Brief communication

The validity and reliability of EQ-5D health state valuations in a survey of Māori

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Abstract

This note reports on a 2000 study of the content validity of the EQ-5D’s representation of health for 66 Māori (New Zealand’s indigenous people, comprising 14.5% of the population) accessed through cultural networks. Also examined was the construct validity of the health state valuation instrument and its test–retest reliability based on repeated valuations for the two extreme health states. The possibility that the EQ-5D fails to capture what Māori regard as ‘health’ derives from the so-called ‘Māori health model’ that augments biological health with mental, spiritual and family well-being. Seventy six percent of respondents considered the EQ-5D’s representation of health to be adequate. This proportion is not statistically significantly different from the rates for non-Māori and Māori respectively in an earlier study and might suggest the EQ-5D has content validity for Māori. However, the high prevalence of missing valuations, particularly for dead, and logical inconsistencies suggests that the health state valuation instrument lacks construct validity, although there is evidence of test–retest reliability.

Key words: Health-related quality of life, Māori, New Zealand, Reliability, Validity

Introduction

Publicly funded health care in New Zealand is increasingly prioritised using CUA, with the EuroQol Group’s EQ-5D in regular use [1, 2]. The EQ-5D, an internationally acceptable health state classification system [3], represents health on five, mostly biological, dimensions – mobility, ability to undertake self-care, ability to participate in usual activities, degree of pain/discomfort, and degree of anxiety/depression – with three levels on each: (1) no problems, (2) some problems, and (3) extreme problems. (More information is available from the EuroQol Group’s website at http://www.euroqol.org).

A key issue, with implications for other countries with large indigenous/ethnic minorities, is the content validity of standard QoL instruments such as the EQ-5D [4] for Māori (New Zealand’s indigenous people and largest ethnic minority, comprising 14.5% of the population [5]). The possibility it fails to capture what Māori regard as ‘health’ derives from the so-called whare tapa wha (‘four-sided house’) model of Māori health hypothesised by Durie [6] that augments biological health with mental/emotional, spiritual and family well-being.

Devlin et al. [7] first examined this hypothesis using data from a 1999 postal survey with 1350 respondents. They found no statistically significant difference in the proportions of Māori and non-Māori (both approximately 75%) for whom the EQ-5D’s representation of health was acceptable. Equal proportions of both groups raised spiritual well-being, for example, as an important aspect ignored by the EQ-5D. However, at just 9%, Māori are under-represented in the study, possibly because of sampling frame bias arising from the
survey being drawn from the general electoral roll. Compared to non-Māori, it is likely that relatively few Māori are registered on the general electoral roll or their address details are incorrect, due to migration for seasonal work for example. The (separate) Māori electoral roll represents an alternative sampling frame. However it too may be unrepresentative because Māori electorates are usually won by the Labour Party (on a ‘first-past-the-post’ basis) and hence Māori who support other parties are less likely to register on that roll (J. Broughton, personal communication).

A third approach, that this note reports on, is to access Māori through established cultural networks. Although such ‘snowball’ or ‘chain’ sampling [8] is itself prone to sampling frame bias, in particular, volunteer selection bias, such bias is likely to be different from that suspected in the earlier survey. Thus, the present study offers a new opportunity to investigate the content validity of the EQ-5D’s representation of health to Māori. In addition, the construct validity of the instrument used to collect the health state valuations is examined with respect to three characteristics prevalent in Devlin et al.’s data set [9]: missing values, particularly for dead; all valued states for individual respondents scored the same; and pairwise logical inconsistencies (i.e. when an unambiguously less severe health state is valued below a more severe state). Also examined is the instrument’s test–retest reliability based on repeated valuations of the two extreme health states.

Data and methods

The EQ-5D questionnaire

The standard EQ-5D questionnaire [10] with a visual analogue scale (VAS) ranging from ‘worst …’ (0) to ‘best imaginable health state’ (100) was used to solicit valuations for the 14 EQ-5D ‘common core’ health states [11] and dead. The states are listed in Table 1 below, where the five digits for each state correspond to particular levels on the dimensions in the order they are listed in the Introduction. Valuations for both 11111 (no problems on any dimensions) and 33333 (extreme problems) are sought twice on neighbouring pages. Also included were the questions: ‘Do you feel that the way of describing “health” used in the questionnaire covers all the aspects of health that are important to you?’, and ‘If you ticked “no”, please tell us what other aspects of health are important to you.’

Along with the standard socio-demographic characteristics, respondents’ memberships of iwi (tribe, people) and proficiencies in te reo (Māori language) were canvassed to gauge their cultural affiliations. Although the questionnaire was self-completed by respondents, it was administered in face-to-face interviews, thereby permitting the interviewer (the first author) to answer respondents’ queries and so gain insights into their reactions to the questionnaire.

