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## **BMJ Open**

## The effect of culture and religion on the perception of health states amongst adults in the United Arab Emirates: a qualitative study

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| 4<br>5<br>6<br>7<br>8<br>9<br>10   | The effect of culture and religion on the perception of health states amongst adults in the United Arab Emirates: a qualitative study<br>Iffat Elbarazi <sup>1</sup> , Nancy J. Devlin <sup>2</sup> , Marina-Selini Katsaiti <sup>3</sup> , Emmanuel A. Papadimitropoulos <sup>4</sup> , Koonal K. Shah <sup>2</sup> , Iain Blair <sup>1</sup>  |
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## **ABSTRACT**

**Objectives:** Investigate how culture and religion may affect the perception of health states amongst Muslim Arabs and the implications for research on self-reported health and quality of life and the use of values in cost effectiveness analysis.

Design: Qualitative analysis of short structured interviews with adult Emiratis carried out by a market research agency.

Setting: Participants were recruited from shopping malls and other public places in the cities of Al Ain and Abu Dhabi.

**Participants:** Two hundred adult Emiratis broadly representative of the Emirati population in terms of age and gender.

**Results:** Eighty three percent of participants said that their valuation of health states was influenced by their spiritual or religious beliefs. Five themes emerged that seemed to explain or classify these influences. Destiny and fate was a common theme along with powerlessness to change what is pre-ordained by God. Fear of disability and particularly diminished mobility was also a common emotion only partially tempered by an appreciation of health and life and the requirement to look after one's health. A final theme was that of acceptance, with respondents expressing a willingness to endure suffering and disability with patience in the expectation of rewards in the hereafter.

**Conclusions:** Our results emphasize the need for further work to establish locally relevant value sets for Muslim majority countries in the Middle East and elsewhere for use in HTA decision making, rather than relying on value sets from other regions.

## Key words

Qualitative Research, Islam, United Arab Emirates, Patient Reported Outcome Measures, Cost-**Effectiveness Analysis** 

## **Article Summary**

#### Strengths and limitations of this study

- Health-related quality-of-life (HRQOL) measures are routine in health technology
  assessment (HTA) and health outcomes research but the health value sets on which they
  are based differ between countries due to social, cultural and particularly religious factors.
  The need for country specific value sets is particularly important in Muslim majority
  countries, such as the United Arab Emirates (UAE), where compared with western more
  secular countries, the general population has very different ways of thinking about the
  trade-offs between health, length of life, and death. This is one of the few studies to
  address these differences.
- This qualitative study involved 144 respondents who were representative of Emirati adults living in the Emirate of Abu Dhabi. However the results are not necessarily generalizable to Muslim Arabs in other settings.
- In a study with this design there will be both interviewer and response bias. In addition there is bias associated with the study design and the experience and judgment of the principal researchers when analyzing and interpreting the data.

#### INTRODUCTION

Use of health-related quality-of-life (HRQOL) measures is routine in health technology assessment (HTA) and health outcomes research. Many such measures are available. The EQ-5D,<sup>1</sup> a short questionnaire developed by the EuroQol Group, is widely used by HTA agencies, including the United Kingdom's National Institute for Health and Care Excellence.<sup>2</sup> The EQ-5D was initially developed for English-speaking populations but has since been translated so that there are now over 176 EQ-5D language versions.<sup>3</sup> EQ-5D describes health in terms of five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). The EQ-5D-3L grades each dimension on one of three levels of severity (no, some and extreme), while the newer five level variant (EQ-5D-5L) uses five levels of severity, thereby defining  $(5^{5})$  3125 unique health states.<sup>4</sup> In order to be used to support cost-effectiveness analyses, the EQ-5D must be accompanied by 'value sets' which summarize how good or bad each unique health state is on a scale anchored at 1 (full health) and 0 (dead). These value sets are derived by assessing the stated preferences of the general population. A variety of methods are available for this including the time trade-off (TTO), which involves asking survey respondents to evaluate health states,<sup>5,6</sup> and discrete choice experiments (DCE), which in its simplest form involves a pairwise choice between two states. Views about health may differ between countries due to social, cultural and religious factors, and so country specific value sets are needed.<sup>7</sup>

The need for country specific value sets is particularly important in Muslim majority countries such as the United Arab Emirates (UAE). When compared with secular western countries, the general population is likely to have very different ways of thinking about the trade-offs between health, length of life, and death. The UAE is unique in its health needs as well as in the medical seeking behavior of its people and the cultural effects on their health.<sup>8</sup> Although EQ-5D-5L value sets have been or are currently being developed in countries such as England, Canada, and China, and there is research evidence that Arabic versions of the EQ-5D-3L are valid and reliable in measuring quality of life in Jordan <sup>9</sup> and Morocco, <sup>10</sup> no local value sets for the EQ-5D-3L or EQ-5D-5L are available in the UAE or elsewhere in the Gulf region.<sup>11</sup> Following calls for research on HRQOL assessment in Arabic countries, we carried out TTO and DCE valuation exercises amongst a sample of 200 adult Emiratis and concluded that the methods were appropriate and feasible.<sup>12</sup> However, in that study there was evidence of striking differences in

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the way that Emiratis valued health states compared to other cultural groups, namely a reluctance to consider that a health state could be "worse than dead". Furthermore, pain/discomfort and anxiety/depression were ranked as the least important dimensions of health, in contrast to findings in England and elsewhere. <sup>7, 13</sup>

As part of our study we explored respondents' feelings when asked to value different health states and what influence their religious and cultural beliefs may have had on their responses. The purpose of this paper is to present the results of those additional enquiries and provide further detailed insights into (a) how culture and religion may affect the perception of health states amongst Muslim Arabs and (b) the implications of our findings for research on selfreported health and quality of life in the region and for the use of values in cost effectiveness analysis.

## Methods

The methods have been described previously but, in summary, interviews were conducted with adult Emiratis in Abu Dhabi and Al Ain.<sup>12</sup> The target sample size was 200 respondents and 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. Each respondent completed a valuation questionnaire administered within a computer-assisted personal interview (CAPI) in accordance with the EuroQol protocol.<sup>5</sup> Each questionnaire comprised TTO and DCE tasks, feedback questions and an (optional) open-ended comment box. After completing the valuation questionnaire, respondents were asked further "debrief" questions focusing on their experience of completing the valuation tasks (Table 1) and a simple ranking exercise in which they were asked to rank the five EQ-5D dimensions from most important to least important. Interviews were conducted in December 2013 in Arabic and responses were later translated into English. The study was approved by the Al Ain Medical District Human Research Ethics Committee in November 2013(N.13/82).

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| No. | Question                            | Response type                                       |
|-----|-------------------------------------|---|
| 1   | Was there anything in the survey    | Open ended  |
|     | that made you feel uncomfortable?   |   |
| 2   | What did you like or dislike about  | Open ended  |
|     | the survey?                         |   |
| 3   | Do you have any suggestions for     | Open ended  |
|     | improving the survey and making it  |   |
|     | more relevant for people like you?  |   |
| 4   | To what extent were your answers to | Closed ended, pre-coded categorical                 |
|     | the questions influenced by your    | [0 = no answer selected; 1 = not influenced at all; |
|     | spiritual or religious views?       | 2 = somewhat influenced; 3 = heavily influenced]    |
| 5   | Please explain how.                 | Open ended  |
|     |                                     |   |

## Table 1. Further questions from which data on respondents' opinions are available.

## Analysis

Thematic analysis was used to define phenomena related to the influence of cultural and religious beliefs on the valuation of health states by the study sample.<sup>14</sup> Responses were first transcribed verbatim (by Ipsos Observer) and were then analyzed systematically by two authors (IE and IB) working independently. The data was coded and organized into emerging themes and subthemes. Following a discussion of themes by all members of the study team, a final index was synthesized by one author (IE) acting as a content expert with detailed knowledge of Islamic faith health considerations. Direct quotes from respondents are presented where this is useful to provide additional insights or to illustrate the themes that emerged. Using an inductive approach the emergent themes were used to make inferences about the way in which cultural and religious beliefs will affect the valuation of health states.

## **Results**

As previously reported, <sup>12</sup> the final sample comprised 200 respondents and complete background demographic data was available for 166 of these. Older and less-educated Emiratis were underrepresented in the sample. All of the respondents were Muslim. 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, for example choosing to give up time or having to choose between two health states. Some respondents stated they found it uncomfortable to think about death and illness. Amongst the 144 respondents who answered the question "To what extent were your answers affected by your spiritual or religious beliefs", 25 (17.4%) replied "not influenced at all", 75 (52.1%) replied "somewhat influenced" and 44 (30.6%) replied "heavily influenced". Participants' responses in general were short and did not need much interpretation. The concepts that kept recurring and were apparent very clearly among the responses were classified into five major themes (Table 2) which are discussed in turn in the following section.

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| Theme                                      | Sub-themes                                       |
|--|--|
| Concept of inevitability and invincibility | Destiny is determined by God                     |
|  | • Death and illness flow from God                |
| Concept of powerlessness/helplessness      | • Difficulty in imagining situations because of  |
| or submission/fatalism                     | the belief that illness and diseases are from    |
|  | God  |
|  | • Difficultly in accepting questions, as illness |
|  | and death are in God's power                     |
| Concept of appreciation                    | • Reminder of death and judgment day             |
|  | • Reminder to become more religious              |
|  | • The exercise acted as a spiritual reminder and |
|  | for most it reminded them of God                 |
|  | • The exercise acted as a reminder for           |
|  | participants to take care of their health.       |
|  | • The exercise reminded them about death and     |

Table 2. Themes and Sub-themes apparent from analysis of respondents' comments

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|  | that life is short and illness can happen at any<br>time. It engendered an appreciation for life<br>and the importance of the preservation of life  |
|--|---|
| Concept of fear  | <ul><li>Fear of death</li><li>Fear of disability/illness</li></ul>  |
| Concept of acceptance and patience<br>Concept of unacceptance of certain ideas | <ul> <li>To accept disability.</li> <li>Unacceptability of making a choice between death and illness</li> <li>Unacceptability of consciously avoiding death which is in God's power.</li> </ul> |

## Theme 1. Concept of inevitability and invincibility

In agreement with the results of studies by other researchers, respondents referred to the concept of destiny and their belief that health, life, and death are in God's hands.<sup>15, 16</sup> They strongly emphasized how individual life conditions heavily depend on God and are thus inevitable. Several individual statements express this belief, examples of which are the following: "I believe in destiny and everything is in the hands of God", "because we believe that destiny is set by God", and "illness and death are preordained by God the Almighty." Participants' answers consistently referred to the same concept of fatalism and submission to God's plans for individuals and humankind.

## Theme 2. Concept of powerlessness and helplessness or submission and fatalism

Respondents stated their powerlessness and helplessness with respect to their health condition. Destiny, and especially health, life and death are preordained by God, and therefore individuals state their belief that they are powerless and helpless when it comes to such issues. They can only submit to God and accept his will. These statements are examples of these beliefs: "Believing in fatalism", "Because such questions are in the hands of God the Almighty and we are incapable of thinking about them", "Because illness is in the hands of God the Great and Almighty; He is the one who punishes us or helps us", "Because destiny is preordained by God and it is impossible to imagine death or life and illness" and "These questions are related to spirituality, imagining death & illness, and they're also related to religion & fatalism".

Many participants used quotes from the prophet of Islam (Muhammad) that indicate that life and death are in God's hands. Some participants also used some of the known names or characteristics of God (Allah) in their replies namely "The All Powerful (القادر)" and "The Creator of All Power (المقتدر)" These two names or description of Allah are usually known to be amongst the 99 names of Allah referred to in the Quran. Also the word or the name of "the One who cures and heals" (الشافي) was quoted by many of the participants referring to the belief that it is Allah who cures all ailments which is also taken from the reported sayings of the prophet.

