## PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (http://bmjopen.bmj.com/site/about/resources/checklist.pdf) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

# **ARTICLE DETAILS**

TITLE (PROVISIONAL)	The effect of religion on the perception of health states amongst
	adults in the United Arab Emirates: a qualitative study
AUTHORS	Elbarazi, Iffat; Devlin, N; Katsaiti, Marina-Selini; Papadimitropoulos,
	Emmanuel; Shah, Koonal, Blair, Iain.

### **VERSION 1 - REVIEW**

REVIEWER	Phantipa Sakthong Chulalongkorn University, Thailand
REVIEW RETURNED	11-May-2017

GENERAL COMMENTS	This paper is interesting but I have following comments. Introduction:
	- I don't' see the gap of knowledge of this study in the literature. Are
	there any other studies exploring the same topic in Muslim world?  How does your study differ from them? Or your study is the first
	study to do it?
	Methods:
	- Did written informed consent obtain from participants?
	- Which sampling was used and how to approach?
	- Please show the data saturation.
	There are many things that you reported in COREQ but you did write in manuscript.
	Results:
	- You should report patients' characteristics of the respondents.
	- You should report open-ended questions of no.1-3 and link to no.4-5
	- You should tell the number of the respondents in each theme and sub-themes.
	- I would like to see the linkage between the effect of culture and
	religion on health state utilities rather than health state perception.
	Discussions:
	- How about limitations?
	Conclusion:
	- You wrote that alternatives to TTO may be more appropriate for
	your populations but I don't see it clearly or connection from the
	results.

REVIEWER	Fatima Al Sayah
	University of Alberta, Canada
REVIEW RETURNED	18-May-2017

### **GENERAL COMMENTS**

### Major:

- The authors indicate that the objective was to investigate how "culture and religion" affect perception of health states; however, in the methods section, there is no mention of any questions pertaining to culture; in the five questions outlined in table 1, there is only one question about "spiritual religious views" and none about culture. I suggest that authors remove the term "culture" from describing the objective as well as in the methods, results and discussion sections (where they refer to culture), as cultural beliefs/practices were not assessed in this study (neither discussed).
- The authors refer to the participants in this study as "Arab Muslims" in the abstract and throughout this paper. I think this is an inaccurate characterization, as Emirati Muslims do not represent "Arab Muslims". There are 1.8 billion Muslims in the world; a quarter (450 million) in Arab countries, and only 3 million in UAE. This study recruited a sample of 200 Emiratis via convenience sampling, which does not represent "Arab Muslims". Further, there are wide cultural differences among Arab countries that impact the practice of religion. So, I urge the authors to use caution is referring to the participants as Arab Muslims, and instead refer to them as "Emirati Muslims" given the importance of religion in the context of this study.
- The authors refer to using "short structured interviews" in the methods section, which is somewhat inaccurate in this study. The valuation exercises are interview-based, however, the data analyzed in this paper were based on open-ended questions that participants completed on an online platform within the context of the valuation study. Stating that the study used "short structured interviews" implies that an interviewer asked the respondents these questions, which is not the case. I suggest replacing that by saying "data was collected via a self-completed survey that included close and openended questions".
- Analysis section: the statement "thematic analysis was used to define phenomena" need to be revised. Thematic analysis is a form of analysis that is used to examine and identify patterns or themes within data (not to define a phenomena).
- The authors state that the sample was "broadly" representative of the Emirati population. It would be useful for readers to include a table of participant characteristics or at least report these characteristics in the first paragraph of the results section (age, sex, education, income etc...).
- The authors stated "the need for country specific value sets is particularly important in Muslim majority countries.... 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". This statement does not seem to be very accurate, as it implies that the differences in perceptions of health/health valuations result from the governance system (without mentioning of the cultural, contextual, and historical factors). Turkey, for example, is Muslim majority country, yet a secular state; Iran is also a Muslim majority country however, it is a religious/theocratic state. I urge the authors to be very cautious in making such statements as Muslim majority countries vary in many aspects, and I suggest reporting this paper within its specific context i.e. Emirati Muslims in UAE. The authors could propose investigating similar observations in other Muslim-majority countries, for example,

Indonesia which is the largest Muslim country in the world (205 million), and where an EQ-5D valuation study is underway. This would help further mitigate the effect of religious beliefs on health state valuations.

