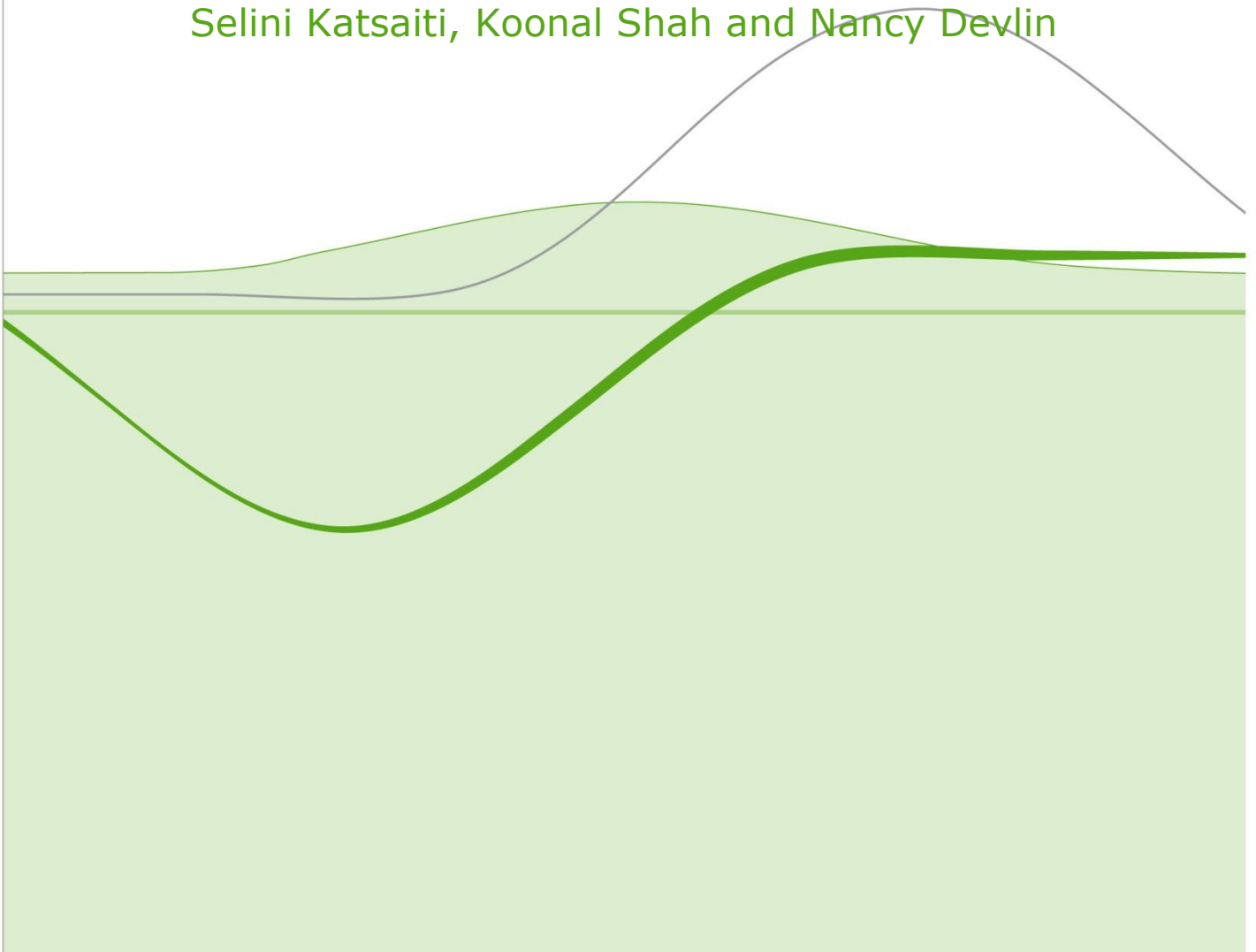


An Investigation of the Feasibility and Cultural Appropriateness of Stated Preference Methods to Generate EQ-5D-5L Values in the United Arab Emirates

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Abstract

Objectives: No EQ-5D-5L value sets are currently available in the Middle East to inform decision making in the region's health care systems. This study tests the feasibility of eliciting EQ-5D-5L values from a general public sample in the United Arab Emirates (UAE) using the EuroQol Group's standardised valuation protocol.

Methods: Values were elicited in face-to-face computer-assisted personal interviews. Adult Emiratis were recruited in public places. Respondents completed 10 time trade-off (TTO) tasks and seven discrete choice experiment (DCE) tasks, followed by debriefing questions about their experience of completing the valuation tasks. Descriptive analyses were used to assess the face validity of the data.

