Agreement between Proxy and Patient Reports of HRQoL using the EQ-5D:

The interaction effect of perspective, timing and patient cognition

Steven McPhail\textsuperscript{1,2} Elaine Beller \textsuperscript{1,2} Terry Haines \textsuperscript{1,2}

\textsuperscript{1}The University of Queensland
\textsuperscript{2}Princess Alexandra Hospital

Health-Related Quality of Life

Domains of Health \quad + \quad Influences

\begin{align*}
- \text{Physical} & \quad - \text{Experiences} \\
- \text{Psychological} & \quad - \text{Expectations} \\
- \text{Social} & \quad - \text{Perceptions} \\
\end{align*}

- \text{Environment}
Measuring HRQoL

- Usually measured via patient self-report
  - Generic instruments
  - Disease specific instruments
- Problematic in some populations
  - Poor cognition
  - Communication difficulty
- Proxy reporting proposed as an alternative to self-report where a valid self-report is not viable

Proxy reporting

- Various investigations of agreement
  - Mixed results
- Two perspectives of Proxy reports are possible
  - Proxy-patient
    - Proxy responds as they believe patient would
  - Proxy-proxy
    - Proxy’s responds with own perspective
- Most prior investigations not clear which, if any consistent perspective has been used by proxies
- No previous investigations of both perspectives
Three things considered

• Perspective
  – proxy-proxy versus proxy-patient
• Timing (exposure to patient)
  – Admission assessment versus discharge assessment
• Basic cognition
  – Intact (MMSE>23) versus not intact (MMSE <23)

Method

• Design:
  • Prospective cohort investigations of inter-rater agreement
• Participants and Settings:
  • Patients admitted to the Geriatric Assessment and Rehabilitation Unit
  • Their treating physiotherapist
• Outcome Measure
  • EQ-5D
**Procedure**

**Admission Assessment**

Perspective A (Proxy-Patient)
Patients admitted to rehabilitation unit
July – January

Proxy-Patient & Patient Self Report
Total pairs n = 169

Discharge Assessment

Usual care during admission

Perspective B (Proxy-Proxy)
Patients admitted to rehabilitation unit
January – June

Proxy-Proxy & Patient Self Report
Total pairs n = 133

Patients in both A & B n=30

Data Analysis

150 complete datasets with proxy reports from Perspective A
130 complete datasets with proxy reports from Perspective B

**Results**

- **Complete datasets**
  - Proxy-patient = 150 (proxies n= 23)
  - Proxy-proxy = 130 (proxies n= 21)

- **22 Incomplete datasets**
  - unexpected transfer/discharge from ward (8)
  - patient self discharged against medical advice without reassessment (6),
  - death before discharge assessment (5),
  - patient refused assessment (2),
  - English translator not available (1)
## Results - Demographics

<table>
<thead>
<tr>
<th></th>
<th>Proxy-Patient (Perspective-A)</th>
<th>Proxy-Proxy (Perspective-B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>n</td>
<td>150</td>
<td>130</td>
</tr>
<tr>
<td><strong>Median Age (IQR)</strong></td>
<td>79 (69-85)</td>
<td>77 (67-84)</td>
</tr>
<tr>
<td><strong>Median Length of stay (IQR)</strong></td>
<td>42 (30-69)</td>
<td>41 (22-67)</td>
</tr>
<tr>
<td><strong>Basic cognition group median MMSE (IQR)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intact group (MMSE &gt;23)</td>
<td>28 (27-30)</td>
<td>28 (26-30)</td>
</tr>
<tr>
<td>(n=99)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not Intact group (MMSE &lt;23)</td>
<td>20 (16-22)</td>
<td>20 (16-22)</td>
</tr>
<tr>
<td>(n=51)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Both groups combined</td>
<td>27 (21-30)</td>
<td>25 (21-29)</td>
</tr>
</tbody>
</table>

### Agreement (kappa)

<table>
<thead>
<tr>
<th></th>
<th>Basic Cognition</th>
<th>Mobility</th>
<th>Personal Care</th>
<th>Usual Activities</th>
<th>Pain / Discomfort</th>
<th>Anxiety / Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Admission</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intact</td>
<td>0.86</td>
<td>0.78</td>
<td>0.75</td>
<td>0.70</td>
<td>0.75</td>
<td></td>
</tr>
<tr>
<td>(n=99)</td>
<td>(0.73,0.95)</td>
<td>(0.66,0.87)</td>
<td>(0.62,0.86)</td>
<td>(0.57,0.81)</td>
<td>(0.62,0.86)</td>
<td></td>
</tr>
<tr>
<td>Not intact</td>
<td>0.53</td>
<td>0.52</td>
<td>0.76</td>
<td>0.60</td>
<td>0.47</td>
<td></td>
</tr>
<tr>
<td>(n=51)</td>
<td>(0.26,0.78)</td>
<td>(0.33,0.70)</td>
<td>(0.56,0.90)</td>
<td>(0.41,0.77)</td>
<td>(0.24,0.68)</td>
<td></td>
</tr>
<tr>
<td>Combined</td>
<td>0.75</td>
<td>0.69</td>
<td>0.76</td>
<td>0.66</td>
<td>0.65</td>
<td></td>
</tr>
<tr>
<td>(n=150)</td>
<td>(0.63,0.86)</td>
<td>(0.58,0.78)</td>
<td>(0.65,0.85)</td>
<td>(0.55,0.76)</td>
<td>(0.54,0.76)</td>
<td></td>
</tr>
<tr>
<td><strong>Discharge</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intact</td>
<td>0.91</td>
<td>0.85</td>
<td>0.78</td>
<td>0.93</td>
<td>0.76</td>
<td></td>
</tr>
<tr>
<td>(n=99)</td>
<td>(0.81,0.98)</td>
<td>(0.73,0.94)</td>
<td>(0.65,0.89)</td>
<td>(0.85,0.98)</td>
<td>(0.56,0.90)</td>
<td></td>
</tr>
<tr>
<td>Not intact</td>
<td>0.84</td>
<td>0.84</td>
<td>0.88</td>
<td>0.95</td>
<td>0.78</td>
<td></td>
</tr>
<tr>
<td>(n=51)</td>
<td>(0.71,1.00)</td>
<td>(0.68,0.96)</td>
<td>(0.76,0.97)</td>
<td>(0.82,1.00)</td>
<td>(0.55,0.95)</td>
<td></td>
</tr>
<tr>
<td>Combined</td>
<td>0.89</td>
<td>0.85</td>
<td>0.83</td>
<td>0.93</td>
<td>0.77</td>
<td></td>
</tr>
<tr>
<td>(n=150)</td>
<td>(0.80,0.95)</td>
<td>(0.76,0.92)</td>
<td>(0.74,0.90)</td>
<td>(0.87,0.98)</td>
<td>(0.63,0.88)</td>
<td></td>
</tr>
</tbody>
</table>
Discussion

- Generally kappa values were quite high compared with previous investigations
- Interaction of all three factors under consideration
  - Perspective
  - Cognition
  - Timing
- Necessary to consider perspective when using proxy reports
  - Important to clearly instruct proxy reporters
  - Describe which perspective used
    - Which perspective? Proxy-proxy for poor cognition
  - No gold standard!
Discussion

• Limitations
  – One population of patients and proxies
  – All patients capable of self report

• Future research
  – Other populations of patients and proxies
  – Criterion related validity

References


Questions?

Contact details:
steven_mcphail@health.qld.gov.au

The University of Queensland & Princess Alexandra Hospital, Brisbane Australia