The sample

With help from leaders in several Māori communities (see Acknowledgements), and with the approval of the University of Otago Ethics Committee, the following groups (all adults) were recruited in 2000. Twenty-seven people with Te Roopu Awhina, a home visit service in Wellington, accessed through HFA Māori Health Group networks; 12 people at a hui (gathering) for Tainui people held in Dunedin, accessed through University of Otago networks; 25 people at Te Wān-

### Table 1. Number (and % of n = 66) of missing valuations for the health states surveyed

<table>
<thead>
<tr>
<th>Health state</th>
<th>Missing valuations (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>11211</td>
<td>10 (15%)</td>
</tr>
<tr>
<td>11111a</td>
<td>12 (18%)</td>
</tr>
<tr>
<td>21232</td>
<td>14 (21%)</td>
</tr>
<tr>
<td>11122</td>
<td>14 (21%)</td>
</tr>
<tr>
<td>11121</td>
<td>13 (20%)</td>
</tr>
<tr>
<td>22233</td>
<td>17 (26%)</td>
</tr>
<tr>
<td>33333a</td>
<td>18 (27%)</td>
</tr>
<tr>
<td>33321</td>
<td>16 (24%)</td>
</tr>
<tr>
<td>21111</td>
<td>21 (32%)</td>
</tr>
<tr>
<td>11111b</td>
<td>21 (32%)</td>
</tr>
<tr>
<td>Unconscious</td>
<td>25 (38%)</td>
</tr>
<tr>
<td>12111</td>
<td>22 (33%)</td>
</tr>
<tr>
<td>11112</td>
<td>20 (30%)</td>
</tr>
<tr>
<td>32211</td>
<td>19 (29%)</td>
</tr>
<tr>
<td>33333b</td>
<td>21 (32%)</td>
</tr>
<tr>
<td>22323</td>
<td>23 (35%)</td>
</tr>
<tr>
<td>Dead</td>
<td>47 (71%)</td>
</tr>
</tbody>
</table>

Note: a and b denote the states for which valuations were sought twice (on separate pages of the questionnaire).
anga O Raukawa, a Māori tertiary institution in Wellington, accessed through a Māori academic; and two people recruited through the Ngāi Tahu Māori Health Research Unit. In total, 66 people completed the questionnaire, of whom five were interviewed afterwards concerning how they went about it.

The analysis

The data were entered to spreadsheet program Excel, which was used by the first author (and checked by the third) to count the following occurrences. Respondents who answered that the EQ-5D’s representation of health was adequate; missing values for each of the health states surveyed; respondents who scored all the valued states the same; and pairwise logical inconsistencies in each respondent’s valuations (from a possible maximum of 52). Finally, intra-class correlation coefficients were calculated for the two values for 11111 and 33333 from each respondent, as a measure of the instrument’s test–retest reliability.

Results

Three people declined to answer the questionnaire. Of the 66 respondents, their average age was 41 years and half were females and students respectively. Compared to the adult Māori population [12], respondents were, on average, older and more likely to be students (and less likely to be workers or unemployed or retired). Compared to Devlin et al.’s sample, they were also more likely to be students, but younger. Fifty-two respondents (79%) could at least understand spoken Māori and 61 (92%) attended functions on marae (tribal gathering places) at least once a year, with 47 (71%) attending more than five times a year. Twenty-nine (44%) did not identify themselves with any ethnic group other than Māori.

Fifty respondents (76%) answered that the EQ-5D’s representation of health was adequate. This proportion is not statistically significantly different to the rates for non-Māori (74%) and Māori (77%) respectively ($p = 0.71$ and $0.89$) in the Devlin et al. study [7]. Of the extra dimensions suggested by the 16 dissenters, many focused on aspects of health care (e.g. diet and exercise) rather than health per se and only eight raised concepts associated with the ‘Māori health model’. The five individuals who were interviewed after completing the questionnaire said they found it challenging and presented ‘strange concepts to think about’. In their opinions, Māori and non-Māori perceptions of health are the same.

The frequencies of missing valuations are reported in Table 1. In particular, 47 respondents (71%) did not value dead. Many of the respondents asked the interviewer for assistance when scoring the other health states. Two (3%) scored all states 100. Figure 1 presents the proportions of respondents with logical inconsistencies. The intra-class correlation coefficient was 0.85 ($n = 43$) for 11111 and 0.96 ($n = 41$) for 33333 (where 1 = perfect agreement between the first and second valuations and 0 = no agreement).

Discussion

This study has demonstrated it is feasible to access Māori respondents via established cultural networks. As noted in the Introduction, although such ‘snowball’ sampling overcomes the potential bias from the electoral roll, other sampling frame biases (e.g. volunteer selection bias) are possible. Indeed, the sample is unrepresentative of the adult Māori population [12] at least with respect to their average age and occupation.

Bearing this limitation in mind, it may nonetheless be concluded that most Māori do not conform to the ‘Māori health model’ and, as for non-Māori and Māori respectively in the Devlin et al. study [7], approximately three-quarters of respondents considered the EQ-5D representation
of health to be adequate. That the majority of respondents supported it might suggest the EQ-5D has content validity.

However, the high prevalence of missing valuations and logical inconsistencies suggests the health state valuation instrument lacks construct validity. In particular, 71% of respondents did not value dead and 70% had at least one logical inconsistency (see Figure 1) respectively. These rates are considerably higher than has been observed in other studies internationally [11, 13, 14]. On the other hand, the instrument exhibited test–retest reliability according to the repeated valuations for 11111 and 33333, although basing the test on the extreme states may not be very informative.

Missing values for dead are especially problematic because this renders all of a respondent’s other valuations unusable for estimating ‘social’ tariffs (for calculating QALYs for CUA), given it is standard practice to ‘rescale’ respondents’ valuations relative to dead and 11111 [15]. Were these respondents unwilling to value dead (perhaps for religious/spiritual reasons)? If so, this suggests there may be important underlying differences between the health state preferences of Māori and others. Or were they simply unaware of the requirement to do so? Near-universal neglect to read the questionnaire instructions was observed, of which a contributing factor may be low Māori literacy rates [16]. These issues could be probed in future interviewer-administered surveys by asking respondents who do not value dead: ‘Why not?’.

Similarly, the causes and interpretations of logical inconsistencies remains an important topic for research [13].

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