Results: Two-hundred respondents were interviewed in December 2013. The face validity of the data appears to be reasonably high. Mean TTO values ranged from 0.81 for the mildest health state (21111) to 0.19 for the worst health state in the EQ-5D-5L descriptive system (55555). Health states were rarely valued as being worse than dead (6.2% of all observations; 10.0% of all valuations of 55555). In a rationality check DCE task whereby a health state (55554) was compared to another that logically dominated it (55211), 99.5% of respondents chose the dominant option. The majority of respondents stated that their religious beliefs influenced their responses to the valuation tasks.

Conclusions: Our results suggest that it is feasible to generate meaningful health state values in the UAE, though some adaptation of the methods may be required to improve their acceptability in the UAE (and other countries with predominantly Muslim populations).

1. Introduction

When making recommendations about the pricing and reimbursement of health technologies, many health technology assessment (HTA) agencies now routinely request evidence on the health-related quality-of-life (HRQOL) of patients. This type of information is increasingly being requested by payers in the United Arab Emirates (UAE) (Al-Abbadi, 2009) and the field of HRQOL measurement is growing slowly in the Arab world (Al Sayah et al., 2013)

To make comparisons across different disease areas and to avoid having to rely on clinical endpoints alone, HRQOL can be described and assessed using generic preference-based measures, such as the Health Utilities Index (Feeny et al., 2002), SF-6D (Braizer, Roberts and Deverill, 2002) or EQ-5D (Kind, Brooks and Rabin, 2005). Many such measures were initially developed for English-speaking populations but have since been translated for use in countries where other languages are predominant. Over 100 EQ-5D language versions currently exist, all of which were produced using a standardised translation protocol (Herdman et al., 2003).

The use of EQ-5D, a short questionnaire developed by the EuroQol Group, is recommended by a number of HTA agencies, including the UK's (NICE, 2013). It describes health in terms of five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. There are two versions of the instrument: the EQ-5D-3L and the EQ-5D-5L. The EQ-5D-3L has three levels of severity for each dimension, defining 243 unique health states. The newer EQ-5D-5L has five levels, defining 3,125 health states (Herdman et al., 2011). To be used in estimating quality-adjusted life-years, the EQ-5D must be accompanied by 'value sets' which summarize how good or bad each health state is on a scale anchored at 1 (full health) and 0 (dead). The EuroQol Group's protocol for valuing EQ-5D-5L elicits these values using two stated preference methods: time trade-off (TTO) and discrete choice experiments (DCE) (Oppe et al., 2014). In accordance with the recommendations of Gold et al. (1996) the values should reflect the general population preferences regarding the relative importance of the five health dimensions.

Views about health differ across countries (Szende, Oppe and Devlin, 2007) necessitating country-specific value sets in order for HTA decisions in a given jurisdiction to reflect the preferences of the local population(s) affected by those decisions. EQ-5D-3L value sets are available in a growing number of countries (Euroqol Research Foundation, no date). EQ-5D-5L value sets are currently being developed in countries such as England, Canada and China. However, no local value sets are available in the UAE or elsewhere in the Middle East to inform decision making in the region's health care systems.

Both the TTO and DCE methods involve asking survey respondents to evaluate health states by making trade-offs. In TTO tasks, respondents make trade-offs between having a better level of HRQOL and having a longer life. In DCE tasks, respondents consider two health states and make trade-offs between the various health problems described by each. Respondents in predominantly Muslim countries, such as the UAE, may respond to such tasks differently from respondents in Western, more secular countries where the methods were originally developed, particularly if Muslims have systematically different ways of thinking about the trade-offs between health, life and death.

There have been calls for research on HRQOL assessment in Arabic countries to add to the scarce existing literature (Al Sayah et al., 2013). To our knowledge, the

appropriateness of using methods such as TTO to elicit health state values from Muslim respondents in such countries has not been established.