## Theme 3. Concept of Appreciation:

Respondents made comments expressing appreciation for their life and health, noting that the questions had reminded them to be more religious. The TTO and the DCE exercises reminded the respondents of how important good health is, and made them express their gratitude to God for granting them good health. It also made them appreciate health in general. Examples of appreciation and gratitude were:

"Health is the most important blessing that the Lord has granted us", "I was touched by the fact that some people suffer from many diseases and that's why I thank God for my good health", "Life is beautiful and we should preserve it and preserve our health in order to enjoy its beauty"

#### Theme 4. Concept of fear:

Participants appeared to have a fear of disability and diminished mobility since in the ranking exercise they ranked mobility as the most important aspect of health, on average. The concept of punishment for bad actions in life as being one of the causes of illness, disability and death also appeared in participants' responses: "I remembered the existence of the day of reckoning after death", "Because illness is in the hands of God the Great and Almighty; He is the one who punishes us or helps us".

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## Theme 5. Concept of acceptance and patience

Some respondents had rejected the notion of choosing to give up time and, in particular, the idea that health states could ever be worse than dead: "One cannot imagine how death or ill life could be, it is all a work of God", "The feeling of losing normal life, the questions are about life and death and it's hard to deal with that.", "Because it's in the hands of God the Almighty and I have never thought about these questions before" and "There is no 100% healthy life but one has to live with the illness anyway".

#### Discussion

This study has shown that religious and cultural beliefs have an important effect on the way that Muslim Arabs think and respond to the stated preference tasks commonly used to value health states. Although our study used only the EQ-5D, the factors outlined in this paper are likely to effect the valuation of other HROOL measures. <sup>16</sup> These factors will influence the values generated from health preference exercises and their use in cost effectiveness analyses. This will have an important effect on efforts to develop value sets for HRQOL measures in these populations.

Our results are comparable with other findings reported in the literature. For example, in the study by Gowani referred to earlier, a conceptual framework of factors affecting noncommunicable disease preventive behaviors is proposed. <sup>16</sup> Among the factors identified are fatalism, invincibility and fear of premature death. As with our results, participants in the study perceived themselves as invincible and lacked any great appreciation of the threats to their health and referred to preordained fate as the main factor influencing health and illness. Despite this reference to fate, the Gowani study, in contrast to our study, does not mention the role of God in people's lives. Both studies identify a fear of premature death but in the Gowani study, fear of death appears to be an instrument toward preventive and self-care behaviors. However in our study, although participants indicated their total submission to the idea of health and illness as God's decision, many indicated that the study has reminded them to take care of their health as a gift from God that they need to value and preserve. Moreover, our study has shown that Muslim Arabs might be more submissive and accepting of the idea of death and illness as in many responses there were indications that a person should be patient and accepting.

Our study captured responses to two stated preference tasks, TTO and DCE. Some of the concepts identified relate to both tasks (e.g. concept of appreciation and concept of acceptance and patience) and would apply equally to other approaches that are used for valuing HRQOL (e.g. visual analogue scale and standard gamble). Other concepts and issues (e.g. concept of fear, rejection of the idea of trading time) appeared to be more specific to the trade-offs required in TTO than to the DCE tasks but would be equally pertinent to variants of the DCE involving duration, and in some cases to the standard gamble. Nevertheless, our earlier study demonstrated that it is feasible and culturally appropriate to carry out studies and derive value sets in Muslim Arab populations using existing methodologies. However, there are a number of ways in which the methods could be adapted for use in these populations, such as an increased emphasis in the instructions that the tasks are not intended to cause conflict with respondents' religious beliefs. Understanding the effect of religious beliefs on respondents' reactions to these tasks will be important in adapting the methods. Below, we detail aspects of the Islamic faith likely to be of particular importance in this respect.

#### Islamic beliefs and their influence on health state valuation

There are many teachings that influence the views of Muslims about health, illness, and dying. Muslims believe in the absolute timeless knowledge of God (Al Qadaa wal Qadar), fate and destiny, and the supreme power of God over human life. Belief in fate and destiny are also fundamental beliefs of the 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 Muhammad describe the preservation of life and health as being an act of worship and being highly praised by God.<sup>17</sup> The Quran encourages Muslims to accept illness, suffering, and dying with patience.<sup>18</sup> Moreover, Islam teaches that calamities can absolve the sins of a pious Muslim. These concepts can influence Muslims' perception of dying and illness and their preferences over different health outcomes. Muslims are strongly encouraged to seek treatment and care and are discouraged from pursuing illness.<sup>18</sup> 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.<sup>19</sup> Ahmad and Harrison argue that

religion continues to be defined as a cultural identity which influences knowledge, attitude and practice including health beliefs and behaviors.<sup>20</sup> Therefore, it is important to remember that health promotion programs and efforts to improve health should remain cognizant of cultural and religious beliefs particularly within Islamic communities. Our study reinforces this principle and also points to the importance of religious beliefs in other areas of public health activity including valuation of health states and HTA. Ahmad and Harrison also discuss the concept of fear as being a motivation for health related actions. They hypothesize that religion may increase responsiveness to fear-arousing messages that will lead eventually to lower health risks. Clearly, religion influences morality, ideology and decision making <sup>21</sup> and the concept of fear amongst Muslims has been recommended by some researcher to be used and integrated in health promotion models deigned for Muslim communities. <sup>16, 20, 22</sup> The notion of acceptance, submission, fatalism and inevitability lead Muslims to value health as being a gift from God and endure suffering and disability with patience and acceptance in expectation of better rewards in the hereafter. Researchers must be aware of all of these aspects of religion that will influence valuation of health states in Muslim populations.

#### Conclusions

Our 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. We also recommend further exploration of how people in the UAE and other, predominantly, Muslim countries interpret the concept of "worse than dead" health states, and whether alternatives to TTO may be more appropriate for these populations.

## Contributors

NJD, KKS and EAP designed the study. KKS, EAP and IE analysed and interpreted the data with input from NJD and MSK. IB and IE wrote the first draft. IB is the guarantor. All authors revised it critically for important intellectual content and approved the final version for publication. All authors agree to be accountable for all aspects of the work.

## **Competing interests**

EAP is an employee of Eli Lilly and Company

## Funding

This study was funded by an unrestricted research grant by Eli Lilly and Company

## Data sharing statement

No additional data are available.

## **Ethical approval**

The study was approved by the Al Ain Medical District Human Research Ethics Committee in November 2013, N.13/82).

## Provenance and peer review

Not commissioned; externally peer reviewed.

## **Research reporting checklists:**

The COREQ criteria have been used where appropriate to guide the reporting of our findings.

## Permissions

Not applicable

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None

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## COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

pen: first published as 10.1 A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

| Торіс                       | Item No. | Guide Questions/Description  | Reporte<br>Page N |
|-----------------------------|----------|--|-------------------|
| Domain 1: Research team     |          |  | 1 4801            |
| and reflexivity             |          |  |                   |
| Personal characteristics    |          |  |                   |
| Interviewer/facilitator     | 1        | Which author/s conducted the interview or focus group?                   |                   |
| Credentials                 | 2        | What were the researcher's credentials? E.g. PhD, MD                     |                   |
| Occupation                  | 3        | What was their occupation at the time of the study?                      |                   |
| Gender                      | 4        | Was the researcher male or female?                                       |                   |
| Experience and training     | 5        | What experience or training did the researcher have?                     |                   |
| Relationship with           |          |  | 1                 |
| participants                |          |  |                   |
| Relationship established    | 6        | Was a relationship established prior to study commencement?              |                   |
| Participant knowledge of    | 7        | What did the participants know about the researcher? e.g. personal       |                   |
| the interviewer             |          | goals, reasons for doing the research                                    |                   |
| Interviewer characteristics | 8        | What characteristics were reported about the inter viewer/facilitator?   |                   |
|                             |          | e.g. Bias, assumptions, reasons and interests in the research topic      |                   |
| Domain 2: Study design      |          |  |                   |
| Theoretical framework       |          |  |                   |
| Methodological orientation  | 9        | What methodological orientation was stated to underpin the study? e.g.   |                   |
| and Theory                  |          | grounded theory, discourse analysis, ethnography, phenomenology,         |                   |
|                             |          | content analysis   |                   |
| Participant selection       | •        |  |                   |
| Sampling                    | 10       | How were participants selected? e.g. purposive, convenience,             |                   |
|                             |          | consecutive, snowball  |                   |
| Method of approach          | 11       | How were participants approached? e.g. face-to-face, telephone, mail,    |                   |
|                             |          | email  |                   |
| Sample size                 | 12       | How many participants were in the study?                                 |                   |
| Non-participation           | 13       | How many people refused to participate or dropped out? Reasons?          |                   |
| Setting                     |          |  |                   |
| Setting of data collection  | 14       | Where was the data collected? e.g. home, clinic, workplace               |                   |
| Presence of non-            | 15       | Was anyone else present besides the participants and researchers?        |                   |
| participants                |          |  |                   |
| Description of sample       | 16       | What are the important characteristics of the sample? e.g. demographic   |                   |
|                             |          | data, date   |                   |
| Data collection             |          |  |                   |
| Interview guide             | 17       | Were questions, prompts, guides provided by the authors? Was it pilot    |                   |
|                             |          | tested?  |                   |
| Repeat interviews           | 18       | Were repeat inter views carried out? If yes, how many?                   |                   |
| Audio/visual recording      | 19       | Did the research use audio or visual recording to collect the data?      |                   |
| Field notes                 | 20       | Were field notes made during and/or after the inter view or focus group? |                   |
| Duration                    | 21       | What was the duration of the inter views or focus group?                 |                   |
| Data saturation             | 22       | Was data saturation discussed?   |                   |
| Transcripts returned        | 23       | Were transcripts returned to participants for comment and/or             |                   |

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| Торіс   | Item No.                       | Guide Questions/Description  | Reported                          |
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|   |                                |  | Page No                           |
|   |                                | correction?  |                                   |
| Domain 3: analysis and  |                                |  |                                   |
| findings  |                                |  |                                   |
| Data analysis   |                                |  |                                   |
| Number of data coders   | 24                             | How many data coders coded the data?   | F                                 |
| Description of the coding                                     | 25                             | Did authors provide a description of the coding tree?  | arot                              |
| tree  |                                |  | Protected by copyright, including |
| Derivation of themes  | 26                             | Were themes identified in advance or derived from the data?  | ed                                |
| Software  | 27                             | What software, if applicable, was used to manage the data?   | oy o                              |
| Participant checking  | 28                             | Did participants provide feedback on the findings?   | op.                               |
| Reporting   |                                |  | ,<br>Vrig                         |
| Quotations presented  | 29                             | Were participant quotations presented to illustrate the themes/findings?   | nt,                               |
|   |                                | Was each quotation identified? e.g. participant number   | Incl                              |
| Data and findings consistent                                  | 30                             | Was there consistency between the data presented and the findings?   | udi                               |
| Clarity of major themes                                       | 31                             | Were major themes clearly presented in the findings?   |                                   |
| Clarity of minor themes                                       | 32                             | Is there a description of diverse cases or discussion of minor themes?   | for                               |
| for interviews and focus group<br>Once you have completed thi | os. Internatio<br>s checklist, | ig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-ite<br>onal Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349<br>please save a copy and upload it as part of your submission. DO NOT includ<br>document. It must be uploaded as a separate file. | - 357 ated to                     |

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## **BMJ Open**

## The effect of religion on the perception of health states amongst adults in the United Arab Emirates: a qualitative study

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| Secondary Subject Heading:           | Health economics   |
| Keywords:                            | QUALITATIVE RESEARCH, Islam, United Arab Emirates, Cost-Effectiveness<br>Analysis, Patient Reported Outcome Measures   |
|                                      |  |

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The effect of religion on the perception of health states amongst adults in the United Arab Emirates: a qualitative study Iffat Elbarazi<sup>1</sup>, Nancy J. Devlin<sup>2</sup>, Marina-Selini Katsaiti<sup>3</sup>, Emmanuel A. Papadimitropoulos<sup>4</sup>, Koonal K. Shah<sup>2</sup>, Iain Blair<sup>1</sup>

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## **ABSTRACT**

**Objectives:** Investigate how religion may affect the perception of health states amongst adults in the United Arab Emirates and the implications for research on self-reported health and quality of life and the use of values in cost effectiveness analysis.

