Quality of Life after traumatic brain injury: Results of the Australian arm of the international QOLIBRI study

Graeme Hawthorne,
Andrew Kaye & Russell Gruen

The University of Melbourne & The Royal Melbourne Hospital

Health Outcomes Conference
Canberra April 2008

The Australian QOLIBRI Project is proudly supported by the Victorian Neurotrauma Initiative

Acknowledgements

• This Australian QOLIBRI Project is supported by a research grant from the Victorian Neurotrauma Initiative
• We would also like to thank Professor Nicole von Steinbuechel (Georg-August University, Gottingen, Germany)
• And our interviewers: Janifer Anderson, Isabelle Bauer, Dahni Houseman and Maritza Thompson
• And all those who gave their time to participate in this study
The assessment of QoL in traumatic brain injury

Traditional indicators of recovery:
- Functional gains (e.g. ability to complete cognitive and/or physical tasks)
- Rehabilitation success (e.g. return to work)

1990s greater interest in HRQoL assessments, including
- Disability recovery estimates (e.g. GOSE)
- Health status (e.g. SF-36; SIP)
- Life satisfaction (e.g. Diener’s SWLS)
- Psycho-social function

But not quite quality of life as understood in mainstream

Assessment using TBI-specific measures

- Profile de la Quality de la Vie Subjective (1989)
- Brain Injury Community Rehabilitation Outcome Scale (1998)
- European Brain Injury Questionnaire (EBIQ, 1997)
- Aachen Life Quality Inventory (2001)
- Trauma Outcome Profile (TOP)/Polytrauma Outcome Chart (POLO) (2001)
- Quality of Life of the Brain Injured (2002)

- Problems with all these measures:
  - generally too long (e.g. ALQI has 117 items)
  - insufficient or poor validity & reliability evidence
QOLIBRI Project

This unsatisfactory situation led to forming the International TBI Consensus Group (TCG; 1999)

- Goal: to develop a new instrument to assess HRQoL in TBI
- Procedure:
  1. Review of existing measures being used
  2. Simultaneous work cross-culturally
  3. Develop a cross-cultural item pool
  4. Translation and verification
  5. Administration to samples (N~1500)
  6. Classical test theory used to develop preliminary model

Preliminary QOLIBRI descriptive system

Part 1 (Life satisfaction):
- Overall satisfaction (6 items)
- Cognition (7)
- Emotion & self-perception (8)
- ADLs (activities of daily living) & autonomy (8)
- Social (6)

- Part 2 (Bothered by)
  - Negative feelings (5)
  - Restrictions & problems (4)
  - Physical condition (4)
  - An overall ‘bothered’ item

Scoring: each scale scored through summation, and reported on percentage scale
Study method - participants

- Royal Melbourne Hospital trauma registry was randomly sampled
  - Inclusion criteria: 15+ years at TBI, TBI at least 3-months previously, Glasgow Coma Scale score available, TBI diagnosed to ICD-10
  - Exclusion criteria: GOSE <3, spinal cord injury, pre-injury psychiatric condition, severe addiction, non-English-speaking, terminally ill

- Participation
  - 203 cases drawn; 92 non-contactable; 44 refusals
  - 66 interviewed
  - Participation rate of those in scope = 61%
  - 55 completed 2-week test-retest interview

Study method – data collected in interview

- Demographics: age, gender, education, relationship, occupation, accommodation, carer support, smoking/drinking
- Clinical record (e.g. injury, GCS, coma length, post-trauma amnesia, clinical disorders (e.g. epilepsy), medication
- Preliminary version of the QOLIBRI
- Health status: SF-36 Version 2
- Anxiety/Depression: HADS
- Life Satisfaction: Diener’s SWLS
- HRQoL: AQoL
- Social isolation: Friendship Scale
- Cognitive function: MMSE/TICS
- Disability recovery: GOSE
### Spearman correlations between QOLIBRI scales

<table>
<thead>
<tr>
<th>Satisfaction Scales</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognition</td>
<td>2</td>
<td>0.76***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotion &amp; self-perception</td>
<td>3</td>
<td>0.79***</td>
<td>0.75***</td>
<td></td>
</tr>
<tr>
<td>ADLs &amp; autonomy</td>
<td>4</td>
<td>0.75***</td>
<td>0.75***</td>
<td>0.71***</td>
</tr>
<tr>
<td>Social</td>
<td>5</td>
<td>0.65***</td>
<td>0.56***</td>
<td>0.56***</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Bothered Scales</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative feelings</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restrictions</td>
<td>6</td>
<td>0.60***</td>
<td></td>
</tr>
<tr>
<td>Physical condition</td>
<td>7</td>
<td>0.54***</td>
<td>0.49***</td>
</tr>
<tr>
<td>Overall negative item</td>
<td>8</td>
<td>0.60***</td>
<td>0.72***</td>
</tr>
</tbody>
</table>