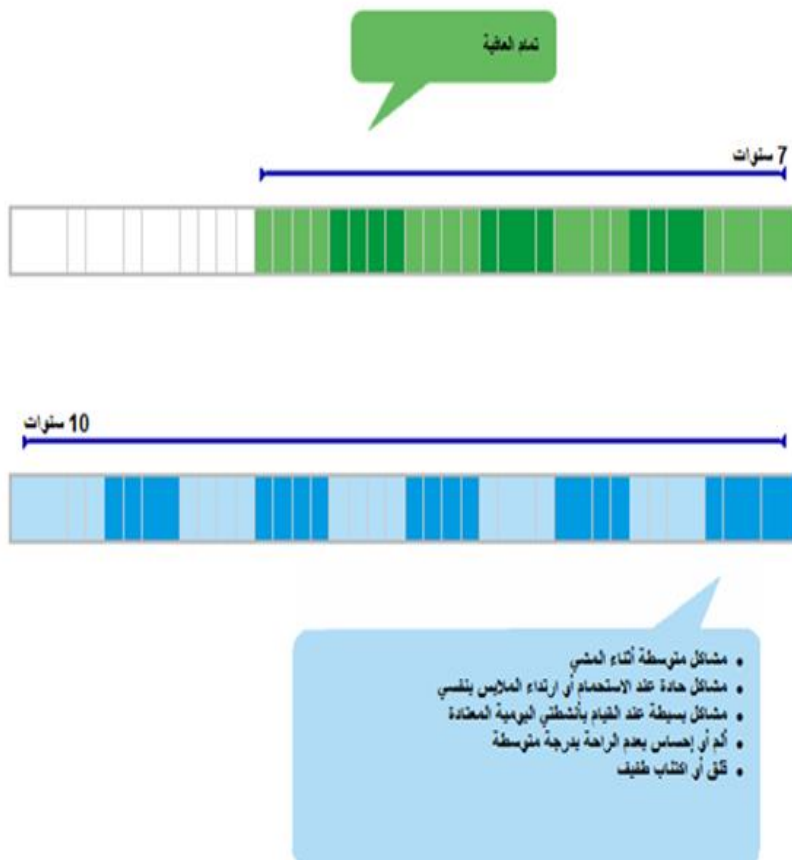
Therefore, the primary objective of this study is to test the feasibility of eliciting EQ-5D-5L health state values from a sample of citizens of the UAE (Emiratis) using the EuroQol Group's standardised valuation protocol. A secondary objective is to investigate cultural issues relating to the use of the methods in this population.

2. Methods

2.1 Study design

In accordance with the EuroQol protocol (Oppe et al., 2014), each respondent completed a valuation questionnaire administered within a computer-assisted personal interview (CAPI). Each questionnaire comprised the following components (in order): self-reported health using EQ-5D-5L; self-reported health using a visual analogue scale (EQ-VAS); basic background questions; four practice TTO tasks; 10 TTO tasks; feedback questions regarding the TTO tasks; seven DCE tasks; feedback questions regarding the DCE tasks; and an (optional) open-ended comment box. After completing the valuation questionnaire, respondents were asked further background questions and a series of feedback questions designed to elicit additional information about their experience of completing the tasks (including a question on the extent to which their responses were influenced by their religious or spiritual beliefs). The valuation questionnaire was administered via the EuroQol Group Valuation Technology (EQ-VT), CAPI software developed specifically for EQ-5D-5L valuation studies. An Arabic version of EQ-VT was developed by the EuroQol Group for this study. It involved reversing the presentation of information to reflect the fact that Arabic is written and read from right to left. The Arabic EQ-VT was tested and validated by an Arabic-speaking and UAE-residing member of the study team. See Figure 1 for an example screenshot.

Figure 1: Screenshot from Arabic Version of the EuroQol Group Valuation Technology (EQ-VT)



In addition, an "Arabic for Egypt" source version of the EQ-5D-5L instrument was adapted to "Arabic for UAE". The translation was led by a qualified language consultant recruited locally in the UAE and followed the established EuroQol methodology for this type of adaptation (Herdman et al., 2003)

TTO is a stated preference technique developed specifically for use in health care (Torrance, Thomas and Sackett, 1972). It establishes the value for the health state under evaluation (h_i) by identifying the amount of time in full health that is considered equally preferable by the respondent to a given amount of time in h_i . A general introduction is provided by Brazier et al. (2007).

A "composite" TTO approach was used in this study. This involved beginning with the "conventional" TTO task for all health states and proceeding to "lead-time" TTO for health states considered by the respondent to be "worse than dead" (WTD). In each task, respondents were asked to imagine living in an EQ-5D-5L health state (h_i) for 10 years, followed by death ("Life B"). They were also asked to imagine an alternative scenario which involved living in full health for x years ("Life A"). The value of h_i was then identified by finding, using an iterative process, the value of x at which the respondent considered Life A and Life B to be equally desirable. Whenever the respondent indicated that they preferred Life A (B), the value of x was reduced (increased) so as to make Life A less (more) desirable. Hence, the task involved a series of repeated trade-offs between a longer life in impaired health and a shorter life in full health.

According to the theory underpinning TTO, the more undesirable the respondent considers h_i , the more time in Life A they would be willing to trade in order to avoid Life B. For particularly undesirable health states, respondents may be willing to give up all of their time in Life A, implying that they would rather be dead than live in h_i for 10 years. For such WTD states, lead-time TTO (Robinson and Spencer, 2006; Devlin et al., 2011; Devlin et al., 2013) was used. This involved adding 10 years of full health to the start of both Life A and Life B, giving respondents more trading time and enabling values to be elicited for WTD states in a manner which is conceptually similar to the conventional approach to obtaining values for better-than-dead (BTD) states. Evidence supporting the use of the composite TTO approach is reported by Janssen et al. (2013).

