<table>
<thead>
<tr>
<th><strong>Title</strong></th>
<th>Choosing the right health-related quality of life (HRQOL) measure; Choosing the right HRQOL measure</th>
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</thead>
<tbody>
<tr>
<td><strong>Author(s)</strong></td>
<td>Lam, CLK</td>
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<td><strong>Citation</strong></td>
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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

<table>
<thead>
<tr>
<th>Measure</th>
<th>Components</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SF-6D</strong></td>
<td>Physical functioning (6)</td>
</tr>
<tr>
<td></td>
<td>Role limitation (4)</td>
</tr>
<tr>
<td></td>
<td>Pain (6)</td>
</tr>
<tr>
<td></td>
<td>Vitality (5)</td>
</tr>
<tr>
<td></td>
<td>Social functioning (5)</td>
</tr>
<tr>
<td></td>
<td>Mental Health (5)</td>
</tr>
<tr>
<td><strong>EQ-5D</strong></td>
<td>Mobility (3)</td>
</tr>
<tr>
<td></td>
<td>Self-care (3)</td>
</tr>
<tr>
<td></td>
<td>Usual activities (3)</td>
</tr>
<tr>
<td></td>
<td>Pain (3)</td>
</tr>
<tr>
<td></td>
<td>Anxiety/depression (3)</td>
</tr>
<tr>
<td><strong>HUI-3</strong></td>
<td>Vision (6)</td>
</tr>
<tr>
<td></td>
<td>Hearing (6)</td>
</tr>
<tr>
<td></td>
<td>Speech (5)</td>
</tr>
<tr>
<td></td>
<td>Ambulation (6)</td>
</tr>
<tr>
<td></td>
<td>Dexterity (6)</td>
</tr>
<tr>
<td></td>
<td>Emotion (5)</td>
</tr>
<tr>
<td></td>
<td>Cognition (6)</td>
</tr>
<tr>
<td></td>
<td>Pain (5)</td>
</tr>
</tbody>
</table>
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 of Stroke Patients

COOP-WONCA Chart Scores (%)
## Health Preference (Utility) Score

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Condition 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
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
## Reliability

<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 (12-60)</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.hrainc.net
- Medical Outcomes Trust www.outcomes-trust.org
- QualityMetric Inc. www.qualitymetric.com