>Some</th>
<th>A lot</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼ 1</td>
<td>▼ 2</td>
<td>▼ 3</td>
<td>▼ 4</td>
<td>▼ 5</td>
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Alternate Forms of QDIS

- 1 global impact item
- 7-item static form
- MCC form
- CAT

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Alternate Forms of QDIS

- 1 global impact item
- 7-item static form
- MCC form
- CAT

MCC: Multiple chronic conditions

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Alternate Forms of QDIS

- 1 global impact item
- 7-item static form
- MCC form
- CAT

Chronic Condition Checklist (CCC) & QDIS

QDIS QOL output includes:
- Impact for each condition
- Profile comparing multiple conditions
- Total score aggregating comorbid conditions
Convergent-Discriminant Validity Tests Require Multiple Constructs and Multiple Methods

• **Convergent validity** is supported when substantial correlations are observed between different methods of measuring the same construct (e.g., disease, health domain)

• **Discriminant validity** is supported when much lower correlations are observed between different constructs measured by the same method

Convergent-Discriminant Validity Correlation Matrix, Comorbid Arthritis and Obesity (N=337)

<table>
<thead>
<tr>
<th>Conditions &amp; Methods</th>
<th>Arthritis</th>
<th>Obesity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ar1</td>
<td>Ar2</td>
</tr>
<tr>
<td>Arthritis (Ar)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ar1 Sx – Joint pain</td>
<td>0.51</td>
<td>0.49</td>
</tr>
<tr>
<td>Ar2 Severity</td>
<td></td>
<td></td>
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<tr>
<td>Ar3 QOL impact</td>
<td></td>
<td></td>
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<tr>
<td>Obesity (Ob)</td>
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<tr>
<td>Ob1 Sx – BMI</td>
<td>0.05</td>
<td>0.15</td>
</tr>
<tr>
<td>Ob2 Severity</td>
<td>0.14</td>
<td>0.22</td>
</tr>
<tr>
<td>Ob3 QOL impact</td>
<td>0.19</td>
<td>0.24</td>
</tr>
</tbody>
</table>

**Convergent validity**: Substantial correlations between different methods of measuring the same disease: $r = 0.49$ to $0.75$

**Discriminant validity**: Lower correlations between different diseases measured with the same ($r = 0.05$ to $0.32$) and different methods ($r = 0.14$ to $0.25$)

**Convergent validity**: $r = 0.39$ to $0.60$

**Note**: Body mass index (BMI)

# Responsiveness of Disease-specific and Generic QOL Measures Across Groups Reporting Better and Worse 9-month Outcomes

<table>
<thead>
<tr>
<th>Measures</th>
<th>Much Better (n=244)</th>
<th>Somewhat Better (n=245)</th>
<th>Same (n=1181)</th>
<th>Somewhat Worse (n=282)</th>
<th>Much Worse (n=378)</th>
<th>F-ratio</th>
<th>RV(^{a})</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disease-specific (−)</strong></td>
<td></td>
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<tr>
<td>QDIS-7</td>
<td>-2.76</td>
<td>-0.04</td>
<td>1.29</td>
<td>3.20</td>
<td>5.87</td>
<td>29.8*</td>
<td>1.00**</td>
</tr>
<tr>
<td><strong>General (+)</strong></td>
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<tr>
<td>SF-8 Physical (PCS)</td>
<td>1.36</td>
<td>-0.71</td>
<td>-0.28</td>
<td>-3.22</td>
<td>-4.98</td>
<td>14.2*</td>
<td>0.47</td>
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<tr>
<td>SF-8 Mental (MCS)</td>
<td>1.33</td>
<td>-0.47</td>
<td>0.14</td>
<td>-0.33</td>
<td>-0.91</td>
<td>2.1</td>
<td>0.07</td>
</tr>
</tbody>
</table>

Note: For each outcome, self-evaluated change groups were defined in response to the question, “Compared to nine months ago, how much better or worse is your <DISEASE> now?”, where DISEASE was a pre-defined and confirmed for nine chronic conditions analyzed here in the aggregate (total N=2330).

\(^{a}\)Relative validity (RV) is the ratio of the comparator general health F-statistic over the best (QDIS) F-statistic

*Significant F-ratio for comparison of average changes

**RV significantly greater in comparison with general measures using bootstrap method.

Source: Ware JE, Gandek B, Guyer R and Deng N. Standardizing Disease-specific Quality of Life Measures Across Multiple Chronic Conditions: Development and Initial Evaluation of the QOL Disease Impact Scale (QDIS\(^{\circ}\)), Health and Quality of Life Outcomes, 2016; 14:84.
Summary

- Comparisons of outcomes across applications requires QOL measurement standardization
- To make results more actionable, generic and disease-specific QOL must be displayed on the same dashboard
- To make data collection more practical, a new generation of single-item super-short forms is required
- Improvements over MOS, PROMIS and utility items for common domains have been linked to single-items with:
  - Broader representation of descriptive content
  - Response categories covering a wider range
  - Direct measurement of higher-order concept
  - Better match between essence of domain and operational definition
- A more aggressive adaptive measurement system that monitors QOL when necessary, and automatically adapts to the presence and severity of multiple chronic conditions is required.

All QDIS measures:
Mean = 50
SD = 10

Asthma (Mod)  Diabetes (Mild)  OA (Severe)
Norm: Chronically-ill

Better (Less impact)  Worse (More impact)
Summary

• Comparisons of effectiveness across applications requires QOL measurement standardization

• To make results more actionable, generic and disease-specific QOL must be displayed on the same dashboard

• To make data collection more practical, a new generation of single-item super-short-forms is required

• Improvements over MOS, PROMIS and utility items for common domains have been linked to single-items with:
  • Broader representation of descriptive content
  • Response categories covering a wider range
  • Direct measurement of higher-order concept
  • Better match between essence of domain and operational definition

• A more aggressive adaptive measurement system that monitors QOL with “super SF items,” drills down when necessary, and automatically adapts to the presence and severity of multiple chronic conditions is required