Each task concluded when the respondent indicated that they considered Life A and Life B to be "about the same". At this point of indifference, the value of h_i is given by $x/10$ for BTD states and $(x-10)/10$ for WTD states. The minimum and maximum values obtainable from this variant of TTO are -1 and 1, respectively.

The automated iterative routing used to seek the point of indifference was based on an adaptation of the original UK EQ-5D-3L value set study (Dolan, 1997). Oppe et al. (2014) provide further details of the EQ-VT and the iterative process.

In each DCE task, respondents were presented with a pair of health states (A and B), with no reference to the duration of the states, and were asked to indicate which they considered to be "better". No indifference option was included.

2.2 Data collection

Interviews were conducted with adult Emiratis in Abu Dhabi and Al Ain. The target sample size of 200 respondents was considered to be appropriate for a feasibility study; for a full EQ-5D-5L valuation study a sample of 1,000 is recommended (Oppe et al., 2014). Data collection was carried out by Ipsos Observer, a market research agency.

Respondents were recruited in shopping malls and other public places. A sample that was broadly representative of the Emirati population in terms of age and gender was sought. The interviews were undertaken by a small team of professional interviewers who had completed a three-day training course on the specifics of the methodology and procedures for the study, but had no prior experience in health state valuation.

The interviews took place in hotel conference rooms and the offices of the fieldwork agency. The interviewers were instructed to guide respondents through each element of the valuation questionnaire, closely following an interview script. The capturing and time-stamping of all respondent actions via EQ-VT provided data on elements such as how long the interviewers had spent explaining the TTO exercise to respondents using the warm-up tasks. It was agreed with the agency that any valuation data collected would be kept only if the data confirmed that the interviewer had adhered to the protocol and covered all elements as instructed. Interviewers spent at least 15 minutes with each respondent, explaining the questions and the rationale behind the study. Respondents were reassured that the questions were not intended to challenge or cause conflict with their beliefs and faith.

2.3 Selection of health states

Each respondent valued 10 EQ-5D-5L health states in the TTO tasks and chose between seven pairs of EQ-5D-5L health states in the DCE tasks. All respondents valued the same health states (Table 1), but the order of presentation was randomised across respondents. The TTO health states were hand-picked to include: a mixture of mild, moderate and severe health states (including 55555, the worst health state in the EQ-5D-5L descriptive system); a mixture of health states that are easy to imagine and those that are more difficult to imagine; and a balance of dimension levels (all dimension levels appear least once).

Table 1. EQ-5D-5L health states included in the study design

TTO health states		DCE pairs of health states			
State	Misery	State 1	State 2	Misery (state 1)	Misery (state 2)
21111	6	43141	25554	13	21
11221	7	25515	22251	18	12
23242	13	31135	11444	13	14
11425	13	22411	43133	10	14
12334	13	33225	53314	15	16
34232	14	42441	21415	15	13
33253	16	55554	55211	24	14
45133	16				
55424	20				
55555	25				

The DCE pairs were taken from one of the blocks in the existing experimental design underpinning the EQ-5D-5L valuation protocol (Oppe et al., 2014) with one slight amendment in order to include a pair in which one health state can be said to logically

“dominate” the other (55554 is worse than 55211 on three dimensions and no better on the other dimensions, so is a logically worse state overall). A large number of respondents failing to choose the dominant option can be interpreted as an indicator of poor data quality. The presentation of the health states was randomised such that for half of the respondents, state 1 (2) was presented as “A” (“B”) and appeared on the right (left) hand side; for the other respondents the presentation was reversed.

3. Results

Data collection was undertaken in December 2013. In 120 of the 320 completed interviews, it was considered that the interviewer had not covered all elements of the protocol. Hence, data for 120 respondents were excluded from the analysis, giving a final sample of 200 respondents. The background characteristics of 166 of the 200 respondents are summarised in Table 2 (these data are unavailable for the remaining 34 respondents due to a recording error; it is not expected that the missing respondents will differ systematically from the rest of the sample).