Design: Qualitative analysis of short structured interviews with adult Emiratis carried out by a market research agency.

Setting: Participants were recruited from shopping malls and other public places in the cities of Al Ain and Abu Dhabi.

**Participants:** Two hundred adult Emiratis broadly representative of the Emirati population in terms of age and gender.

**Results:** Eighty three percent of participants said that their valuation of health states was influenced by their spiritual or religious beliefs. The two overarching themes that seemed to explain or classify these influences were "fatalism" and "preservation of life". Sub-themes included powerlessness to change what is pre-ordained by God, fear of disability (particularly diminished mobility) and appreciation of health and life and the requirement to look after one's health. A final theme was that of acceptance, with respondents expressing a willingness to endure suffering and disability with patience in the expectation of rewards in the hereafter. **Conclusions:** Our results emphasize the need for further work to establish locally relevant value sets for Muslim majority countries in the Middle East and elsewhere for use in HTA decision making, rather than relying on value sets from other regions.

## Key words

Qualitative Research, Islam, United Arab Emirates, Patient Reported Outcome Measures, Cost-Effectiveness Analysis

## **Article Summary**

| Sti | rengths and limitations of this study   |  |  |  |
|-----|---|--|--|--|
| ٠   | Health-related quality-of-life (HRQOL) measures are routine in health technology assessment         |  |  |  |
|     | (HTA) and health outcomes research but the health value sets on which they are based differ         |  |  |  |
|     | between countries due to social, cultural and particularly religious factors. The need for country  |  |  |  |
|     | specific value sets is particularly important in Muslim majority countries, such as the United Arab |  |  |  |
|     | Emirates (UAE), where the population may think differently about the trade-offs between health,     |  |  |  |
|     | length of life, and death. This is one of the few studies to address these differences.             |  |  |  |
| •   | This qualitative study involved Emirati adults living in the Emirate of Abu Dhabi (the cities of Al |  |  |  |
|     | Ain and Abu Dhabi). However our respondents were younger and more-educated than the general         |  |  |  |
|     | Emirati population of Abu Dhabi. Also Emiratis from the other six emirates were not included. Our   |  |  |  |
|     | finding therefore cannot be generalized to the whole of the UAE Emirati population. Also the        |  |  |  |
|     | findings from our study cannot be applied with certainty to other Muslim Arab populations in other  |  |  |  |
|     | countries.  |  |  |  |

- The assessment of the impact of "spiritual or religious views" on health valuations was limited to one open-ended question asked via a self-administered survey. This will inevitable affect the validity of our results and the strength of our conclusions.
- In a study with this design there will be both interviewer and response bias. In addition there is bias associated with the study design and the experience and judgment of the principal researchers when analyzing and interpreting the data.
- Finally, the UAE, as a high income Middle East country has a very specific set of social characteristics. Our findings can only be interpreted within the context of those characteristics.

INTRODUCTION

Use of health-related quality-of-life (HRQOL) measures is routine in health technology assessment (HTA) and health outcomes research. Many such measures are available. The EQ-5D, a short questionnaire developed by the EuroQol Group, is widely used by HTA agencies, including the United Kingdom's National Institute for Health and Care Excellence.<sup>1, 2</sup> The EO-5D was initially developed for English-speaking populations but has since been translated so that there are now over 176 EQ-5D language versions.<sup>3</sup> EQ-5D describes health in terms of five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). The EQ-5D-3L grades each dimension on one of three levels of severity (no, some and extreme), while the newer five level variant (EQ-5D-5L) uses five levels of severity, thereby defining  $(5^{5})$  3125 unique health states.<sup>4</sup> In order to be used to support cost-effectiveness analyses, the EQ-5D must be accompanied by 'value sets' which summarize how good or bad each unique health state is on a scale anchored at 1 (full health) and 0 (dead). These value sets are derived by assessing the stated preferences of the general population. A variety of methods are available for this including the time trade-off (TTO), which involves asking survey respondents to evaluate health states,<sup>5,6</sup> and discrete choice experiments (DCE), which in its simplest form involves a pairwise choice between two states. Views about health may differ between countries due to social, cultural and religious factors, and so country specific value sets are needed.<sup>7</sup>

The need for country specific value sets is particularly important in Muslim majority countries such as the United Arab Emirates (UAE). Differences in the religious beliefs of the population will lead to very different ways of thinking about the trade-offs between health, length of life, and death compared to non-Muslim countries. The UAE is unique in its health needs as well as in the medical seeking behavior of its people and the cultural effects on their health.<sup>8</sup> Although EQ-5D-5L value sets have been or are currently being developed in countries such as England, Canada, and China, and there is research evidence that Arabic versions of the EQ-5D-3L are valid and reliable in measuring quality of life in Jordan <sup>9</sup> and Morocco, <sup>10</sup> no local value sets for the EQ-5D-3L or EQ-5D-5L are available in the UAE or elsewhere in the Gulf region.<sup>11</sup> Following calls for research on HRQOL assessment in Arabic countries, we carried out TTO and DCE valuation exercises amongst a sample of 200 adult Emiratis and concluded that the methods were appropriate and feasible.<sup>12</sup> However, in that study there was evidence of striking

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To our knowledge there have been no previous studies that have explored the influence of religion on the perception of health states amongst Muslims. A study was conducted in Tunisia on TTO utilities with rheumatoid arthritis patients but this study did not investigate the influence of religion or culture.<sup>14</sup> Therefore, as part of our study we explored respondents' feelings when asked to value different health states and what influence their religious beliefs may have had on their responses. The purpose of this paper is to present the results of those additional enquiries and provide further detailed insights into (a) how religion may affect the perception of health states amongst Emiratis and (b) the implications of our findings for research on self-reported health and quality of life in the region and for the use of values in cost effectiveness analysis.

#### **Methods**

The methods have been described previously but, in summary, interviews were conducted with adult Emiratis in Abu Dhabi and Al Ain.<sup>12</sup> The target sample size was 200 respondents and data collection was carried out by Ipsos Observer, a market research agency. Participants were Emirati citizens residing in the Emirate of Abu Dhabi. Of the one million Emiratis in the UAE, about 40% live in Abu Dhabi while the remaining 60% live in the six other Emirates. <sup>15</sup> Emiratis are predominantly Arab and Muslim. It would be disrespectful to suggest otherwise. It is acknowledged that our participants are not representative of all Arab Muslims or of all Emiratis. However for simplicity we refer to them in this paper as Emiratis. A convenience sampling approach was used, whereby members of the public were approached in shopping malls and other public places by recruiters working for Ipsos Observer. Information sheets (both in English and in Arabic) were provided and interview appointments were made for those who expressed an interest in participating. A sample that was broadly representative of the Emirati population in terms of age and gender was sought. Each respondent completed a valuation questionnaire administered within a computer-assisted personal interview (CAPI) in accordance with the EuroQol protocol.<sup>5</sup> Each questionnaire comprised TTO and DCE tasks, feedback questions and

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an (optional) open-ended comment box. After completing the valuation questionnaire, respondents were asked further "debrief" questions focusing on their experience of completing the valuation tasks via a self-completed survey that included closed and open-ended questions (Table 1). Participants' responses to these questions provided us with the data for the qualitative study reported here. Specifically we used the answers to the open-ended question about the extent to which participants' answers were influenced by their spiritual or religious views in our analysis. Since we wished to investigate participants' own perspectives on the ways in which their religiosity and spirituality might influence their valuation of health states we used a phenomenological study design. Data was collected in December 2013 in Arabic and responses were later translated into English. The study was approved by the Al Ain Medical District ι Νυ. ) from all res<sub>b</sub>. Human Research Ethics Committee in November 2013(N.13/82) and informed consent was obtained (using paper consent forms) from all respondents prior to their participation in the study.

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| No. | Question                            | Response type                                       |
|-----|-------------------------------------|---|
| 1   | Was there anything in the survey    | Open ended  |
|     | that made you feel uncomfortable?   |   |
| 2   | What did you like or dislike about  | Open ended  |
|     | the survey?                         |   |
| 3   | Do you have any suggestions for     | Open ended  |
|     | improving the survey and making it  |   |
|     | more relevant for people like you?  |   |
| 4   | To what extent were your answers to | Closed ended, pre-coded categorical                 |
|     | the questions influenced by your    | [0 = no answer selected; 1 = not influenced at all; |
|     | spiritual or religious views?       | 2 = somewhat influenced; 3 = heavily influenced]    |
| 5   | Please explain how.                 | Open ended  |
|     |                                     |   |

## Analysis

Thematic analysis was used to identify themes related to the influence of religious beliefs on the valuation of health states by the respondents.<sup>16</sup> Responses were first transcribed verbatim (by Ipsos Observer) and were then analyzed systematically by two authors (IE and IB) working independently. The data was coded and organized into emerging themes and subthemes. Following a discussion of themes by all members of the study team, a final index was synthesized by one author (IE) acting as a content expert with detailed knowledge of Islamic faith health considerations. Direct quotes from respondents are presented where this is useful to provide additional insights or to illustrate the themes that emerged. Using an inductive approach the emergent themes were used to make inferences about the way in which religious beliefs will affect the valuation of health states. The study reported here was part of a pilot study, the primary purpose of which was to investigate the feasibility and cultural appropriateness of stated preference methods to generate EQ-5D-5L values in the United Arab Emirates. The target sample size for this pilot study was 200 and this provided 134 completed interviews for the qualitative element of the study. This figure is pragmatic rather that theoretical but in the

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authors' opinion will provide data of sufficient quality and quality to provide for data saturation. Indeed the final finite themes emerged promptly during the data analysis.

#### **Results**

As previously reported,<sup>12</sup> the final sample comprised 200 respondents and complete background demographic data was available for 166 of these (Table 2). Background data are unavailable for the remaining 34 respondents due to a recording error but it is not expected that the missing respondents will differ systematically from the rest of the sample. 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.<sup>17</sup> 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.<sup>18</sup> All of the respondents were Muslim.

| Characteristic      | n   | %      |
|---------------------|-----|--------|
|                     |     |        |
| Total               | 166 | 100.0% |
| Gender              |     |        |
| Male                | 93  | 56.0%  |
| Female              | 73  | 44.0%  |
| Age group (years)   |     |        |
| 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%   |

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

|                                 | n  | n     |
|---------------------------------|----|-------|
| 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 no university     | 42 | 25.3% |
| Current university student      | 46 | 27.7% |
| Graduate                        | 58 | 34.9% |
| No answer given                 | 13 | 7.8%  |

In their answers to open-ended questions No. 1-3, some participants mentioned that they disliked the sensitive nature of the questions or took issue with fundamental aspects of the valuation methods, for example choosing to give up time or having to choose between two health states. Others reported feeling uncomfortable with the questions such as the idea of imagining living with some disability or other condition and thinking about illness and death. However one participant stated: "Living in a wheelchair and living with severe problems moved me because in our religion we believe in fate". Others indicated that they liked the questionnaire because it made them reflect on their current life and made them appreciate health and life being a precious gift and an Amana from God that one should protect: "I liked the survey because it made me think about the gifts I have"

Amongst the 144 respondents who answered the question "To what extent were your answers affected by your spiritual or religious beliefs", 25 (17.4%) replied "not influenced at all", 75 (52.1%) replied "somewhat influenced" and 44 (30.6%) replied "heavily influenced". One hundred and thirty four participants provided an answer to open-ended question No.5. Participants' responses in general were short and did not require detailed interpretation.

