Moving beyond numbers: Using Rasch analysis to understand the meaning of change in HRQL

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Mr Jones goes to clinic....

When he gets there, the nurse measures:
his height = 1.83m
his weight = 82kg

He is told that there is a waiting time of 15 minutes

He is asked to fill in a questionnaire and after a while the nurse tells him that his quality of life score is 67
Of course, Mr Jones knows....... 

1 metre = the length of the path travelled by light in vacuum during a time interval of 1/299,792,458 of a second 

1 kilogram = the mass of the prototype kilogram made of platinum-iridium alloy in Paris 

1 second = 9,192,631,770 cycles of the radiation that corresponds to the transition between two electron spin energy levels of the ground state of the Cs atom
...so, he can work out that...

- he is taller than his wife, but not as tall as the top shelf of the bookcase at home
- if he treads on someone’s toe it is likely to hurt, but it probably won’t break any bones
- he will have to wait longer than it takes to make a cup of tea but not as long as an episode of Coronation Street
...without realising it Mr Jones uses the standard definitions of a metre, a kilogram and a second

...but there is no standard definition of quality of life, so he doesn’t know what 67 means
Quantitative ways of describing change do not help the patient

- Minimal Important Difference (MID)
- Normative and reference groups
- Statistical significance
- Effect size

No information about:
- **what** the patient can do now that they couldn’t do before
- **how** the concerns of a patient change
- **where** to focus interventions or care
How Rasch methods help interpret change

• Rasch analysis gives us important information about both the person and the items on the same continuum
  
  – we know the location of each person (e.g. Mr Jones)
  
  – we know the location of each item (and each threshold)
  
  – therefore we can use the location of the items to characterise (or describe) the location of the person
  
  – if the items are good then this can provide a meaningful interpretation (description) of the quantitative statistics of change
Method

- 875 patients attending a first Memory Assessment Clinic appointment and 6 month follow up

- DEMQOL scores at baseline & 6 month follow up
  - based on an equated DEMQOL/DEMQL-Proxy Rasch model anchored on the patients’ self reported data
  - 23 items included (‘positive emotion’ items not part of the unidimensional model)

- quantitative anchor and distribution based MID statistics

- three example scenarios of MID change and identified the item descriptions related to this MID change, using Rasch based methods
DEMQOL Minimal Important Difference

- **Distribution based MID** (Norman et al 2003; 0.5 SD):
  
  \[ = 0.5 \times 12.30 = 6.15 \]

- **Anchor based MID** (mean difference between “about the same” and “a little better”):
  
  \[ = 5.14 - 3.22 = 1.92 \]

<table>
<thead>
<tr>
<th>DEMQOL Rasch score</th>
<th>N</th>
<th>Mean</th>
<th>(SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Much worse</td>
<td>19</td>
<td>-0.85</td>
<td>(8.17)</td>
<td>-27.25 - 8.94</td>
</tr>
<tr>
<td>A little worse</td>
<td>105</td>
<td>-0.75</td>
<td>(8.26)</td>
<td>-36.20 - 18.19</td>
</tr>
<tr>
<td>About the same</td>
<td>538</td>
<td>3.22</td>
<td>(10.43)</td>
<td>-36.20 - 38.93</td>
</tr>
<tr>
<td>A little better</td>
<td>107</td>
<td>5.14</td>
<td>(9.45)</td>
<td>-38.80 - 20.95</td>
</tr>
<tr>
<td>Much better</td>
<td>99</td>
<td>7.27</td>
<td>(11.17)</td>
<td>-23.68 - 39.82</td>
</tr>
<tr>
<td>Rasch scores (0-100)</td>
<td>Description</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------</td>
<td>-------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38</td>
<td>A lot distressed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A lot irritable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A lot worried about how you feel in yourself</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A lot/quite a bit worried about how you get on with people close to you</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>A lot worried about people not listening to you</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A lot worried about making yourself understood</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A lot/quite a bit worried about getting to the toilet in time</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>56</td>
<td>A little distressed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A little worried about forgetting what day it is</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>A little worried about forgetting who people are</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>A little worried about difficulty making decisions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Quite a bit worried about forgetting things that happened recently</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A little worried about forgetting what day it is</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>67</td>
<td>A little worried or anxious</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>A little frustrated</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>A little fed-up</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>A little worried that there are things you wanted to do but couldn’t</td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td>A little worried about forgetting things that happened recently</td>
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</tbody>
</table>
### 6 month follow-up picture (+6 points)

<table>
<thead>
<tr>
<th>Rasch Scores (0-100)</th>
<th>Not at all distressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>44 (38+6)</td>
<td>Quite a bit distressed</td>
</tr>
<tr>
<td></td>
<td>Quite a bit irritable</td>
</tr>
<tr>
<td></td>
<td>Quite a bit worried about how you feel in yourself</td>
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<tr>
<td></td>
<td>A little/not at all worried about how you get on with people close to you</td>
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<td>Quite a bit worried about making yourself understood</td>
</tr>
<tr>
<td></td>
<td>A little/not at all worried about getting to the toilet in time</td>
</tr>
<tr>
<td>62 (56+6)</td>
<td>Not at all worried about forgetting what day it is</td>
</tr>
<tr>
<td></td>
<td>Not at all worried about forgetting who people are</td>
</tr>
<tr>
<td></td>
<td>Not at all worried about difficulty making decisions</td>
</tr>
<tr>
<td></td>
<td>A little worried about forgetting things that happened recently</td>
</tr>
<tr>
<td>73 (67+6)</td>
<td>Not at all worried or anxious</td>
</tr>
<tr>
<td></td>
<td>Not at all frustrated</td>
</tr>
<tr>
<td></td>
<td>Not at all fed-up</td>
</tr>
<tr>
<td></td>
<td>Not at all worried that there are things you wanted to do but couldn’t</td>
</tr>
<tr>
<td></td>
<td>Not at all worried about forgetting things that happened recently</td>
</tr>
</tbody>
</table>
What does this mean for Mr Jones?

A little worried or anxious
A little frustrated
A little fed-up
A little worried that there are things you wanted to do but couldn’t
A little worried about forgetting things that happened recently

Not at all worried or anxious
Not at all frustrated
Not at all fed-up
Not at all worried that there are things you wanted to do but couldn’t
Not at all worried about forgetting things that happened recently
Conclusion

• Mr Jones understands his score and what a 6 point improvement would mean

• We can begin to tell the story of what it means for a person with dementia to walk up and down the DEMQOL ruler

Next steps:
• From our previous work we know that one domain important for HRQL is not well captured by the Rasch version of the scores; future work needs to address this