Table 2. Background characteristics of the sample (n=166)

Characteristic	n	%
Total	166	100.0%
Gender		
Male	93	56.0%
Female	73	44.0%
Age group (years)	n	%
Under 30	77	46.4%
30-39	67	40.4%
40-49	20	12.0%
50 and over	2	1.2%
Marital status		
Single	64	38.6%
Married	92	55.4%
Divorced or widowed	3	1.8%
No answer given	7	4.2%
Employment status		
Homemaker/housewife	36	21.7%
Retired/student/not working	32	19.3%
Working part time	18	10.8%
Working full time	68	41.0%
No answer given	12	7.2%
Education		
No education	7	4.2%
Schooling but not university	42	25.3%
Current university student	46	27.7%
Graduate	58	34.9%
No answer given	13	7.8%

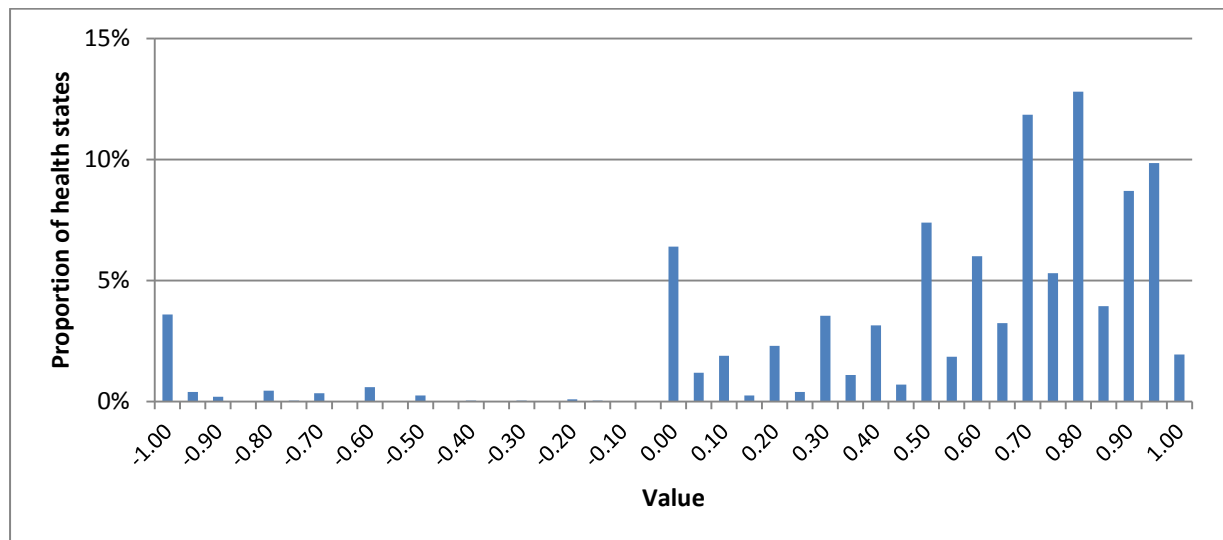
Older and less educated individuals are underrepresented in our sample, though it should be noted that the Emirati population of Abu Dhabi is very youthful, with a median age of approximately 19 years (Statistics Center Abu Dhabi, no date). The population is also relatively well-educated: in a recent study involving a random sample of Emirati households, 29% of heads of household were educated to college or postgraduate level (Yeatts et al., 2012). All of the respondents are Muslim.

The mean (median) amount of time taken to complete the valuation questionnaire was 32.0 (32.4) minutes. This varied considerably across interviewers.

3.1 TTO tasks

Figure 2 shows the distribution of TTO valuations for all 10 health states combined. We observe clustering at “round number” values such as 0.7 and 0.8. Only 39 valuations (2.0%) resulted in a value of 1, indicating that respondents were willing to engage in the trading of time required for the TTO to generate meaningful data. One-hundred and twenty-three of the valuations (6.2%) resulted in the health states being valued as WTD (i.e. value of less than 0). Twenty respondents (10.0%) valued the worst health state, 55555, as being WTD. Most respondents (82.5%) did not value any health states as being WTD. The proportion of WTD valuations differed considerably across interviewers.