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> The recurring themes were apparent very clearly among the responses and were classified into two major categories each with three sub-themes (Table 3). These are discussed in turn in the following section.

Table 3. Themes and Sub-themes apparent from analysis of respondents' comments

| (n=134) <b>Theme</b>  | Sub-themes                      | Examples                                  |  |
|---|---------------------------------|---|--|
| Fatalism  | Inevitability and invincibility | • Destiny is determined by God            |  |
| (95)  | (63)                            | • Death and illness flow from God         |  |
|   | Powerlessness, helplessness or  | • Reminder that illness is in the hands   |  |
|   | submission (6)                  | of God and He is the one who grants       |  |
|   |                                 | or punishes                               |  |
|   | Unacceptance of certain ideas   | Unacceptability of making choice          |  |
|   | (23)                            | between death and illness                 |  |
|   |                                 | Unacceptability of consciously            |  |
|   |                                 | avoiding death which is in God's          |  |
|   |                                 | power.                                    |  |
| Preservation of   | Appreciation (33)               | • Reminder of death and judgment day      |  |
| life  |                                 | • Reminder to become more religious       |  |
| (51)  |                                 | • Reminder to look after our health.      |  |
|   |                                 | • Reminder that life is short and illness |  |
|   |                                 | or death can happen at any time, and      |  |
|   |                                 | thus appreciation and importance of       |  |
|   |                                 | the preservation of life.                 |  |
|   | Fear (5)                        | • Fear of death                           |  |
|   |                                 | • Fear of disability/illness              |  |
|   | Acceptance and patience (13)    | • To accept disability.                   |  |
| Note: numbers in parentheses are the number of responses that were classified according to each |                                 |   |  |

category

#### Theme 1. Fatalism

Under the concept of fatalism we identified three subthemes. First, the sub-theme of inevitability and invincibility which strongly emphasized how individual life conditions heavily depend on God and are thus inevitable. Several individual statements express this belief, examples of which are the following: "I believe in destiny and everything is in the hands of God", "because we believe that destiny is set by God". The second sub-theme is the concept of powerlessness, helplessness or submission. Respondents stated their powerlessness and helplessness with respect to their health condition and that they can only submit to God and accept his will. The following statements are examples of these beliefs: "Because destiny is preordained by God and it is impossible to imagine death or life and illness" and "Because these questions are related to the power of God, He who grants and assists". Many participants used quotes from the prophet of Islam (Muhammad) that indicate that life and death are in God's hands. Some participants also used some of the known names or characteristics of God (Allah) in their replies namely "The All Powerful (القادر)" and "The Creator of All Power (المقتدر)". These two names or description of Allah are usually known to be amongst the 99 names of Allah referred to in the Quran. Also the word or the name of "the One who cures and heals" was also quoted by many of the participants referring to the belief that it is Allah who cures all ailments which is also taken from the الشافى) reported sayings of the prophet. The third "fatalism" sub-theme was the "unacceptability of certain ideas". Participants highlighted in their answers the unacceptability of i) choosing between death and illness, and ii) consciously avoiding death, which is in God's power. Some respondents who felt that the survey made them uncomfortable mentioned the following reasons: "I was always trying not to choose death", "Many questions made me feel uncomfortable, especially when you have to choose between death and living with a chronic disease".

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#### Theme 2. Preservation of Life

Under this second main theme we also identified three sub-themes: appreciation, fear and acceptance and patience. Respondents made comments expressing appreciation for their life and health, noting that the questions had reminded them to be more religious. The TTO and the DCE exercises reminded the respondents of how important good health is, and made them express their gratitude to God for granting them good health. It also made them appreciate health in general. Examples were: "Health is the most important blessing that the Lord has granted us", "I

was touched by the fact that some people suffer from many diseases and that's why I thank God for my good health", "Life is beautiful and we should preserve it and preserve our health in order to enjoy its beauty". Participants appeared to have a fear of disability and diminished mobility since in the ranking exercise, they ranked mobility as the most important aspect of health. The concept of punishment for bad actions in life as being one of the causes of illness, disability and death also appeared in participants' responses: "I remembered the existence of the day of reckoning after death", "Because illness is in the hands of God the Great and Almighty; He is the one who punishes us or helps us". Respondents also revealed acceptance and patience in the way they view life. These are discernible elements in the Muslim religion and become fundamental components when faced with life challenges. Examples of this final sub-theme are: "There is no 100% healthy life but one has to live with the illness anyway" and "We live life in its good and bad".

#### Discussion

This study has shown that religious beliefs have an important effect on the way that Emiratis think and respond to the stated preference tasks commonly used to value health states. We found that the responses of nearly one third of participants were heavily influenced by their religious views. Although our study used only the EQ-5D, the factors outlined in this paper are likely to effect the valuation of other HROOL measures.<sup>19</sup> These factors will influence the values generated from health preference exercises and their use in cost effectiveness analyses. This will have an important effect on efforts to develop value sets for HRQOL measures in these populations. In our study, fatalism and preservation of life were the two overarching concepts that influenced participants' valuation of health states. Our results are comparable with other findings reported in the literature on the role of religion in health perceptions, behaviors and outcomes.<sup>19, 20</sup> For example, in the study by Gowani, a conceptual framework of factors affecting non-communicable disease preventive behaviors is proposed including fatalism, invincibility and fear of premature death. In agreement with these results, our respondents also referred to the concept of destiny and their belief that health, life, and death are in God's hands. In contrast, Rasool discusses Muslims' belief of acceptance rather than fatalism, as for Muslims, suffering and dying are considered a test from Allah: 'Be sure we shall test you with something of fear, hunger, some loss In wealth, lives or the produce, but give glad tidings to those who patiently

persevere (Ai-Baqarah 2:155). <sup>21</sup> Acceptance and patience was a prominent theme in our study, suggesting that Emiratis might be more submissive and accepting of the idea of death and illness. In earlier studies, Athar had explained that illness, for Muslims, is an atonement for their sins and will help them meet God cleansed of their sins. <sup>22, 23</sup> This was also a theme that featured in our study. Participants in the Gowani study perceived themselves to be invincible and lacking any great appreciation of the threats to their health and in agreement with our study they referred to preordained fate as the main factor influencing health and illness. However, in contrast to our study, Gowani does not mention the role of God in people's lives. Both studies identify a fear of premature death but while in the Gowani study, fear of death appears to be an instrument toward preventive and self-care behaviors, in our study it is seen as a reminder to value and preserve health as a gift from God.

Our study captured responses to two stated preference tasks, TTO and DCE. Some of the concepts identified relate to both tasks (e.g. concept of appreciation and concept of acceptance and patience) and would apply equally to other approaches that are used for valuing HRQOL (e.g. visual analogue scale and standard gamble). Other concepts and issues (e.g. concept of fear, rejection of the idea of trading time) appeared to be more specific to the trade-offs required in TTO than to the DCE tasks but would be equally pertinent to variants of the DCE involving duration, and in some cases to the standard gamble. Nevertheless, our earlier study demonstrated that it is feasible and culturally appropriate to carry out studies and derive value sets in Muslim Arab populations using existing methodologies. However, there are a number of ways in which the methods could be adapted for use in these populations, such as an increased emphasis in the instructions that the tasks are not intended to cause conflict with respondents' religious beliefs. Understanding the effect of religious beliefs on respondents' reactions to these tasks will be important in adapting the methods. Below, we detail aspects of the Islamic faith likely to be of particular importance in this respect.

#### Islamic beliefs and their influence on health state valuation

There are many teachings that influence the views of Muslims about health, illness, and dying. Muslims believe in the absolute timeless knowledge of God (Al Qadaa wal Qadar), fate and destiny, and the supreme power of God over human life. Belief in fate and destiny are also fundamental beliefs of the 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 Muhammad describe the preservation of life and health as being an act of worship and being highly praised by God.<sup>24</sup> The Ouran encourages Muslims to accept illness, suffering, and dving with patience.<sup>21</sup> Moreover, Islam teaches that calamities can absolve the sins of a pious Muslim. These concepts can influence Muslims' perception of dying and illness and their preferences over different health outcomes. Muslims are strongly encouraged to seek treatment and care and are discouraged from pursuing illness.<sup>21</sup> 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.<sup>25</sup> Ahmad and Harrison argue that religion continues to be defined as a cultural identity which influences knowledge, attitude and practice including health beliefs and behaviors.<sup>26</sup> Therefore, it is important to remember that health promotion programs and efforts to improve health should remain cognizant of cultural and religious beliefs particularly within Islamic communities. Our study reinforces this principle and also points to the importance of religious beliefs in other areas of public health activity including valuation of health states and HTA. Ahmad and Harrison also discuss the concept of fear as being a motivation for health related actions. They hypothesize that religion may increase responsiveness to fear-arousing messages that will lead eventually to lower health risks. Clearly, religion influences morality, ideology and decision making <sup>27</sup> and the concept of fear amongst Muslims has been recommended by some researcher to be used and integrated in health promotion models designed for Muslim communities.<sup>19, 25, 28</sup> The notion of acceptance, submission, fatalism and inevitability lead Muslims to value health as being a gift from God and endure suffering and disability with patience and acceptance in expectation of better rewards in the hereafter. Researchers must be aware of all of these aspects of religion that will influence valuation of health states in Muslim populations.

As discussed above, the UAE, as a high income Middle East country has a very specific set of social characteristics and our findings can only be interpreted within the context of those characteristics and not generalized to other Arab or Muslim populations. That said, EQ-5D valuation research has recently been undertaken in Indonesia, the world's largest Muslimmajority country, so an investigation of whether the findings of our study in the UAE are also observed in Indonesia would be of particular interest.<sup>29</sup> Such comparative research would help to establish whether the effects that we have observed are generalisable to other Muslim populations.

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#### Conclusions

Our 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. We also recommend further exploration of how people in the UAE and other, predominantly, Muslim countries interpret the concept of "worse than dead" health states, and whether alternatives to TTO (that do not involve choosing between different life expectancies) may be more appropriate for these populations.

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# Contributors

NJD, KKS and EAP designed the study. KKS, EAP and IE analysed and interpreted the data with input from NJD and MSK. IB and IE wrote the first draft. IB is the guarantor. All authors revised it critically for important intellectual content and approved the final version for publication. All authors agree to be accountable for all aspects of the work.

# **Competing interests**

EAP is an employee of Eli Lilly and Company

# Funding

This study was funded by an unrestricted research grant by Eli Lilly and Company

# Data sharing statement

No additional data are available.

# **Ethical approval**

The study was approved by the Al Ain Medical District Human Research Ethics Committee in November 2013, N.13/82).

# Provenance and peer review

Not commissioned; externally peer reviewed.

#### **Research reporting checklists:**

The COREQ criteria have been used where appropriate to guide the reporting of our findings.

