Choosing the Right Health-related Quality of Life (HRQOL) Measure

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Choosing the Right HRQOL Measure

- Applications of HRQOL measures
- Types of HRQOL measures
- Selection Criteria of HRQOL measures
- Translation of HRQOL measures
Health Outcomes

- Patient Reported Outcomes
- Quality of life
- HRQOL
- Health status
- Morbidity (diseases, illness, disability)
- Mortality/survival
Relevance of HRQOL Outcomes

- Incurable diseases, e.g. cancer, AIDS
- Chronic diseases, e.g. asthma, arthritis
- Disabling diseases, e.g. stroke, CHD
- Psychological illnesses, e.g. depression
- Functional disorders, e.g. dyspepsia, impotence
- Cost-effectiveness analysis
Purposes of HRQOL Assessment

- **Evaluative**
  - Impact of illness
  - Effects of treatment
  - Quality of care

- **Discriminative**
  - Population groups
  - Severity of illness

- **Predictive Outcome**
  - Screening tool
  - Service utilization
  - Mortality

- **Cost-effectiveness**
  - Quality adjusted life years (QALYs)
工欲善其事，必先利其器
A good instrument is the pre-requisite of success
Purpose of HRQOL Measures

• **Generic**
  – Ambulatory/hospitalized/adults/children

• **Disease Specific**
  – disease group/individual disease
  – Modular (generic + disease specific)

• **Utility**
  – Preference-based measure of health
Conceptualization of HRQOL Measures

Latent Variable: Health-related Quality of Life

Dimension/Domain (Scale):
- Physical fitness
- General health
- Daily role functioning

Indicator (Item):
- running
- Walking
- Health worse
- Get sick easier
- Cut down work
- Less careful
HRQOL Domains


**Essential**
- Subjective
- Functioning- physical, daily role, social
- Mental (emotional) health status
- General health perception

**Important**
- Vitality
- Symptoms, e.g. pain
Generic HRQOL Measures

SF-36 Health Survey
- Physical Functioning
- Role – physical
- Bodily pain
- General health
- Vitality
- Social functioning
- Role-emotional
- Mental health

WHO-QOL-BREF (HK)
- Overall QOL
- Physical health (pain, energy, sleep, mobility, ADL, work,)
- Psychological (feeling, cognition, self-esteem, eating, spirituality)
- Social (support, sex)
- Environment (safety, home, finance, access to care, leisure, pollution)
Disease Specific HRQOL Measures

**FACT-C (CRC)**
- FACT-G scales
  - Physical well-being
  - Social well-being
  - Emotional well-being
  - Functional well-being
- Colorectal cancer scales
  - Abdominal pain, weight, bowel control, digestion, diarrhoea, appetite, self-image, stoma problems

**EORTC – CRC specific**
- EORTC QLQ-C30 scales
  - 6 Functional (incl. cognitive & general health status)
  - 9 Symptoms scales (dyspnoea, pain, fatigue, insomnia, appetite, nausea, constipation, diarrhoea, finance)
- EORTC QLQ-CR38
  - 4 functional scales (image, future, & 2 on sex)
  - 7 symptom scales (urination, chemo S/E, GI, sex, defecation, stoma, wt)
Health Preference (Utility) Measures

- **SF-6D**
  - Physical functioning (6)
  - Role limitation (4)
  - Pain (6)
  - Vitality (5)
  - Social functioning (5)
  - Mental Health (5)

- **EQ-5D**
  - Mobility (3)
  - Self-care (3)
  - Usual activities (3)
  - Pain (3)
  - Anxiety/depression (3)

- **HUI-3**
  - Vision (6)
  - Hearing (6)
  - Speech (5)
  - Ambulation (6)
  - Dexterity (6)
  - Emotion (5)
  - Cognition (6)
  - Pain (5)
Scoring HRQOL Measures

• **Response Choices**
  – Dichotomous
  – Likert scale
  – Visual analogue scales