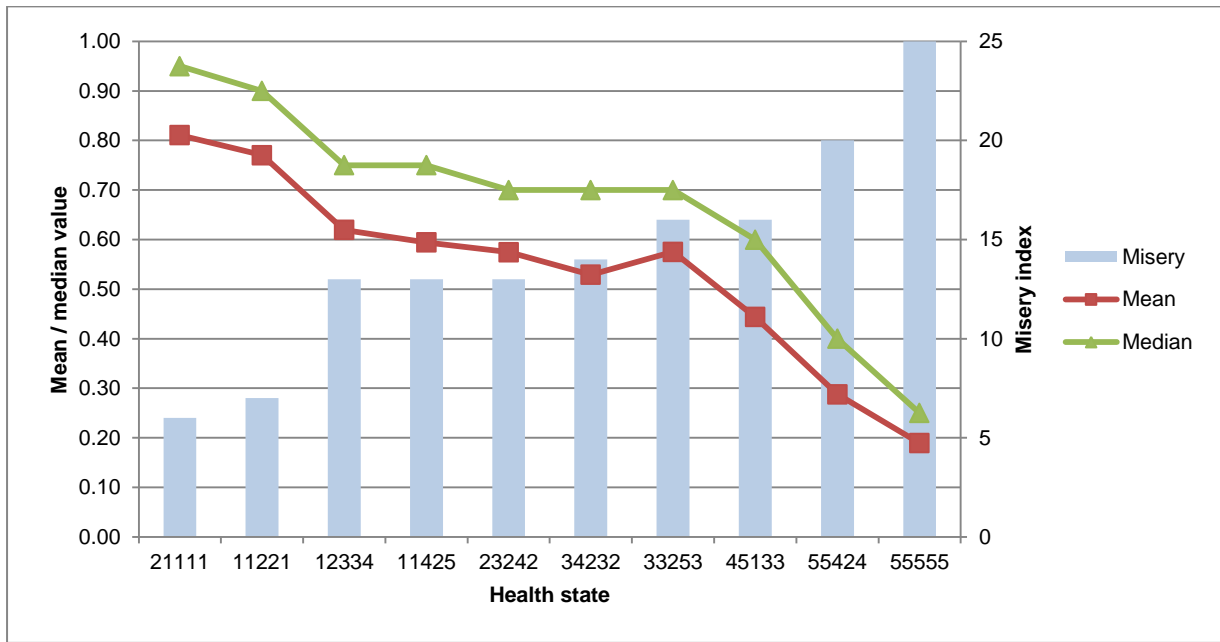
Figure 2. TTO value distribution across all tasks and health states



The mean (median) health state values ranged from 0.81 (0.95) for 21111, to 0.19 (0.25) for 55555. The face validity of the TTO data can be assessed by comparing the observed average values for each health state to the “misery index” (defined as the sum of the five dimension levels; a proxy for severity (Xie et al., 2014; Ramos-Goñi et al., 2013)) of that state. We would expect a health state with a relatively low misery index (e.g. for 21111, $2+1+1+1+1=6$) to have a higher average value than one with a relatively high misery index (e.g. for 55424, $5+5+4+2+4=20$). Figure 3 shows that higher values were elicited for “mild” (low misery) and lower values for “severe” (high misery) health states.

The median time taken to complete each TTO task was 49.7 seconds. Respondents generally completed the tasks increasingly quickly as they proceeded through the exercise, with the majority of respondents completing their final task within 40 seconds.

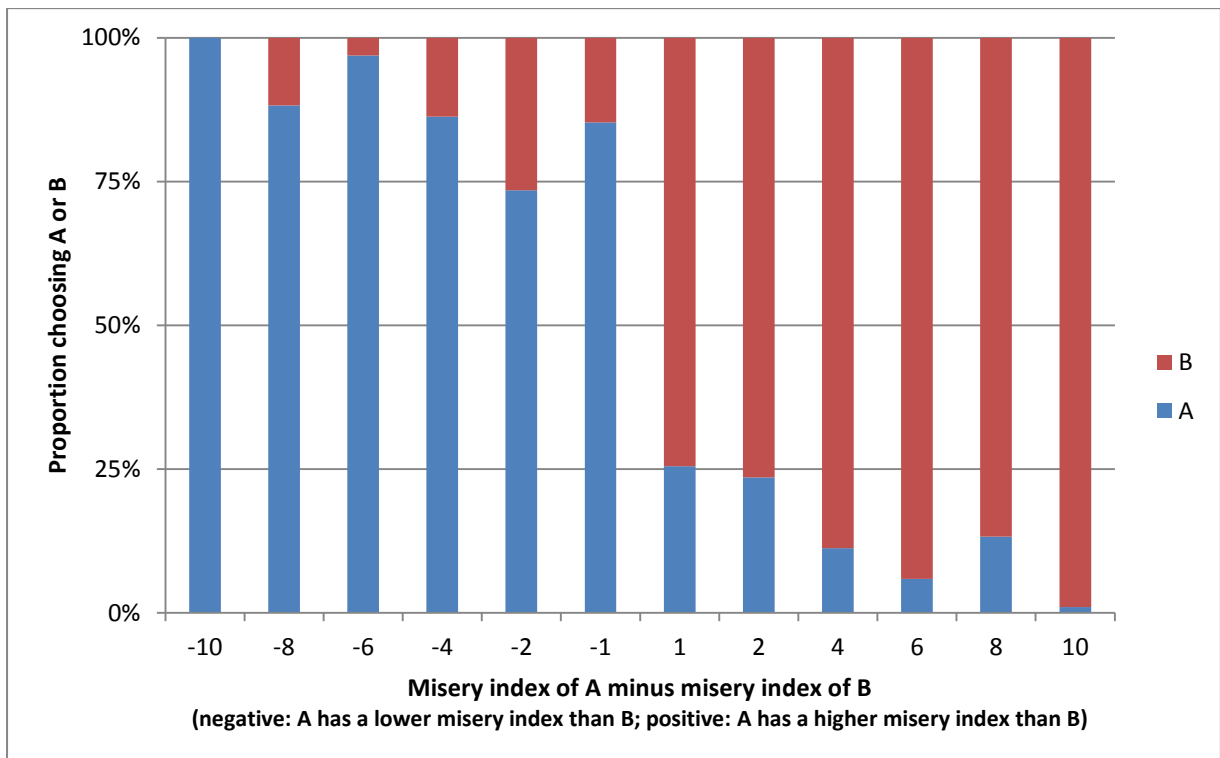
Figure 3. Mean and median TTO value, by health state