#### Permissions

Not applicable

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# Table 1

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| No   | Item                        | Guide questions/description                                 | Response   |
|--|-----------------------------|---|--|
| Domain 1:<br>Research team<br>and<br>reflexivity |                             |   |  |
| Personal<br>Characteristics                      | 0                           |   |  |
| 1.   | Interviewer/<br>facilitator | Which author/s conducted the interview or focus group?      | Not applicable, interviews carried out by professional interviewers  |
| 2.   | Credentials                 | What were the researcher's credentials? <i>E.g. PhD, MD</i> | DrPH and MD  |
| 3.   | Occupation                  | What was their occupation at the time of the study?         | Research assistant and public health academic  |
| 4.   | Gender                      | Was the researcher male or female?                          | There were both male and female researchers  |
| 5.   | Experience and training     | What experience or training did the researcher have?        | The interviews were undertaken by a small<br>team of professional interviewers who had<br>completed a three-day training course on the<br>specifics of the methodology and procedures<br>for the study, but had no prior experience in<br>health state valuation.<br>The interviews took place in hotel conference<br>rooms and the offices of the fieldwork agency.<br>The interviewers were instructed to guide<br>respondents through each element of the<br>valuation questionnaire, closely following an<br>interview script. The capturing and time-<br>stamping of all respondent actions via EQ-VT<br>provided data on elements such as how long<br>the interviewers had spent explaining the TTO<br>exercise to respondents using the warm-up<br>tasks. It was agreed with the agency that any<br>valuation data collected would be kept only if<br>the data confirmed that the interviewer had<br>adhered to the protocol and covered all<br>elements as instructed. Interviewers spent at<br>least 15 minutes with each respondent,<br>explaining the questions and the rationale<br>behind the study. Respondents were reassured |

|      | pe     |    |
|------|--------|----|
| Page | 20.70f | 24 |

|                                     |  |   | that the questions were not intended to<br>challenge or cause conflict with their beliefs<br>and faith.  |
|-------------------------------------|--|---|--|
| Celationship<br>vith<br>articipants |  |   |  |
|                                     | Relationship<br>established                    | Was a relationship established prior to study commencement?   | No   |
|                                     | Participant<br>knowledge of<br>the interviewer | What did the participants know about the researcher? e.g. <i>personal goals, reasons for doing the research</i>   | Participants had no prior knowledge about the researcher? e.g. personal goals, reasons for doing the research  |
|                                     | Interviewer<br>characteristics                 | What characteristics were reported<br>about the interviewer/facilitator? e.g.<br><i>Bias, assumptions, reasons and</i><br><i>interests in the research topic</i>            | No         Participants had no prior knowledge about the researcher? e.g. personal goals, reasons for doing the research         Not applicable, see above         Phenomenology       |
| omain 2:<br>tudy design             |  | 0   |  |
| heoretical<br>amework               |  | R   |  |
|                                     | Methodological<br>orientation and<br>Theory    | What methodological orientation was<br>stated to underpin the study? <i>e.g.</i><br>grounded theory, discourse analysis,<br>ethnography, phenomenology, content<br>analysis | Phenomenology  |
| articipant<br>election              |  |   |  |
| 0.                                  | Sampling                                       | How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>   | A convenience sampling approach was used,<br>whereby members of the public were<br>approached in shopping malls and other public<br>places by recruiters working for Ipsos<br>Observer |
| 1.                                  | Method of<br>approach                          | How were participants approached?<br>e.g. face-to-face, telephone, mail,<br>email   | Potential participants were approached directly, face-to-face  |
| 2.                                  | Sample size                                    | How many participants were in the study?  | The target sample was 200. Data was available on 134.  |
| 3.                                  | Non-   | How many people refused to  | The sample comprised 200 respondents but   |

|  | participation                       | participate or dropped out? Reasons?   | complete background demographic data we<br>unavailable for 34 due to a recording error<br>the 166, 134 provided data for the qualitati<br>study                                |
|--|-------------------------------------|--|--|
| Setting                                |                                     |  |  |
| 14.                                    | Setting of data collection          | Where was the data collected? e.g. home, clinic, workplace                               | Respondents were recruited in shopping m<br>and other public places. The interviews too<br>place in hotel conference rooms and the<br>offices of the fieldwork agency          |
| 15.                                    | Presence of<br>non-<br>participants | Was anyone else present besides the participants and researchers?                        | No   |
| 16.                                    | Description of sample               | What are the important characteristics of the sample? <i>e.g. demographic data, date</i> | Broadly representative of adult Emiratis<br>(citizens of the United Arab Emirates)   |
| Data collection                        |                                     | 0  |  |
| 17.                                    | Interview<br>guide                  | Were questions, prompts, guides<br>provided by the authors? Was it pilot<br>tested?      | Questions were provided. The interviewer<br>were instructed to guide respondents throu<br>each element of the valuation questionnair<br>closely following an interview script. |
| 18.                                    | Repeat<br>interviews                | Were repeat interviews carried out? If yes, how many?                                    | No   |
| 19.                                    | Audio/visual recording              | Did the research use audio or visual recording to collect the data?                      | Computer-assisted personal interview (CA was used  |
| 20.                                    | Field notes                         | Were field notes made during and/or after the interview or focus group?                  | No   |
| 21.                                    | Duration                            | What was the duration of the interviews or focus group?                                  | Minimum of 15 minutes  |
| 22.                                    | Data saturation                     | Was data saturation discussed?   | Yes.   |
| 23.                                    | Transcripts returned                | Were transcripts returned to<br>participants for comment and/or<br>correction?           | No   |
| Domain 3:<br>analysis and<br>findingsz |                                     |  |  |

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| Data analysis |                                 |  |  |
| 1             | lumber of data<br>oders         | How many data coders coded the data?   | Two  |
|               | Description of ne coding tree   | Did authors provide a description of the coding tree?  | No   |
| 6             | Derivation of nemes             | Were themes identified in advance or derived from the data?  | Derived from data  |
| 27. So        | oftware                         | What software, if applicable, was used to manage the data?   | Software was not used  |
|               | articipant<br>hecking           | Did participants provide feedback on the findings?   | No   |
| Reporting     |                                 | 0  |  |
|               | Puotations<br>resented          | Were participant quotations presented<br>to illustrate the themes / findings?<br>Was each quotation identified? e.g.<br>participant number | Pag   Two   No   Derived from data   Software was not used   No   Yes, but participant numbers were not given   The authors believe so |
| 60. fii       | Data and<br>ndings<br>onsistent | Was there consistency between the data presented and the findings?   | The authors believe so   |
|               | clarity of hajor themes         | Were major themes clearly presented in the findings?   | The authors believe so   |
|               | Clarity of<br>hinor themes      | Is there a description of diverse cases or discussion of minor themes?   | Sub-themes are discussed   |
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# COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

pen: first published as 10.1 A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

| Торіс                       | Item No. | Guide Questions/Description  | Reporte<br>Page N |
|-----------------------------|----------|--|-------------------|
| Domain 1: Research team     |          |  | - Tuge I          |
| and reflexivity             |          |  |                   |
| Personal characteristics    |          |  |                   |
| Interviewer/facilitator     | 1        | Which author/s conducted the interview or focus group?                   |                   |
| Credentials                 | 2        | What were the researcher's credentials? E.g. PhD, MD                     |                   |
| Occupation                  | 3        | What was their occupation at the time of the study?                      |                   |
| Gender                      | 4        | Was the researcher male or female?                                       |                   |
| Experience and training     | 5        | What experience or training did the researcher have?                     |                   |
| Relationship with           |          |  | 1                 |
| participants                |          |  |                   |
| Relationship established    | 6        | Was a relationship established prior to study commencement?              |                   |
| Participant knowledge of    | 7        | What did the participants know about the researcher? e.g. personal       |                   |
| the interviewer             |          | goals, reasons for doing the research                                    |                   |
| Interviewer characteristics | 8        | What characteristics were reported about the inter viewer/facilitator?   |                   |
|                             |          | e.g. Bias, assumptions, reasons and interests in the research topic      |                   |
| Domain 2: Study design      |          |  |                   |
| Theoretical framework       |          |  |                   |
| Methodological orientation  | 9        | What methodological orientation was stated to underpin the study? e.g.   |                   |
| and Theory                  |          | grounded theory, discourse analysis, ethnography, phenomenology,         |                   |
| ,                           |          | content analysis   |                   |
| Participant selection       |          |  |                   |
| Sampling                    | 10       | How were participants selected? e.g. purposive, convenience,             |                   |
|                             |          | consecutive, snowball  |                   |
| Method of approach          | 11       | How were participants approached? e.g. face-to-face, telephone, mail,    |                   |
|                             |          | email  |                   |
| Sample size                 | 12       | How many participants were in the study?                                 |                   |
| Non-participation           | 13       | How many people refused to participate or dropped out? Reasons?          |                   |
| Setting                     |          |  |                   |
| Setting of data collection  | 14       | Where was the data collected? e.g. home, clinic, workplace               |                   |
| Presence of non-            | 15       | Was anyone else present besides the participants and researchers?        |                   |
| participants                | _        |  |                   |
| Description of sample       | 16       | What are the important characteristics of the sample? e.g. demographic   |                   |
| · ·                         |          | data, date   |                   |
| Data collection             | I        | 1  | 1                 |
| Interview guide             | 17       | Were questions, prompts, guides provided by the authors? Was it pilot    |                   |
| 2                           |          | tested?  |                   |
| Repeat interviews           | 18       | Were repeat inter views carried out? If yes, how many?                   |                   |
| Audio/visual recording      | 19       | Did the research use audio or visual recording to collect the data?      |                   |
| Field notes                 | 20       | Were field notes made during and/or after the inter view or focus group? |                   |
| Duration                    | 21       | What was the duration of the inter views or focus group?                 |                   |
| Data saturation             | 22       | Was data saturation discussed?   |                   |
| Transcripts returned        | 23       | Were transcripts returned to participants for comment and/or             |                   |

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| Торіс   | Item No. | Guide Questions/Description  | Reported<br>Page No |
|---|----------|--|---------------------|
|   |          | correction?  |                     |
| Domain 3: analysis and findings   |          | ·  |                     |
| Data analysis   |          |  |                     |
| Number of data coders   | 24       | How many data coders coded the data?   | _                   |
| Description of the coding tree  | 25       | Did authors provide a description of the coding tree?  | rotected            |
| Derivation of themes  | 26       | Were themes identified in advance or derived from the data?  | eq                  |
| Software  | 27       | What software, if applicable, was used to manage the data?   | by c                |
| Participant checking  | 28       | Did participants provide feedback on the findings?   |                     |
| Reporting   |          |  |                     |
| Quotations presented  | 29       | Were participant quotations presented to illustrate the themes/findings?<br>Was each quotation identified? e.g. participant number | rigni, including    |
| Data and findings consistent  | 30       | Was there consistency between the data presented and the findings?   | 4                   |
| Clarity of major themes   | 31       | Were major themes clearly presented in the findings?   |                     |
| Clarity of minor themes   | 32       | Is there a description of diverse cases or discussion of minor themes?   |                     |
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 Clarity of minor themes
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 Is there a description of diverse cases or discussion of minor themes?
 Image: Clarity of minor themes?

 Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklis for interviews and focus groups. International Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349 – 357
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# The effect of religion on the perception of health states amongst adults in the United Arab Emirates: a qualitative study

| Journal:                             | BMJ Open   |
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| <b>Primary Subject<br/>Heading</b> : | Qualitative research   |
| Secondary Subject Heading:           | Health economics   |
| Keywords:                            | QUALITATIVE RESEARCH, Islam, United Arab Emirates, Cost-Effectiveness<br>Analysis, Patient Reported Outcome Measures   |
|                                      |  |

SCHOLARONE<sup>™</sup> Manuscripts

The effect of religion on the perception of health states amongst adults in the United Arab Emirates: a qualitative study
Iffat Elbarazi<sup>1</sup>, Nancy J. Devlin<sup>2</sup>, Marina-Selini Katsaiti<sup>3</sup>, Emmanuel A. Papadimitropoulos<sup>4</sup>, Koonal K. Shah<sup>2</sup>, Iain Blair<sup>1</sup>

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# ABSTRACT

**Objectives:** Investigate how religion may affect the perception of health states amongst adults in the United Arab Emirates and the implications for research on self-reported health and quality of life and the use of values in cost effectiveness analysis.