• **Scoring algorithm**
  – Equal/weighted summation
  – Profile (continuous/categorical)
  – Summary/overall
  – Preference (utility) index
  – Norm-based scoring
The COOP/WONCA Charts

• Six single-item charts (domains)
  – physical fitness
  – feelings
  – daily activities
  – social activities
  – change in health
  – overall health

• 5-point Likert scales
  – No difficulty
  – A little
  – Some
  – Much
  – Extreme

• One categorical score for each domain, higher score = worse
HRQOL Profile Scores
(Lam CLK et al. AP Fam Med 2003; 2:98-106)

HK Chinese Norm-based SF-36 Scores

- PF
- RP
- BP
- GH
- VT
- SF
- RE
- MH
# Health Preference (Utility) Score

<table>
<thead>
<tr>
<th>Component</th>
<th>Description</th>
<th>Level</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF</td>
<td>Your health limits you a little in vigorous activities</td>
<td>2</td>
<td>-0.05</td>
</tr>
<tr>
<td>RL</td>
<td>You accomplish less than you would like</td>
<td>3</td>
<td>-0.035</td>
</tr>
<tr>
<td>SF</td>
<td>Your health limits your social activities none of the time</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Pain</td>
<td>You have pain that interferes with your normal work a little</td>
<td>3</td>
<td>-0.037</td>
</tr>
<tr>
<td>MH</td>
<td>You feel tense or downhearted and low a little of the time</td>
<td>2</td>
<td>-0.038</td>
</tr>
<tr>
<td>VT</td>
<td>You have a lot of energy some of the time</td>
<td>3</td>
<td>-0.056</td>
</tr>
</tbody>
</table>

SF-6D score = 1 - 0.050 -0.035 – 0 – 0.037 – 0.038 – 0.056 = 0.784
Health Preference of HK Population

Lam et al, 1998 (N=2410)

SF-6D Preference Score

- HK norm
- Age 60+
- Mental Dx
- Pulmonary
- Heart Dx
- DM
- Dyspepsia
- Arthritis
- HT
- Any Chr Dx
- No Chr Dx
Selection Criteria of HRQOL Measures

• Conceptualization
  – Fit for purpose
  – Suitable population
  – Appropriate domains

• Operation
  – Language
  – Respondent burden
  – Administration method
  – Recall time frame
  – Scoring algorithm

• Psychometric properties
  – Validity
  – Reliability
  – Sensitivity
  – Responsiveness
  – Interpretation

• Administration
  – Copyright
  – Loyalty
Validity of HRQOL Measures

- **Face**
  - Expert & lay evaluation

- **Content**
  - Relevant, important, representative

- **Construct (conceptual)**
  - Scaling & factor structure
  - Concurrent
  - Correlations with external criteria

- **Criterion**
  - Gold standard
<table>
<thead>
<tr>
<th>SF-36 (n=2410)</th>
<th>Cronbach’s alpha</th>
<th>Test-retest difference</th>
<th>Intraclass correlation</th>
<th>Reliability coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>PF</td>
<td>0.81</td>
<td>0.66</td>
<td>0.91</td>
<td>0.81</td>
</tr>
<tr>
<td>RP</td>
<td>0.83</td>
<td>5.54**</td>
<td>0.79</td>
<td>0.41</td>
</tr>
<tr>
<td>BP</td>
<td>0.74</td>
<td>2.30</td>
<td>0.73</td>
<td>0.41</td>
</tr>
<tr>
<td>GH</td>
<td>0.65</td>
<td>-0.90</td>
<td>0.88</td>
<td>0.83</td>
</tr>
<tr>
<td>VT</td>
<td>0.72</td>
<td>1.13</td>
<td>0.83</td>
<td>0.65</td>
</tr>
<tr>
<td>SF</td>
<td>0.75</td>
<td>2.03*</td>
<td>0.73</td>
<td>0.49</td>
</tr>
<tr>
<td>RE</td>
<td>0.82</td>
<td>-1.97</td>
<td>0.77</td>
<td>0.33</td>
</tr>
<tr>
<td>MH</td>
<td>0.78</td>
<td>1.02</td>
<td>0.68</td>
<td>0.38</td>
</tr>
</tbody>
</table>
## Sensitivity to Group Differences