3.2 DCE tasks

The face validity of the DCE data also appear reasonably high, with respondents tending to choose the lower misery index health states (Figure 4).

Figure 4. Proportion of respondents choosing A or B in the DCE tasks vs. relative severities of A and B (as proxied by their misery indices)



When the difference in misery between the health states was large, the proportion of respondents choosing the lower-misery state tended to be greater than when the difference was relatively small. In the rationality check task whereby one state (55554) was compared to another that logically dominated it (55211), 199 respondents (99.5%) chose the dominant option. There were no observations of respondents making the same choice in all seven DCE tasks (i.e. AAAAAAA or BBBBBBB; such sets of choices could be interpreted as an indication of poor respondent engagement).

The median time taken to complete a DCE task was 27.3 seconds. Respondents completed the DCE tasks increasingly quickly as they proceeded through the exercise, but the effect was smaller than that observed for the TTO tasks.

3.3 Feedback questions

The majority of respondents agreed or strongly agreed with the statement "It was easy to understand the questions I was asked" in relation to the TTO tasks (80.0%) and DCE tasks (55.6%). However, almost all respondents disagreed that "The instructions that I was given made it clear what I needed to do" and that "The way in which the information was presented on the computer screen was helpful" (less than 2% of respondents agreed or strongly agreed with either statement).

When probed further, the TTO warm-up task (which involved imagining being confined to a wheelchair) and the repetitiveness of the questions were most commonly mentioned by respondents as aspects of the questionnaire that they disliked. A small number of respondents mentioned that they disliked the sensitive nature of the questions or took issue with fundamental aspects of the valuation methods (e.g. choosing to give up time; having to choose between two health states).

Some respondents stated they found it uncomfortable to think about death and illness. Overall, however, the comments provided were more positive than negative. Of the respondents who suggested ways of improving the survey, most recommended shortening its length.

When asked "To what extent were your answers affected by your spiritual or religious beliefs?" a number of respondents made comments expressing appreciation for their life and health, and noting that the questions had reminded them to be more religious. At least 70 respondents referred to the concept of destiny and their belief that health, life and death are in God's hands. Similarly, the interviewers reported that some respondents had rejected the notion of choosing to give up time and, in particular, the idea that health states could ever be WTD.

The majority of respondents rated mobility as the most important, and pain/discomfort and anxiety/depression as the least important of the five EQ-5D-5L dimensions.

4. Discussion

This study has elicited the preferences of a sample of Emiratis regarding EQ-5D-5L health states. It is not possible to model the data to develop a full value set for the UAE, given the limited size and geographic coverage of the sample, and the limited number of health states included in the design. Nevertheless, the results provide several insights into the feasibility and cultural appropriateness of the methods in this country.

First, *prima facie*, the TTO and DCE data look sensible: the mean TTO values and the distributions of responses to both tasks seem plausible, and correlate in an expected way with the severity of the health states being valued. Although we observe some clustering in the TTO value distribution (Figure 2), the spikes at 0, 0.5, and 1 are smaller than has been observed in EQ-5D-5L valuation studies carried out in other countries such as England and Spain (van Hout et al., 2014; Ramos-Goñi et al., 2015). Only one respondent chose the dominated option in the rationality check DCE task, which provides reassurance that respondents were engaged in what they were asked to do. The feedback from respondents was broadly positive. All this points to the use of TTO and DCE being feasible in this population.

Second, the results suggest important differences in the preferences of this population compared to those of other populations. Whereas pain/discomfort and anxiety/depression are the least important dimensions in this study, they were found to be the most important dimensions in a comparable study in England (van Hout et al., 2014) and in EQ-5D valuation studies conducted elsewhere (Szende, Oppe and Devlin, 2007). This highlights the importance of developing local value sets for use in decision making, rather than relying on those from other countries.