Design: Qualitative analysis of short structured interviews with adult Emiratis carried out by a market research agency.

Setting: Participants were recruited from shopping malls and other public places in the cities of Al Ain and Abu Dhabi.

**Participants:** Two hundred adult Emiratis broadly representative of the Emirati population in terms of age and gender.

**Results:** Eighty one percent of participants said that their perception of health states was influenced by their spiritual or religious beliefs. The two overarching themes that seemed to explain or classify these influences were "fatalism" and "preservation of life". Sub-themes included powerlessness to change what is pre-ordained by God, fear of disability (particularly diminished mobility) and appreciation of health and life and the requirement to look after one's health. A final theme was that of acceptance, with respondents expressing a willingness to endure suffering and disability with patience in the expectation of rewards in the hereafter. **Conclusions:** Our results emphasize the need for further work to establish locally relevant value sets for Muslim majority countries in the Middle East and elsewhere for use in HTA decision making, rather than relying on value sets from other regions.

#### Key words

Qualitative Research, Islam, United Arab Emirates, Patient Reported Outcome Measures, Cost-Effectiveness Analysis

# **Article Summary**

| S | Strengths and limitations of this study   |  |  |
|---|---|--|--|
| • | Health-related quality-of-life (HRQOL) measures are routine in health technology assessment         |  |  |
|   | (HTA) and health outcomes research but the health value sets on which they are based differ         |  |  |
|   | between countries due to social, cultural and particularly religious factors. The need for country  |  |  |
|   | specific value sets is particularly important in Muslim majority countries, such as the United Arab |  |  |
|   | Emirates (UAE), where the population may think differently about the trade-offs between health,     |  |  |
|   | length of life, and death. This is one of the few studies to address these differences.             |  |  |
| • | This qualitative study involved Emirati adults living in the Emirate of Abu Dhabi (the cities of Al |  |  |
|   | Ain and Abu Dhabi). However our respondents were younger and more-educated than the general         |  |  |

- Emirati population of Abu Dhabi. Also Emiratis from the other six emirates were not included. Our finding therefore cannot be generalized to the whole of the UAE Emirati population. Also the findings from our study cannot be applied with certainty to other Muslim Arab populations in other countries.
- The assessment of the impact of "spiritual or religious views" on the perception of health states . was limited to one open-ended question asked via a self-administered survey. This will inevitably affect the validity of our results and the strength of our conclusions.
- In a study with this design there will be both interviewer and response bias. In addition there is bias • associated with the study design and the experience and judgment of the principal researchers when analyzing and interpreting the data.
- . Finally, the UAE, as a high income Middle East country has a very specific set of social characteristics. Our findings can only be interpreted within the context of those characteristics.

# INTRODUCTION

Use of health-related quality-of-life (HRQOL) measures is routine in health technology assessment (HTA) and health outcomes research. Many such measures are available. The EQ-5D, a short questionnaire developed by the EuroQol Group, is widely used by HTA agencies, including the United Kingdom's National Institute for Health and Care Excellence.<sup>1, 2</sup> The EO-5D was initially developed for English-speaking populations but has since been translated so that there are now over 176 EQ-5D language versions.<sup>3</sup> EQ-5D describes health in terms of five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). The EQ-5D-3L grades each dimension on one of three levels of severity (no, some and extreme), while the newer five level variant (EQ-5D-5L) uses five levels of severity, thereby defining  $(5^{5})$  3125 unique health states.<sup>4</sup> In order to be used to support cost-effectiveness analyses, the EQ-5D must be accompanied by 'value sets' which summarize how good or bad each unique health state is on a scale anchored at 1 (full health) and 0 (dead). These value sets are derived by assessing the stated preferences of the general population. A variety of methods are available for this including the time trade-off (TTO), which involves asking survey respondents to evaluate health states,<sup>5,6</sup> and discrete choice experiments (DCE), which in its simplest form involves a pairwise choice between two states. Views about health may differ between countries due to social, cultural and religious factors, and so country specific value sets are needed.<sup>7</sup>

The need for country specific value sets is particularly important in Muslim majority countries such as the United Arab Emirates (UAE). Differences in the religious beliefs of the population will lead to very different ways of thinking about the trade-offs between health, length of life, and death compared to non-Muslim countries. The UAE is unique in its health needs as well as in the medical seeking behavior of its people and the cultural effects on their health.<sup>8</sup> Although EQ-5D-5L value sets have been or are currently being developed in countries such as England, Canada, and China, and there is research evidence that Arabic versions of the EQ-5D-3L are valid and reliable in measuring quality of life in Jordan <sup>9</sup> and Morocco, <sup>10</sup> no local value sets for the EQ-5D-3L or EQ-5D-5L are available in the UAE or elsewhere in the Gulf region.<sup>11</sup> Following calls for research on HRQOL assessment in Arabic countries, we carried out TTO and DCE valuation exercises amongst a sample of 200 adult Emiratis and concluded that the methods were appropriate and feasible.<sup>12</sup> However, in that study there was evidence of striking

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differences in the way that Emiratis valued health states compared to other cultural groups, namely a reluctance to consider that a health state could be "worse than dead". Furthermore, pain/discomfort and anxiety/depression were ranked as the least important dimensions of health, in contrast to findings in England and elsewhere. <sup>7, 13</sup>

To our knowledge there have been no previous studies that have explored the influence of spiritual or religious beliefs on the perception of health states amongst Muslims. A study was conducted in Tunisia on TTO utilities with rheumatoid arthritis patients but this study did not investigate the influence of religion or culture.<sup>14</sup> Therefore, as part of our study we explored respondents' feelings when asked to value different health states and what influence their spiritual or religious beliefs may have had on their responses. The purpose of this paper is to present the results of those additional enquiries and provide further detailed insights into (a) how spiritual or religious beliefs may affect the perception of health states amongst Emiratis and (b) the implications of our findings for research on self-reported health and quality of life in the region and for the use of values in cost effectiveness analysis.

#### Methods

The methods have been described previously but, in summary, interviews were conducted with adult Emiratis in Abu Dhabi and Al Ain.<sup>12</sup> The target sample size was 200 respondents and data collection was carried out by Ipsos Observer, a market research agency. Participants were Emirati citizens residing in the Emirate of Abu Dhabi. Of the one million Emiratis in the UAE, about 40% live in Abu Dhabi.<sup>15</sup> Emiratis are predominantly Arab and Muslim. It is acknowledged that our participants are not representative of all Arab Muslims or of all Emiratis. However for simplicity we refer to them in this paper as Emiratis. A convenience sampling approach was used, whereby members of the public were approached in shopping malls and other public places by recruiters working for Ipsos Observer. Information sheets (both in English and in Arabic) were provided and interview appointments were made for those who expressed an interest in participating. A sample that was broadly representative of the Emirati population in terms of age and gender was sought. Each respondent completed a valuation questionnaire administered within a computer-assisted personal interview (CAPI) in accordance with the EuroQol protocol.<sup>5</sup> Each questionnaire comprised TTO and DCE tasks, feedback questions and

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an (optional) open-ended comment box. After completing the valuation questionnaire, respondents were asked further "debrief" questions focusing on their experience of completing the valuation tasks via a self-completed survey that included closed and open-ended questions (Table 1). Participants' responses to these questions provided us with the data for the qualitative study reported here. Specifically we used the answers to the open-ended question about the extent to which participants' answers were influenced by their spiritual or religious views in our analysis. Since we wished to investigate participants' own perspectives on the ways in which their religiosity and spirituality might influence their perception of health states we used a descriptive, qualitative study design. Data was collected in December 2013 in Arabic and responses were later translated into English. The study was approved by the Al Ain Medical District Human Research Ethics Committee in November 2013(N.13/82) and informed consent was obtained (using paper consent forms) from all respondents prior to their participation in the study.

#### Analysis

Thematic analysis was used to identify themes related to the influence of spiritual or religious beliefs on the perception of health states by the respondents.<sup>16</sup> Responses were first transcribed verbatim (by Ipsos Observer) and were then analyzed systematically by two authors (IE and IB) working independently. The data was coded and organized into emerging themes and subthemes. Following a discussion of themes by all members of the study team, a final index was synthesized by one author (IE) acting as a content expert with detailed knowledge of Islamic faith health considerations. Direct quotes from respondents are presented where this is useful to provide additional insights or to illustrate the themes that emerged. Using an inductive approach the emergent themes were used to make inferences about the way in which spiritual or religious beliefs will affect the perception of health states. The study reported here was part of a pilot study, the primary purpose of which was to investigate the feasibility and cultural appropriateness of stated preference methods to generate EQ-5D-5L values in the United Arab Emirates. The target sample size for this pilot study was 200 and this provided 88 completed interviews for the qualitative element of the study. This figure is pragmatic rather that theoretical but in the authors' opinion will provide data of sufficient quality and quality to provide for data saturation. Indeed the final finite themes emerged promptly during the data analysis.

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| No. | Question                            | Response type                                       |
|-----|-------------------------------------|---|
| 1   | Was there anything in the survey    | Open ended  |
|     | that made you feel uncomfortable?   |   |
| 2   | What did you like or dislike about  | Open ended  |
|     | the survey?                         |   |
| 3   | Do you have any suggestions for     | Open ended  |
|     | improving the survey and making it  |   |
|     | more relevant for people like you?  |   |
| 4   | To what extent were your answers to | Closed ended, pre-coded categorical                 |
|     | the questions influenced by your    | [0 = no answer selected; 1 = not influenced at all; |
|     | spiritual or religious beliefs?     | 2 = somewhat influenced; 3 = heavily influenced]    |
| 5   | Please explain how.                 | Open ended  |

Table 1. Further questions from which data on respondents' opinions are available.