- Results: There seems to be quite a bit of an overlap among the identified themes, particularly themes 1 and 2. Theme 2 seems to be the reverse of theme 1. The concept of "fatalism" is listed under theme 2; however, fatalism is about the belief of inevitability of all events (i.e. theme 1). Further, theme 5 is the "concept of unacceptance of certain ideas" and the sub-themes listed under are the "unacceptability of making a choice between death and illness ... avoiding death which is in God's power"... these concepts all pertain to fatalism, which seems to be the overarching theme across themes 1, 2, and 5. "Preservation of life" is another theme that overarches themes 3 and 4. Both fatalism and preservation of life are key beliefs in the Muslim faith. The authors need to review the themes, and probably collapse them, as the differences are not very clear as is.
- The first sentence in the discussion section is misleading. Again, the authors did not investigate cultural beliefs (there was only one question that asked about spiritual/religious views". The term "Muslim Arabs" need to be replaced by "Muslim Emiratis" throughout the discussion section.
- Discussion, para 1: Referring to the last sentence of this paragraph. Why do the authors think that the effect of religion on health state valuations will affect developing value sets in these populations? Value sets are intended to reflect the health preferences of the population, and these vary widely. Several factors including age, gender and other socio-demographic or cultural factors impact health valuations; why should we worry about the impact of religion? If the developed value set for UAE was influenced by the religious beliefs of Emiratis, then it does reflect their preferences, which is the intent of these value sets.
- The findings need to be discussed in further depth, as the discussion in its current format is a reiteration of the results section. The concepts of fatalism and preservation of life and their effect on perception of health and ultimately impact on health behaviors/outcomes are crucial. The authors can draw on literature on these concepts from other religions. For instance, fatalism is key principle in Hinduism, and preservation of life is key principle in Judaism. There is a vast literature on both.
- Only one paper on fatalism and healthcare behaviors was referred to in the discussion section. There is a large body of literature that examined the role of religion in health perceptions, behaviors and outcomes that the authors can refer to.
- In the discussion section, it was stated "participants in this study perceived themselves as invincible and lack any great appreciation of the threats to their health.... 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"... this characterization of the results seems to be too critical of the participants in this study. Previous literature reported that religious fatalism may be primarily a "coping response" to illness rather than an inhibitory belief. The authors should discuss all possible explanations of the findings that are supported by the literature.
- There are several limitations in this study that the authors need to discuss including: 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, the interpretation of the results without addressing the wider cultural context is not

sufficient, the generalizability of the results etc
Minor: - In the article summary, need to add "Al Ain", not just Abu Dhabi The examples (excerpts from participants) provided in the results section need to be reviewed as some do not fit under the theme they were reported under.

REVIEWER	Pr ZEGGWAGH Amine Ali Faculty of Medicine and Pharmacy - University Moàhammed V -
	Rabat Morocco
REVIEW RETURNED	22-May-2017

GENERAL COMMENTS	The authors explored what influence the religious and cultural beliefs of 166 respondents when asked to value their health states. They conclude that culture and religion may affect the perception of health states amongst Muslim Arabs. The responses were classified into five major themes: Concept of inevitability and invincibility, Concept of powerlessness/helplessness or submission/fatalism, Concept of appreciation, Concept of fear and Concept of acceptance and patience.
	This study is the continuation of previous studies that have led to these questions. The methodolog is correct.
	These results seem to be very interesting and should allow for a better interpretation of the responses to the health assessment questionnaires like EQ-5D.

## **VERSION 1 – AUTHOR RESPONSE**

### Reviewer: 1

1. Introduction: I don't' see the gap of knowledge of this study in the literature. Are there any other studies exploring the same topic in Muslim world? How does your study differ from them? Or your study is the first study to do it?

To our knowledge there have been no previous studies that have explored 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. This is now made clear in the text.

### Methods:

- 2. Did written informed consent obtain from participants? Yes, a sentence confirming this has been added to the text
- 3. Which sampling was used and how to approach? 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.

The text has been changed to make this clear

4. Please show the data saturation. This is now shown.

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 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.

5. There are many things that you reported in COREQ but you did write in manuscript. An updated COREQ statement is attached

#### Results:

- 6. You should report patients' characteristics of the respondents. This is now included. A table has been added
- 7. You should report open-ended questions of no.1-3 and link to no.4-5 We hope this has now been added
- 8. You should tell the number of the respondents in each theme and sub-themes. This has now been added to Table 3.