<table>
<thead>
<tr>
<th>Chronic Dx</th>
<th>SF-36 PCS</th>
<th>Effect size</th>
<th>SF-36 MCS</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>55.12</td>
<td>------</td>
<td>47.82</td>
<td>------</td>
</tr>
<tr>
<td>DM</td>
<td>45.50*</td>
<td>1.32</td>
<td>47.84#</td>
<td>0.002</td>
</tr>
<tr>
<td>Heart</td>
<td>43.70*</td>
<td>1.56</td>
<td>45.83*</td>
<td>0.21</td>
</tr>
<tr>
<td>Mental</td>
<td>47.78</td>
<td>1.00</td>
<td>39.14*</td>
<td>0.9</td>
</tr>
</tbody>
</table>

* p<0.01; # p>0.05
### Responsiveness to Change with Treatment

*(Lam CLK & HU W, Quality of Life Research 2002; 11: 668.)*

<table>
<thead>
<tr>
<th>Mean Change in Scores</th>
<th>SF36 PCS (0-100)</th>
<th>SF36 MCS (0-100)</th>
<th>SF-6D preference (0-1)</th>
<th>symptom (0-120)</th>
</tr>
</thead>
<tbody>
<tr>
<td>OGD (n=83)</td>
<td>2.42^</td>
<td>1.48</td>
<td>0.029^</td>
<td>-5.13^</td>
</tr>
<tr>
<td>HP test &amp; treat (n=74)</td>
<td>2.79^</td>
<td>3.94^*</td>
<td>0.063^*</td>
<td>-5.21^</td>
</tr>
<tr>
<td>Cisapride (n=72)</td>
<td>2.92^</td>
<td>0.13*</td>
<td>0.026^*</td>
<td>-4.08^</td>
</tr>
</tbody>
</table>

^ Significant difference between baseline & wk 6 scores by paired t test \( p<0.05 \)

* Significant difference between groups by 2-sample t tests \( p<0.05 \)
Translation of QOL Measures
ISPOR Task Force for Translation and Cultural Adaptation. VIH 2005; 8:94-104

- Forward translation (double)
- Reconciliation among expert & translators
- Back translation: semantic equivalence
- Harmonization (multiple translations)
- Cognitive debriefing (5 to 10 subjects)
- Review of cognitive debriefing results
- Final revision
- Proof-reading
Semantic Equivalence

....... Were limited in the kind of work or other activities

- 工作或從事某些活動受到限制
  BT: doing some kind of work or activities had limitations

- 工作或其它活動的種類受到限制
  BT: work or other activity kind were limited
Cognitive Debriefing

I am as healthy as anyone I know

- 您和所有您認識的人一樣健康 (BT: You and all the people you know are equally healthy)
  - I don’t know whether other people are healthy or not!

- 您好像所有您認識的人一樣健康 (BT: You are similar to people you know in health)
Choosing the Right HRQOL Measure

✓ Is HRQOL an appropriate outcome?
✓ Does the measure fit for the purpose of the HRQOL assessment?
✓ Are the data collected suitable for the analysis?
✓ Is the HRQOL measure feasible or valid for the target population and setting?
Useful Resources

• International Society for Quality of Life (Asian Chinese Chapter) www.isoqol.org
• HK Society for Quality of Life (HKSoQOL) www.hksoqol.org
• PROQOLID, MAPI Research Trust www.proqolid.org
• Health Research Associates Inc. www.hraine.net
• Medical Outcomes Trust www.outcomes-trust.org
• QualityMetric Inc. www.qualitymetric.com