#### Results

As previously reported,<sup>12</sup> the final sample comprised 200 respondents and complete background demographic data was available for 166 of these. Background data are unavailable for the remaining 34 respondents due to a recording error but it is not expected that the missing respondents will differ systematically from the rest of the sample. In their answers to open-ended questions No. 1-3, some participants mentioned that they disliked the sensitive nature of the questions or took issue with fundamental aspects of the valuation methods, for example choosing to give up time or having to choose between two health states. Others reported feeling uncomfortable with the questions such as the idea of imagining living with some disability or other condition and thinking about illness and death. However one participant stated: "Living in a wheelchair and living with severe problems moved me because in our religion we believe in fate". Others indicated that they liked the questionnaire because it made them reflect on their current life and made them appreciate health and life being a precious gift and an Amana (meaning in English: something to be trusted and protected) from God that one should protect: "I liked the survey because it made me think about the gifts I have". Amongst the 116 respondents

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who answered the question "To what extent were your answers affected by your spiritual or religious beliefs", 22 (19%) replied "not influenced at all", 60 (51%) replied "somewhat influenced" and 34 (30%) replied "heavily influenced". Of the 94 respondents who said that they were "somewhat, or heavily influenced", 88 provided an answer to open-ended question No.5. Their characteristics are summarized in Table 2. 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.<sup>17</sup> 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.<sup>18</sup> All of the respondents were Muslim. Participants' responses in general were short and did not require detailed interpretation. From the 88 responses to question 5, 146 themes were discerned. The recurring themes were apparent very clearly and were classified into two major categories each with three sub-themes (Table 3). These are discussed in turn in the following section.

| Characteristic      | n  | %      |   |
|---------------------|----|--------|---|
| Total               | 88 | 100.0% |   |
| Gender              |    |        |   |
| Male                | 43 | 48.9%  |   |
| Female              | 45 | 51.10% |   |
| Age group (years)   |    |        | 2 |
| Under 30            | 18 | 20.58% |   |
| 30-39               | 44 | 50.0%  |   |
| 40-49               | 18 | 20.5%  |   |
| 50 and over         | 7  | 7.9%   |   |
| No answer given     | 1  | 1.1%   | _ |
| Marital status      |    |        | _ |
| Single              | 31 | 35.2%  | _ |
| Married             | 51 | 58.0%  |   |
| Divorced or widowed | 2  | 2.3%   | - |
| No answer given     | 4  | 4.5%   | - |

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| Employment status               |    |       |
|---------------------------------|----|-------|
| Homemaker / housewife           | 21 | 23.9% |
| Retired / student / not working | 13 | 14.8  |
| Working part time               | 14 | 15.9% |
| Working full time               | 32 | 36.4% |
| No answer given                 | 8  | 9.1%  |
| Education                       |    |       |
| No education                    | 6  | 6.8%  |
| Schooling but no university     | 5  | 5.7%  |
| Current university student      | 14 | 15.9% |
| Graduate                        | 58 | 65.9% |
| No answer given                 | 5  | 5.7%  |

Note. Percentages do not always sum to 100% because of missing values and rounding.

| Theme (n=146)   | Sub-themes                      | Examples                                  |
|-----------------|---------------------------------|---|
| Fatalism        | Inevitability and invincibility | Destiny is determined by God              |
| (95)            | (63)                            | • Death and illness flow from God         |
|                 | Powerlessness, helplessness or  | • Reminder that illness is in the hands   |
|                 | submission (6)                  | of God and He is the one who grants       |
|                 |                                 | or punishes                               |
|                 | Unacceptance of certain ideas   | Unacceptability of making choice          |
|                 | (23)                            | between death and illness                 |
|                 |                                 | • Unacceptability of consciously          |
|                 |                                 | avoiding death which is in God's          |
|                 |                                 | power.                                    |
| Preservation of | Appreciation (33)               | • Reminder of death and judgment day      |
| life            |                                 | • Reminder to become more religious       |
| (51)            |                                 | • Reminder to look after our health.      |
|                 |                                 | • Reminder that life is short and illness |
|                 |                                 | or death can happen at any time, and      |

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|                              |   | thus appreciation and importance of |
|------------------------------|---|-------------------------------------|
|                              |   | the preservation of life.           |
| Fear (5)                     | ٠ | Fear of death                       |
|                              | • | Fear of disability/illness          |
| Acceptance and patience (13) | • | To accept disability.               |
| •                            |   |                                     |

Note: numbers in parentheses are the number of responses that were classified according to each category

#### **Theme 1. Fatalism**

Under the concept of fatalism we identified three subthemes. First, the sub-theme of inevitability and invincibility which strongly emphasized how individual life conditions heavily depend on God and are thus inevitable. Several individual statements express this belief, examples of which are the following: "I believe in destiny and everything is in the hands of God", "because we believe that destiny is set by God". The second sub-theme is the concept of powerlessness, helplessness or submission. Respondents stated their powerlessness and helplessness with respect to their health condition and that they can only submit to God and accept his will. The following statements are examples of these beliefs: "Because destiny is preordained by God and it is impossible to imagine death or life and illness" and "Because these questions are related to the power of God, He who grants and assists". Many participants used quotes from the prophet of Islam (Muhammad) that indicate that life and death are in God's hands. Some participants also used some of the known names or characteristics of God (Allah) in their replies namely "The All Powerful (القادر)" and "The Creator of All Power (المقتدر)". These two names or description of Allah are usually known to be amongst the 99 names of Allah referred to in the Quran. Also the word or the name of "the One who cures and heals" was also quoted by many of the participants ) referring to the belief that it is Allah who cures all ailments which is also taken from the reported sayings of the prophet. The third "fatalism" sub-theme was the "unacceptability of certain ideas". Participants highlighted in their answers the unacceptability of i) choosing between death and illness, and ii) consciously avoiding death, which is in God's power. Some respondents who felt that the survey made them uncomfortable mentioned the following reasons: "I was always trying not to choose death", "Many questions made me feel uncomfortable, especially when you have to choose between death and living with a chronic disease".

### Theme 2. Preservation of Life

Under this second main theme we also identified three sub-themes: appreciation, fear and acceptance and patience. Respondents made comments expressing appreciation for their life and health, noting that the questions had reminded them to be more religious. The TTO and the DCE exercises reminded the respondents of how important good health is, and made them express their gratitude to God for granting them good health. It also made them appreciate health in general. Examples were: "Health is the most important blessing that the Lord has granted us", "I was touched by the fact that some people suffer from many diseases and that's why I thank God for my good health", "Life is beautiful and we should preserve it and preserve our health in order to enjoy its beauty". Participants appeared to have a fear of disability and diminished mobility since in the ranking exercise, they ranked mobility as the most important aspect of health. The concept of punishment for bad actions in life as being one of the causes of illness, disability and death also appeared in participants' responses: "I remembered the existence of the day of reckoning after death", "Because illness is in the hands of God the Great and Almighty; He is the one who punishes us or helps us". Respondents also revealed acceptance and patience in the way they view life. These are discernible elements in the Muslim religion and become fundamental components when faced with life challenges. Examples of this final sub-theme are: "There is no 100% healthy life but one has to live with the illness anyway" and "We live life in its good and bad".

#### Discussion

This study has shown that spiritual or religious beliefs have an important effect on the way that Emiratis think and respond to the stated preference tasks commonly used to value health states. We found that the responses of over three quarters of respondents were influenced by their spiritual or religious views. Although our study used only the EQ-5D, the factors outlined in this paper are likely to effect the valuation of other HRQOL measures.<sup>19</sup> In our study, fatalism and preservation of life were the two overarching concepts that influenced participants' perception of health states. Our results are comparable with other findings reported in the literature on the role of religion in health valuations, behaviors and outcomes.<sup>19, 20</sup> For example, in the study by Gowani, a conceptual framework of factors affecting non-communicable disease preventive

behaviors is proposed including fatalism, invincibility and fear of premature death. In agreement with these results, our respondents also referred to the concept of destiny and their belief that health, life, and death are in God's hands. In contrast, Rasool discusses Muslims' belief of acceptance rather than fatalism, as for Muslims, suffering and dying are considered a test from Allah: 'Be sure we shall test you with something of fear, hunger, some loss In wealth, lives or the produce, but give glad tidings to those who patiently persevere (Al-Bagarah 2:155).<sup>21</sup> Acceptance and patience was a prominent theme in our study, suggesting that Emiratis might be more submissive and accepting of the idea of death and illness. In earlier studies, Athar had explained that illness, for Muslims, is an atonement for their sins and will help them meet God cleansed of their sins. <sup>22, 23</sup> This was also a theme that featured in our study. Participants in the Gowani study perceived themselves to be invincible and lacking any great appreciation of the threats to their health and in agreement with our study they referred to preordained fate as the main factor influencing health and illness. However, in contrast to our study, Gowani does not mention the role of God in people's lives. Both studies identify a fear of premature death but while in the Gowani study, fear of death appears to be an instrument toward preventive and selfcare behaviors, in our study it is seen as a reminder to value and preserve health as a gift from God.

Our study has a number of limitations. Our respondents were younger and more-educated than the general Emirati population of Abu Dhabi and Emiratis from the other six emirates were not included so our finding therefore cannot be generalized to the whole of the UAE Emirati population. Also the findings from our study cannot be applied with certainty to other Muslim Arab populations in other countries. The assessment of the impact of "spiritual or religious views" on the perception of health states was limited to one open-ended question asked via a self-administered survey. This will inevitably affect the validity of our results and the strength of our conclusions. In a study with this design there will be both interviewer and response bias and bias associated with the study design and the experience and judgment of the principal researchers when analyzing and interpreting the data. Finally, the UAE, as a high income Middle East country has a very specific set of social characteristics. Our findings can only be interpreted within the context of those characteristics.

Our study captured responses to two stated preference tasks, TTO and DCE. Some of the concepts identified relate to both tasks (e.g. concept of appreciation and concept of acceptance and patience) and would apply equally to other approaches that are used for valuing HRQOL (e.g. visual analogue scale and standard gamble). Other concepts and issues (e.g. concept of fear, rejection of the idea of trading time) appeared to be more specific to the trade-offs required in TTO than to the DCE tasks but would be equally pertinent to variants of the DCE involving duration, and in some cases to the standard gamble. Nevertheless, our earlier study demonstrated that it is feasible and culturally appropriate to carry out studies and derive value sets in Muslim Arab populations using existing methodologies. However, there are a number of ways in which the methods could be adapted for use in these populations, such as an increased emphasis in the instructions that the tasks are not intended to cause conflict with respondents' spiritual or religious beliefs.

Our study has shown that religious and spiritual beliefs will influence the values generated from health preference exercises and their use in cost effectiveness analyses amongst Emiratis. Specifically health states involving disability may be given lower values than those involving pain and anxiety and depression. Also, overall HRQOL scores amongst Emiratis may be higher than those in other populations because an aversion to contemplating health states as "worse than death". These factors will have an important effect on efforts to develop value sets for HRQOL measures. Understanding the effect of spiritual or religious beliefs on respondents' reactions to valuation tasks will be important in adapting the valuation methods that are currently in use. Below, we detail aspects of the Islamic faith likely to be of particular importance in this respect.

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### Islamic beliefs and their influence on health state perception

There are many teachings that influence the views of Muslims about health, illness, and dying. Muslims believe in the absolute timeless knowledge of God (Al Qadaa wal Qadar), fate and destiny, and the supreme power of God over human life. Belief in fate and destiny are also fundamental beliefs of the 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 Muhammad describe the preservation of life and health as being an act

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of worship and being highly praised by God.<sup>24</sup> The Quran encourages Muslims to accept illness, suffering, and dying with patience.<sup>21</sup> Moreover, Islam teaches that calamities can absolve the sins of a pious Muslim. These concepts can influence Muslims' perception of dying and illness and their preferences over different health outcomes. Muslims are strongly encouraged to seek treatment and care and are discouraged from pursuing illness.<sup>21</sup> 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.<sup>25</sup> Ahmad and Harrison argue that religion continues to be defined as a cultural identity which influences knowledge, attitude and practice including health beliefs and behaviors.<sup>26</sup> Therefore, it is important to remember that health promotion programs and efforts to improve health should remain cognizant of cultural and religious beliefs particularly within Islamic communities. Our study reinforces this principle and also points to the importance of spiritual or religious beliefs in other areas of public health activity including perception of health states and HTA. Ahmad and Harrison also discuss the concept of fear as being a motivation for health related actions. They hypothesize that religion may increase responsiveness to fear-arousing messages that will lead eventually to lower health risks. Clearly, religion influences morality, ideology and decision making <sup>27</sup> and the concept of fear amongst Muslims has been recommended by some researcher to be used and integrated in health promotion models designed for Muslim communities.<sup>19, 25, 28</sup> The notion of acceptance, submission, fatalism and inevitability lead Muslims to value health as being a gift from God and endure suffering and disability with patience and acceptance in expectation of better rewards in the hereafter. Researchers must be aware of all of these aspects of spiritual and religious beliefs that will influence perception of health states in Muslim populations.

#### Conclusions

Our 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. We also recommend further exploration of how people in the UAE and other, predominantly, Muslim countries interpret the concept of "worse than dead" health states, and whether alternatives to TTO may be more appropriate for these populations.