Fatalism: 95

-inevitability and invincibility: 63

powerlessness, helplessness and submission: 6concept of unacceptance of certain ideas: 23

Preservation of life: 51 -concept of appreciation: 33

-concept of fear: 5

-concept of acceptance and patience: 13

9. I would like to see the linkage between the effect of culture and religion on health state utilities rather than health state perception. We feel that this could be a topic for a future study

#### Discussions:

10. How about limitations? These have now been discussed in more detail.

### Conclusion:

11. You wrote that alternatives to TTO may be more appropriate for your populations but I don't see it clearly or connection from the results.

On page 13 we discuss how our finding might affect the results from the different methods including TTO, DCE and standard gamble. We have also added some text to clarify that it is the choosing between different life expectancies in TTO that may be problematic for these populations.

Reviewer: 2

Major:

- 12. The authors indicate that the objective was to investigate how "culture and religion" affect perception of health states; however, in the methods section, there is no mention of any questions pertaining to culture; in the five questions outlined in table 1, there is only one question about "spiritual religious views" and none about culture. I suggest that authors remove the term "culture" from describing the objective as well as in the methods, results and discussion sections (where they refer to culture), as cultural beliefs/practices were not assessed in this study (neither discussed). We have clarified this by referring only to religion
- 13. The authors refer to the participants in this study as "Arab Muslims" in the abstract and throughout this paper. I think this is an inaccurate characterization, as Emirati Muslims do not represent "Arab Muslims". There are 1.8 billion Muslims in the world; a quarter (450 million) in Arab countries, and only 3 million in UAE. This study recruited a sample of 200 Emiratis via convenience sampling, which does not represent "Arab Muslims". 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 (ref). The other 60% live in the six other Emirates. 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.
- 14. Further, there are wide cultural differences among Arab countries that impact the practice of religion. So, I urge the authors to use caution is referring to the participants as Arab Muslims, and instead refer to them as "Emirati Muslims" given the importance of religion in the context of this study See above
- 15. The authors refer to using "short structured interviews" in the methods section, which is somewhat inaccurate in this study. The valuation exercises are interview-based, however, the data analyzed in this paper were based on open-ended questions that participants completed on an online platform within the context of the valuation study. Stating that the study used "short structured interviews" implies that an interviewer asked the respondents these questions, which is not the case. I suggest replacing that by saying "data was collected via a self-completed survey that included close and openended questions". This has been corrected

## Analysis section:

- 16. The statement "thematic analysis was used to define phenomena" need to be revised. Thematic analysis is a form of analysis that is used to examine and identify patterns or themes within data (not to define a phenomena). First sentence in analysis section has been replaced with: "Thematic analysis was used to identify themes related to the influence of cultural and religious beliefs on the valuation of health states by the respondents"
- 17. The authors state that the sample was "broadly" representative of the Emirati population. It would be useful for readers to include a table of participant characteristics or at least report these characteristics in the first paragraph of the results section (age, sex, education, income etc...).

This has been added See comment No.6

18. The authors stated "the need for country specific value sets is particularly important in Muslim majority countries.... 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". This statement does not seem to be very accurate, as it implies that the differences in perceptions of health/health valuations result from the governance system (without mentioning of the cultural, contextual, and historical factors). Turkey, for example, is Muslim majority country, yet a secular state;

Iran is also a Muslim majority country however, it is a religious/theocratic state. I urge the authors to be very cautious in making such statements as Muslim majority countries vary in many aspects, and I suggest reporting this paper within its specific context i.e. Emirati Muslims in UAE. We accept this.

The word "secular" hints at some kind of linkage between the governance system and peoples' valuations which is definitely not the point we are trying to make.

The term secular was used in two places in the text (once in the introduction and once in the limitations of the study). Reference to secular has now been removed and alternative text has been inserted to emphasize the UAE/Emirati context of this study.

19. The authors could propose investigating similar observations in other Muslim-majority countries, for example, Indonesia which is the largest Muslim country in the world (205 million), and where an EQ-5D valuation study is underway. This would help further mitigate the effect of religious beliefs on health state valuations.

Yes, EQ-5D valuation research has recently been undertaken in Indonesia (Purba et al., 2016), the world's largest Muslim-majority country, so an investigation of whether the findings of our study in the UAE are also observed in Indonesia would be of particular interest. Such comparative research would help to establish whether the effects observed are generalizable to other Muslim populations.