Third, we did encounter, however, some challenges in implementing the standard valuation protocol in this study. For example, there were some difficulties in getting the interviewers to comply with the protocol. Specifically, all of the interviewers failed on at least one occasion to demonstrate all elements of the lead-time TTO task (for valuing WTD health states) during the TTO warm-up task. When queried about this, some interviewers suggested that respondents had been reluctant to accept the notion of health states being WTD. Large amounts of data had to be excluded for this reason – with a risk that those excluded respondents may hold systematically different preferences. Further, respondents' feedback regarding the instructions and computer-based presentation indicated high levels of dissatisfaction with the interview approach, in contrast to much more favourable feedback from samples in comparable studies in other countries (Shah et al., 2014). Older and less educated respondents, who were underrepresented in our sample, might have found the computer-based tasks even more problematic. Future studies should seek a more representative sample in order to improve the generalizability of the results.

Finally, there were some important semantic issues encountered in the translation of the tasks – for example, terms such as “full health” did not translate exactly into Arabic, with the consequent risk that the TTO exercise was interpreted somewhat differently by respondents in the UAE than in other countries where the EQ-5D-5L valuation protocol has been used. Taken together, these factors suggest that, whilst it is feasible to use methods such as the TTO and DCE to obtain valuation data, the tasks may require adapting to make them both more appropriate and acceptable for this population. However, it should be borne in mind that any adaptation of the standardised methods will come at the cost of limiting the comparability of results across countries.

This study used a translated version of the EQ-5D-5L instrument adapted for the Emirati population in accordance with the EuroQol Group's standardised protocol. However, the study did not include a full validation exercise seeking to establish whether the dimensions and framing of the level descriptors are relevant and culturally appropriate for the Emirati population. Research elsewhere suggests that Arabic versions of the EQ-5D-3L are valid and reliable in measuring quality of life in Jordan (Aburuz et al., 2009) and Morocco (Khoudri et al., 2012). We are not aware of any such research in the UAE.

Further aims of the study were to explore: how culture and religion affect Emiratis' views about the relative importance of different aspects of health; whether Emiratis feel differently from people in other countries about illness and death; and the extent to which the TTO method is compatible with the beliefs of an exclusively Muslim sample.

We observe a relatively low number of WTD values in this study – only 10.0% of respondents valued 55555 as being WTD. The corresponding proportion in the EQ-5D-5L value set for England study was almost three times greater (van Hout et al., 2014). These results emphasize the importance of further work to establish locally-relevant value sets for the Middle East for use in HTA decision making, rather than relying on value sets from other regions. They also suggest that the culture and beliefs of people in this region might influence the way in which they value health states; specifically, the role of the Islamic faith in the Emirati population.

There are many teachings that can affect the views of Islamic religion followers (Muslims) about health, illness and dying. Muslims believe in the absolute timeless knowledge of God (AlQadaa wal Qadar), fate and destiny, and the supreme power of God over human life. Belief in fate and destiny are also fundamental beliefs of Islamic faith. On the other hand, Islam teaches that Muslims have choice over their actions and that they should protect their health and preserve their lives. The teachings of the prophet Mohamad describe the preservation of life and health as being an act of worship and being highly praised by God (Khayat, 1997).

The *Quran* encourages Muslims to accept illness, suffering and dying with patience (Rassol, 2000). Moreover, Islam teaches that calamities can shed the sins of a pious Muslim. These concepts can influence Muslims' perception of dying and illness and their preferences over different health outcomes. Rasool reports that Muslims are strongly encouraged to seek treatment and care, and are discouraged from seeking illness (Khayat, 1997). However, some Muslims misunderstand this concept and may choose to ignore seeking treatment and preventive measures in the belief that they are submitting to their fate and destiny (Elbarazi, 2005).

When asked about the influence of their religious or spiritual beliefs, the majority of respondents in this study stated that their beliefs had at least some influence on their responses to the valuation tasks. When asked how, a sizeable minority of respondents referred explicitly to the notion of destiny. The difficulties reported by interviewers in explaining the concept of WTD health states to respondents may be linked to Islamic teachings encouraging the preservation of life.

5. Conclusions

The results of this feasibility study suggest that meaningful health state valuation data can be collected in the UAE (and potentially in other countries in the Middle East). However, there are a number of ways in which the methods could be adapted for use in this population, such as increased emphasis in the instructions that the tasks are not intended to cause conflict with respondents' religious beliefs and improvements to the computer-based presentation of the tasks. Future studies could include in-depth interviews in which respondents are encouraged to describe which specific elements of the protocol should be adapted, and how.

Given the issues encountered with interviewer protocol compliance, we recommend training academic researchers in health state valuation and stated preference methods in order to increase the pool of potential interviewers. We also recommend further exploration of how people in the UAE and other predominantly Muslim countries interpret the concept of WTD health states, and whether alternatives to lead-time TTO may be more appropriate for these populations.

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