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# Contributors

NJD, KKS and EAP designed the study. KKS, EAP and IE analysed and interpreted the data with input from NJD and MSK. IB and IE wrote the first draft. IB is the guarantor. All authors revised it critically for important intellectual content and approved the final version for publication. All authors agree to be accountable for all aspects of the work.

# **Competing interests**

EAP is an employee of Eli Lilly and Company

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Data sharing statement

November 2013, N.13/82).

Provenance and peer review

**Research reporting checklists:** 

Not commissioned; externally peer reviewed.

**Ethical approval** 

No additional data are available.

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The study was approved by the Al Ain Medical District Human Research Ethics Committee in

The COREQ criteria have been used where appropriate to guide the reporting of our findings.

This study was funded by an unrestricted research grant by Eli Lilly and Company

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# Acknowledgement

Permissions

Not applicable

None

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# Table 1

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| No   | Item                        | Guide questions/description                                 | Response   |
|--|-----------------------------|---|--|
| Domain 1:<br>Research team<br>and<br>reflexivity |                             |   |  |
| Personal<br>Characteristics                      | 0                           |   |  |
| 1.   | Interviewer/<br>facilitator | Which author/s conducted the interview or focus group?      | Not applicable, interviews carried out by professional interviewers  |
| 2.   | Credentials                 | What were the researcher's credentials? <i>E.g. PhD, MD</i> | DrPH and MD  |
| 3.   | Occupation                  | What was their occupation at the time of the study?         | Research assistant and public health academic  |
| 4.   | Gender                      | Was the researcher male or female?                          | There were both male and female researchers  |
| 5.   | Experience and training     | What experience or training did the researcher have?        | The interviews were undertaken by a small<br>team of professional interviewers who had<br>completed a three-day training course on the<br>specifics of the methodology and procedures<br>for the study, but had no prior experience in<br>health state valuation.<br>The interviews took place in hotel conference<br>rooms and the offices of the fieldwork agency.<br>The interviewers were instructed to guide<br>respondents through each element of the<br>valuation questionnaire, closely following an<br>interview script. The capturing and time-<br>stamping of all respondent actions via EQ-VT<br>provided data on elements such as how long<br>the interviewers had spent explaining the TTO<br>exercise to respondents using the warm-up<br>tasks. It was agreed with the agency that any<br>valuation data collected would be kept only if<br>the data confirmed that the interviewer had<br>adhered to the protocol and covered all<br>elements as instructed. Interviewers spent at<br>least 15 minutes with each respondent,<br>explaining the questions and the rationale<br>behind the study. Respondents were reassured |

|      | pe     |    |
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| Page | 22.70f | 26 |

|                                   |  |   | that the questions were not intended to<br>challenge or cause conflict with their beliefs<br>and faith.  |
|-----------------------------------|--|---|--|
| elationship<br>ith<br>irticipants |  |   |  |
|                                   | Relationship<br>established                    | Was a relationship established prior to study commencement?   | No   |
|                                   | Participant<br>knowledge of<br>the interviewer | What did the participants know about the researcher? e.g. <i>personal goals, reasons for doing the research</i>   | Participants had no prior knowledge about the researcher? e.g. personal goals, reasons for doing the research  |
|                                   | Interviewer<br>characteristics                 | What characteristics were reported<br>about the interviewer/facilitator? e.g.<br><i>Bias, assumptions, reasons and</i><br><i>interests in the research topic</i>            | Not applicable, see above  |
| omain 2:<br>udy design            |  |   |  |
| heoretical<br>amework             |  | CC.   |  |
|                                   | Methodological<br>orientation and<br>Theory    | What methodological orientation was<br>stated to underpin the study? <i>e.g.</i><br>grounded theory, discourse analysis,<br>ethnography, phenomenology, content<br>analysis | No         Participants had no prior knowledge about the researcher? e.g. personal goals, reasons for doing the research         Not applicable, see above         Phenomenology       |
| articipant<br>lection             |  |   |  |
| ).                                | Sampling                                       | How were participants selected? <i>e.g.</i><br><i>purposive, convenience, consecutive,</i><br><i>snowball</i>   | A convenience sampling approach was used,<br>whereby members of the public were<br>approached in shopping malls and other public<br>places by recruiters working for Ipsos<br>Observer |
|                                   | Method of<br>approach                          | How were participants approached?<br>e.g. face-to-face, telephone, mail,<br>email   | Potential participants were approached directly, face-to-face  |
| 2.                                | Sample size                                    | How many participants were in the study?  | The target sample was 200. Data was available on 134.  |
| 8.                                | Non-   | How many people refused to  | The sample comprised 200 respondents but   |

|  | participation                       | participate or dropped out? Reasons?   | complete background demographic data was<br>unavailable for 34 due to a recording error. (<br>the 166, 134 provided data for the qualitativ<br>study                                |
|--|-------------------------------------|--|---|
| Setting                                |                                     |  |   |
| 14.                                    | Setting of data collection          | Where was the data collected? e.g. home, clinic, workplace                               | Respondents were recruited in shopping mal<br>and other public places. The interviews took<br>place in hotel conference rooms and the<br>offices of the fieldwork agency            |
| 15.                                    | Presence of<br>non-<br>participants | Was anyone else present besides the participants and researchers?                        | No  |
| 16.                                    | Description of sample               | What are the important characteristics of the sample? <i>e.g. demographic data, date</i> | Broadly representative of adult Emiratis<br>(citizens of the United Arab Emirates)  |
| Data collection                        |                                     |  |   |
| 17.                                    | Interview<br>guide                  | Were questions, prompts, guides<br>provided by the authors? Was it pilot<br>tested?      | Questions were provided. The interviewers<br>were instructed to guide respondents through<br>each element of the valuation questionnaire,<br>closely following an interview script. |
| 18.                                    | Repeat<br>interviews                | Were repeat interviews carried out? If yes, how many?                                    | No  |
| 19.                                    | Audio/visual recording              | Did the research use audio or visual recording to collect the data?                      | Computer-assisted personal interview (CAPI<br>was used  |
| 20.                                    | Field notes                         | Were field notes made during and/or after the interview or focus group?                  | No  |
| 21.                                    | Duration                            | What was the duration of the interviews or focus group?                                  | Minimum of 15 minutes   |
| 22.                                    | Data saturation                     | Was data saturation discussed?   | Yes.  |
| 23.                                    | Transcripts<br>returned             | Were transcripts returned to<br>participants for comment and/or<br>correction?           | No  |
| Domain 3:<br>analysis and<br>findingsz |                                     |  |   |

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| Data analysis |                                    |  |   |
| 24.           | Number of data coders              | How many data coders coded the data?   | Two   |
| 25.           | Description of the coding tree     | Did authors provide a description of the coding tree?  | No  |
| 26.           | Derivation of themes               | Were themes identified in advance or derived from the data?  | Derived from data   |
| 27.           | Software                           | What software, if applicable, was used to manage the data?   | Software was not used   |
| 28.           | Participant<br>checking            | Did participants provide feedback on the findings?   | No  |
| Reporting     |                                    | 0  |   |
| 29.           | Quotations<br>presented            | Were participant quotations presented<br>to illustrate the themes / findings?<br>Was each quotation identified? e.g.<br>participant number | Yes, but participant numbers were not given   |
| 30.           | Data and<br>findings<br>consistent | Was there consistency between the data presented and the findings?   | The authors believe so  |
| 31.           | Clarity of major themes            | Were major themes clearly presented in the findings?   | The authors believe so  |
| 32.           | Clarity of<br>minor themes         | Is there a description of diverse cases or discussion of minor themes?   | Sub-themes are discussed  |
|               |                                    |  | Image: Page         Image: Im |
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#### **BMJ Open**

# COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

pen: first published as 10.1 A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

| Торіс                                      | Item No. | Guide Questions/Description  | Reporte<br>Page |
|--|----------|--|-----------------|
| Domain 1: Research team<br>and reflexivity |          | ·  | 1               |
| Personal characteristics                   |          |  |                 |
| Interviewer/facilitator                    | 1        | Which author/s conducted the interview or focus group?   |                 |
| Credentials                                | 2        | What were the researcher's credentials? E.g. PhD, MD   |                 |
| Occupation                                 | 3        | What was their occupation at the time of the study?  |                 |
| Gender                                     | 4        | Was the researcher male or female?   |                 |
| Experience and training                    | 5        | What experience or training did the researcher have?   |                 |
| Relationship with<br>participants          |          |  |                 |
| Relationship established                   | 6        | Was a relationship established prior to study commencement?  |                 |
| Participant knowledge of the interviewer   | 7        | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research   |                 |
| Interviewer characteristics                | 8        | What characteristics were reported about the inter viewer/facilitator?<br>e.g. Bias, assumptions, reasons and interests in the research topic            |                 |
| Domain 2: Study design                     |          |  |                 |
| Theoretical framework                      |          |  |                 |
| Methodological orientation<br>and Theory   | 9        | What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis |                 |
| Participant selection                      |          |  |                 |
| Sampling                                   | 10       | How were participants selected? e.g. purposive, convenience, consecutive, snowball   |                 |
| Method of approach                         | 11       | How were participants approached? e.g. face-to-face, telephone, mail, email  |                 |
| Sample size                                | 12       | How many participants were in the study?   |                 |
| Non-participation                          | 13       | How many people refused to participate or dropped out? Reasons?  |                 |
| Setting                                    |          |  |                 |
| Setting of data collection                 | 14       | Where was the data collected? e.g. home, clinic, workplace   |                 |
| Presence of non-<br>participants           | 15       | Was anyone else present besides the participants and researchers?  |                 |
| Description of sample                      | 16       | What are the important characteristics of the sample? e.g. demographic data, date  |                 |
| Data collection                            | 1        | 1  |                 |
| Interview guide                            | 17       | Were questions, prompts, guides provided by the authors? Was it pilot tested?  |                 |
| Repeat interviews                          | 18       | Were repeat inter views carried out? If yes, how many?   |                 |
| Audio/visual recording                     |          |  |                 |
| Field notes 20                             |          | Were field notes made during and/or after the inter view or focus group?   |                 |
| Duration                                   | 21       | What was the duration of the inter views or focus group?   |                 |
| Data saturation                            | 22       | Was data saturation discussed?   |                 |

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| Торіс                        | Item No.      | n No. Guide Questions/Description  |        |
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|                              |               |  | Page N |
|                              |               | correction?  |        |
| Domain 3: analysis and       |               |  |        |
| findings                     |               |  |        |
| Data analysis                |               |  |        |
| Number of data coders        | 24            | How many data coders coded the data?   |        |
| Description of the coding    | 25            | Did authors provide a description of the coding tree?  |        |
| tree                         |               |  |        |
| Derivation of themes         | 26            | Were themes identified in advance or derived from the data?  |        |
| Software                     | 27            | What software, if applicable, was used to manage the data?   |        |
| Participant checking         | 28            | Did participants provide feedback on the findings?   |        |
| Reporting                    |               |  |        |
| Quotations presented         | 29            | Were participant quotations presented to illustrate the themes/findings?   |        |
|                              |               | Was each quotation identified? e.g. participant number   |        |
| Data and findings consistent | 30            | Was there consistency between the data presented and the findings?   |        |
| Clarity of major themes      | 31            | Were major themes clearly presented in the findings?   |        |
| Clarity of minor themes      | 32            | Is there a description of diverse cases or discussion of minor themes?   |        |
| Once you have completed the  | is checklist, | ig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-ite<br>onal Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349<br>please save a copy and upload it as part of your submission. DO NOT includ<br>document. It must be uploaded as a separate file. |        |

 Clarity of minor themes
 32
 Is there a description of diverse cases or discussion of minor themes?
 Image: Clarity of minor themes?

 Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklis for interviews and focus groups. International Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349 – 357
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 Training, Attaining, and similar recomogies.