We have added text that makes this point.

#### Reference:

Purba FD, Hunfeld J, Iskandarsyah A, Fitriana TS, Sadarjoen SS, Passchier J, van Busschbach J. The first Indonesian health-related quality of life valuation study: an EQ-5D-5L value set. Value Health 2016; 19(7):A820.

#### Results:

20. There seems to be quite a bit of an overlap among the identified themes, particularly themes 1 and 2. Theme 2 seems to be the reverse of theme 1. The concept of "fatalism" is listed under theme 2; however, fatalism is about the belief of inevitability of all events (i.e. theme 1). Further, theme 5 is the "concept of unacceptance of certain ideas" and the sub-themes listed under are the "unacceptability of making a choice between death and illness ... avoiding death which is in God's power"... these concepts all pertain to fatalism, which seems to be the overarching theme across themes 1, 2, and 5. "Preservation of life" is another theme that overarches themes 3 and 4. Both fatalism and preservation of life are key beliefs in the Muslim faith. The authors need to review the themes, and probably collapse them, as the differences are not very clear as is. Yes, there is overlap among the previously identified themes.

Following the suggestion of the reviewer we have restructured the table and concentrate the main themes into two: "Fatalism" and "Preservation of life".

### Discussion

21. The first sentence in the discussion section is misleading. Again, the authors did not investigate cultural beliefs (there was only one question that asked about spiritual/religious views". The term "Muslim Arabs" need to be replaced by "Muslim Emiratis" throughout the discussion section.

We now refer to religious views.

We also refer to "Emiratis"

22. Referring to the last sentence of this paragraph. Why do the authors think that the effect of religion on health state valuations will affect developing value sets in these populations? Value sets are intended to reflect the health preferences of the population, and these vary widely. Several factors including age, gender and other socio-demographic or cultural factors impact health valuations; why should we worry about the impact of religion? If the developed value set for UAE was influenced by the religious beliefs of Emiratis, then it does reflect their preferences, which is the intent of these value sets.

I hope we have clarified this. Because religious views will affect the values that are placed on health states, we recommend that where appropriate county-specific value sets are generated

- 23. The findings need to be discussed in further depth, as the discussion in its current format is a reiteration of the results section. The concepts of fatalism and preservation of life and their effect on perception of health and ultimately impact on health behaviors/outcomes are crucial. The authors can draw on literature on these concepts from other religions. For instance, fatalism is key principle in Hinduism, and preservation of life is key principle in Judaism. There is a vast literature on both. We have now referred to a greater selection of the relevant published literature
- 24. Only one paper on fatalism and healthcare behaviors was referred to in the discussion section. There is a large body of literature that examined the role of religion in health perceptions, behaviors and outcomes that the authors can refer to. We have now referred to a greater selection of the relevant published literature
- 25. In the discussion section, it was stated "participants in this study perceived themselves as invincible and lack any great appreciation of the threats to their health.... 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"... this characterization of the results seems to be too critical of the participants in this study. Previous literature reported that religious fatalism may be primarily a "coping response" to illness rather than an inhibitory belief. The authors should discuss all possible explanations of the findings that are supported by the literature. We were referring to the Gowani study. We have now made this clear in the text.

We have attempted to discuss other explanations for our finding and link this to the available literature.

26. There are several limitations in this study that the authors need to discuss including: the assessment of the impact of "spiritual or religious views" on health valuations was limited to one openended question asked via a self-administered survey, the interpretation of the results without addressing the wider cultural context is not sufficient, the generalizability of the results etc... We believe we are now much clearer about the limitations of this study

### 27. Minor:

- In the article summary, need to add "Al Ain", not just Abu Dhabi.
- The examples (excerpts from participants) provided in the results section need to be reviewed as some do not fit under the theme they were reported under.
- "Al Ain" has been added

Excerpts from participants, in the results section have been reviewed and extensively revised to ensure they align with the appropriate sub-theme.