### Psychometric properties

**Internal consistency & Homogeneity analyses**

<table>
<thead>
<tr>
<th></th>
<th>Mokken p</th>
<th>Loewinger H</th>
<th>ICC</th>
<th>95%CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>0.89</td>
<td>0.62</td>
<td>0.68</td>
<td>0.61-0.80</td>
</tr>
<tr>
<td>Cognition</td>
<td>0.92</td>
<td>0.67</td>
<td>0.79</td>
<td>0.66-0.87</td>
</tr>
<tr>
<td>Emotion &amp; self-perception</td>
<td>0.88</td>
<td>0.53</td>
<td>0.81</td>
<td>0.70-0.88</td>
</tr>
<tr>
<td>ADLs &amp; autonomy</td>
<td>0.93</td>
<td>0.65</td>
<td>0.73</td>
<td>0.58-0.83</td>
</tr>
<tr>
<td>Social</td>
<td>0.87</td>
<td>0.58</td>
<td>0.78</td>
<td>0.66-0.87</td>
</tr>
<tr>
<td>Negative feelings</td>
<td>0.87</td>
<td>0.58</td>
<td>0.69</td>
<td>0.52-0.80</td>
</tr>
<tr>
<td>Restrictions &amp; problems</td>
<td>0.54</td>
<td>0.24</td>
<td>0.68</td>
<td>0.51-0.80</td>
</tr>
<tr>
<td>Physical condition</td>
<td>0.46</td>
<td>0.22</td>
<td>0.71</td>
<td>0.55-0.82</td>
</tr>
<tr>
<td>Overall negative item</td>
<td>-</td>
<td>-</td>
<td>0.74</td>
<td>0.59-0.84</td>
</tr>
</tbody>
</table>
### Spearman correlations with other measures

<table>
<thead>
<tr>
<th></th>
<th>AQoL (Utility)</th>
<th>SF-36V2 PCS</th>
<th>SF-36V2 MCS</th>
<th>SWLS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>0.50***</td>
<td>0.52***</td>
<td>0.51***</td>
<td>0.54***</td>
</tr>
<tr>
<td>Cognition</td>
<td>0.44***</td>
<td>0.53***</td>
<td>0.44***</td>
<td>0.43***</td>
</tr>
<tr>
<td>Emotion &amp; self-perception</td>
<td>0.45***</td>
<td>0.42***</td>
<td>0.54***</td>
<td>0.49***</td>
</tr>
<tr>
<td>ADLs &amp; autonomy</td>
<td>0.55***</td>
<td>0.57***</td>
<td>0.49***</td>
<td>0.60***</td>
</tr>
<tr>
<td>Social</td>
<td>0.59***</td>
<td>0.43***</td>
<td>0.38***</td>
<td>0.60***</td>
</tr>
<tr>
<td>Negative feelings</td>
<td>-0.53***</td>
<td>-0.28*</td>
<td>-0.57***</td>
<td>-0.37**</td>
</tr>
<tr>
<td>Restrictions &amp; problems</td>
<td>-0.57***</td>
<td>-0.50***</td>
<td>-0.52***</td>
<td>-0.45***</td>
</tr>
<tr>
<td>Physical condition</td>
<td>-0.57***</td>
<td>-0.41***</td>
<td>-0.46***</td>
<td>-0.38**</td>
</tr>
<tr>
<td>Overall negative item</td>
<td>-0.54***</td>
<td>-0.41**</td>
<td>-0.61***</td>
<td>-0.39**</td>
</tr>
</tbody>
</table>

### Sensitivity to disability recovery (GOSE)

**QOLIBRI: Satisfaction scales by GOSE**

(All sig. p<0.01)

<table>
<thead>
<tr>
<th>GOSE classification (1=poor recovery)</th>
<th>% score (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>100</td>
</tr>
<tr>
<td>2</td>
<td>90</td>
</tr>
<tr>
<td>3</td>
<td>80</td>
</tr>
<tr>
<td>4</td>
<td>70</td>
</tr>
<tr>
<td>5</td>
<td>60</td>
</tr>
<tr>
<td>6</td>
<td>50</td>
</tr>
<tr>
<td>7</td>
<td>40</td>
</tr>
<tr>
<td>8</td>
<td>30</td>
</tr>
<tr>
<td>9</td>
<td>20</td>
</tr>
<tr>
<td>10</td>
<td>10</td>
</tr>
</tbody>
</table>
Sensitivity to social isolation (Friendship Scale)

QOLIBRI Satisfaction scales by social isolation (All sig., p<0.001)

![Bar chart showing percentage score (95% CIs) for different scales across isolated and non-isolated statuses.]

Work in progress

- Finalise the descriptive system
  - weed out the remaining weak items
  - decide how to handle the negative scales (collapse?)
  - identify if there really is a single underlying common factor, as suggested by the correlations
    - (if so, should the current structure be kept?)
- Prepare a short version for use by those with moderate/severe cognitive impairment
- Full validation using SEM and Rasch modelling
- Testing for responsiveness over time
- Testing for predictive power
  - What predicts good HRQoL recovery?
Conclusion

- Reliability (Mokken rho):
  - Satisfaction scales = excellent
  - Bothered scale = a work in progress!
  - ICC Test-retest = good
- Scales unidimensionality (Loevinger H)
  - Satisfaction scales = excellent
  - Bothered scales = a work in progress!
- Construct validity tests with other scales
  - Moderate correlations as expected
- Sensitivity tests (GOSE & FS)
  - Satisfaction scales = excellent

Preliminary QOLIBRI descriptive system looking good
  - (but more work to be done....)

If you would like to learn more about the QOLIBRI project, or use the QOLIBRI instrument, contact me:

A/Prof Graeme Hawthorne
E: graemeeh@unimelb.edu.au