Positive, no revisions requested

### **VERSION 2 - REVIEW**

REVIEWER	Fatima Al Sayah
	University of Alberta, Canada
REVIEW RETURNED	21-Jun-2017

# **GENERAL COMMENTS** - The terms "religious beliefs", "spirituality" and "religion" were used interchangeably throughout the manuscript; I suggest using one term i.e. "spiritual or religious beliefs" (as the question in Table 1 asks). - Methods, pg. 5, lines 40-41: it is stated that ".... it would be disrespectful to suggest otherwise...". I don't think such a statement should be included in a paper. I believe this was added in response to a previous comment that I made about referring to the study population as "Muslim Arabs". While the vast majority of Emiratis are Muslim and Arabs, my previous comment was purely driven by methodological concerns regarding the generalizability of the findings of this study to a larger group of people who are not fully represented by this study population. This methodological concern would hold for any study conducted in any country. - Methods, pg. 6, lines 17-18: it is stated that "a phenomenological study design" was used. I think it is inaccurate to describe this study as a phenomenological one. Based on the described methods, this study did not investigate the meaning of lived experiences i.e. phenomenology. It would be more accurate to describe it as a descriptive study that used qualitative methods for data analysis. - Throughout the manuscript, the statements "religious beliefs affecting perceptions of health" and "religious beliefs affecting valuations of health" were used; for consistency, I suggest referring to the former, as the latter was not explored in this study. - Analysis, pg. 7, lines 55-56: it is stated here that the target sample was 200, and there were 134 complete interviews that provided data for this study. Demographic data (pg. 8) should be reported for the 134 participants that were included in this study (not the 166 as qualitative data were not available for all of them). - Pg. 9 lines 41-42: the word "Amana" is an Arabic word that needs to be explained in English. - Pg. 13, lines 3-4: minor edit "Al Baqarah" not Ai. - The discussion section lacks a paragraph describing the limitations of this study and how these limitations might have influences the observed results. - The authors stated in the introduction/objectives that the paper will provide insights on the implications of the study findings on research on quality of life ... and use of values in cost-effectiveness analysis. While the last section of the discussion partly addressed the first part of this stated objective, there was no discussion about how these findings might impact the use of the derived values in costeffectiveness analysis.

#### **VERSION 2 – AUTHOR RESPONSE**

#### Reviewer 2: Comments to Author

### Authors' response

The terms "religious beliefs", "spirituality" and "religion" were used interchangeably throughout the manuscript; I suggest using one term i.e. "spiritual or religious beliefs" (as the question in Table 1 asks).

As recommended, the phrase "spiritual and religious beliefs" is now used.

- Methods, pg. 5, lines 40-41: it is stated that ".... it would be disrespectful to suggest otherwise...". I don't think such a statement should be included in a paper. I believe this was added in response to a previous comment that I made about referring to the study population as "Muslim Arabs". While the vast majority of Emiratis are Muslim and Arabs, my previous comment was purely driven by methodological concerns regarding the generalizability of the findings of this study to a larger group of people who are not fully represented by this study population. This methodological concern would hold for any study conducted in any country.

#### This statement has been removed

- Methods, pg. 6, lines 17-18: it is stated that "a phenomenological study design" was used. I think it is inaccurate to describe this study as a phenomenological one. Based on the described methods, this study did not investigate the meaning of lived experiences i.e. phenomenology. It would be more accurate to describe it as a descriptive study that used qualitative methods for data analysis.

#### This has been corrected

- Throughout the manuscript, the statements "religious beliefs affecting perceptions of health" and "religious beliefs affecting valuations of health" were used; for consistency, I suggest referring to the former, as the latter was not explored in this study.

### This change has been made

- Analysis, pg. 7, lines 55-56: it is stated here that the target sample was 200, and there were 134 complete interviews that provided data for this study. Demographic data (pg. 8) should be reported for the 134 participants that were included in this study (not the 166 as qualitative data were not available for all of them).

As requested, this has now been clarified in the text and in Table 2.

- Pg. 13, lines 3-4: minor edit "Al Baqarah" not Ai.

### This has been corrected

- The discussion section lacks a paragraph describing the limitations of this study and how these limitations might have influences the observed results.

## This has now been added

- The authors stated in the introduction/objectives that the paper will provide insights on the implications of the study findings on research on quality of life ... and use of values in cost-

effectiveness analysis. While the last section of the discussion partly addressed the first part of this stated objective, there was no discussion about how these findings might impact the use of the derived values in cost-effectiveness analysis.

This is now discussed

- Pg. 9 lines 41-42: the word "Amana" is an Arabic word that needs to be explained in English.

This is now explained