Author's response to reviews

Title: Illness beliefs and the sociocultural context of diabetes self-management in British South Asians: A mixed methods study

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Author's response to reviews: see over
Dear Dr Crosson,

Re: MS: 1367373254147855. Research Article: *Illness beliefs and the sociocultural context of diabetes self-management in British South Asians: A mixed methods study*

We are thankful for your time in considering our revised manuscript.

We have made changes to our manuscript to address the comments of Reviewer 1 and 2.

Please see overleaf a point-by-point response to the reviewer’s comments and a revised manuscript for your consideration.

We look forward to hearing from you soon.

Yours faithfully,

Dr Neesha Patel

Drs Anne Kennedy, Christian Blickem, Christine Bundy, David Reeves and Professor Carolyn Chew-Graham.
Reviewer 1

1. Were the questionnaires presented in the participants’ first language or in English? Given that some participants required the use of an interpreter for the qualitative study, I wonder whether all participants would have adequately understood all of the questions without a translation if the questionnaires were indeed printed in English?

Could the authors add this information to the manuscript, and if the questionnaires were printed in English, some consideration of the point which I raise regarding comprehension difficulties could perhaps be included in the Discussion.

The questionnaires were presented to participants in English and participants were clearly informed to advise us if they had any difficulty or would like assistance with completing the questionnaire. Some participants preferred to ask family members for help with completing the questionnaire. Any missing information due to language comprehension was overcome after the qualitative interview wherein participants returned the questionnaire and asked the researcher or the interpreter for help.

As suggested we have now included some information on the point about comprehension in the discussion – lines 593-597.

2. If I understand the demographic questions correctly, it seems that 84% of participants in this sample had a chronic comorbid condition. Could this have impacted on the study findings?

It is correct that 84% of participants had another chronic condition in addition to diabetes. Comorbidity is very common in older diabetic patients in general, and therefore we do not think this is a concern in terms of how representative the sample is. We have added a comment on this to the paper – lines 602-604.

However, a second concern is whether patient illness beliefs can be meaningfully interpreted as being diabetes-related in the presence of additional chronic conditions. We have added some more text on the approach we used to direct participants towards responding in relation to their diabetes and also added a note to the limitations section – lines 165-169 and 602-604.
3. Both Type 1 and Type 2 diabetes patients are included, but it is likely that there are substantial differences between these two groups with respect to a number of the concepts under investigation. Could the authors comment further?

Response: The total sample did comprise of participants with type 1 and type 2 but 90% of the sample had type 2 diabetes and we believe that our findings relate to this sample and we have now included some information on this in the discussion – lines 572-573.

4. A substantial sub-section of the Results describes the average values for the illness beliefs, social network and health outcome data. While I appreciate the value of the reporting of these descriptive statistics, I wonder whether such an in depth description of these averages is warranted here. Particularly because there is no comparison group against which any meaningful conclusions can be drawn (i.e. it would have been interesting to compare the South Asian sample with a sample of White British individuals to investigate precisely how these ethnic groups may differ. I understand that this is beyond the scope of the study, but I nevertheless wonder whether the Results section could be trimmed back a little in this regard, and the authors could mention in the Discussion the potential benefits to clinical practice of a direct comparison of these two ethnic groups).

We have given this careful consideration. We feel it important to retain the text description of the illness beliefs as the main study outcomes, so the suggestion would result in the removal of only one paragraph, describing demographics and self-care. However, we feel that the paragraph provides useful descriptions of the variables themselves (as well as their means etc) without which the summary table is harder to interpret, and have therefore decided not to remove this. We now discuss the potential benefits of a comparison group in the discussion section lines 623-625.

5. It is stated (line 309) that participants’ ages will be included with the qualitative annotations, but this doesn’t seem to have been incorporated into the manuscript.

Response: Thank you for highlighting this omission. We have now included the age in each of the qualitative annotations.

6. Line 536: It is stated that the quantitative finding that control beliefs are positively related to health status ‘contradict’ the qualitative findings. However, this argument should be toned down/reconceptualised, as while the qualitative study investigated control beliefs, it was not really geared up to investigate the relationship between control beliefs and health status.

Response: Thank you for your suggestion. We have toned down our argument on control beliefs and health status – line 554-555.
7. The manuscript comprises several typographical/grammatical errors, some of which are noted below. The authors should carefully proofread their manuscript prior to resubmission:

Line 47: “Beliefs about diabetes beliefs” please reword
Response: - This error has now been corrected (line 48)

Line 58-60: This sentence is a little unclear; consider rewording
Response: - This sentence has now been revised (line 60-61)

Line 95: “inform” should read ‘informing
Response: - This error has now been corrected (line 96)

Line 97-98: “insights into causal on self-management”- this is unclear and needs Rewording
Response: - This has now been corrected (line 99)

Line 104-106: This sentence is also unclear and needs rewording
Response: - This has now been corrected and the word ‘impede’ has been included before the word management to improve the flow of this sentence (line 106).

Line 177: “exercise, smoking” should read “exercise and smoking”
Response: - This error has now been corrected (line 182)

Line 539: “finding” should be plural
Response: - This error has now been corrected (line 558)
**Discretionary Revisions**

8. It is a shame that self-care questions relating to blood glucose testing were not included, as this may well have been very insightful. Could the authors comment upon this?

9. I wonder whether it would be possible within the scope of this investigation to also run some regression analyses to determine which illness beliefs best predict diabetes self-management in this population?

Response to comments 8 & 9: Thank you for your suggestions. We have spent some time considering the key messages of this study, and although the questions concerning blood glucose and predictors of diabetes management would be of interest, we feel these additions will detract from the key messages and aims of this manuscript. In addition, we are preparing a separate manuscript on this topic for submission in the near future.

**Reviewer 2**

1. Whilst the introduction presents a nicely up to date summary of the role cognitions play in diabetes self-management, and contextualises those within the common sense model of illness SRM (which indeed needs tested in non-Caucasian samples), there is a lack of theoretical positioning here in terms of what the authors seek to do- are they theory testing or theory building?

Sociocultural context appears to be operationalised as social network- I would like to see greater consideration of other aspects of sociocultural context e.g. socioeconomics, language barriers, healthcare access etc.

Response: Our aim was to build on the CS-SRM by exploring additional factors such as social network as part of but not synonymous with the sociocultural context, which may influence self-management behaviours and illness beliefs. We have made this clearer on lines 120-122.

We would like to clarify that social networks in the context of this study has been operationalised using the CLAHRC model, which aims to identify individuals considered to be most helpful to manage diabetes (please see lines 198-204 for further information). We then designed the nested qualitative study to consider for the wider sociocultural factors (not specifically captured by the CLAHRC model) but we had a specific focus and wanted to gain a deeper insight in some of the factors explored in the quantitative study such as fatalism, social networks but also explore additional factors such as the use of alternative medicine. However, we are aware of the wider sociocultural factors on self-management of diabetes in the British South Asian population, and we have stated this on lines 82-83 with a relevant reference.
2. The authors report a mixed method study where a purposive sample of British South Asians diagnosed with Type II diabetes complete a series of questionnaires, with a subsample also completing a social network survey and semistructured interview. This latter component has quite a few limitations. The abstract states that 'thematic analysis' is employed, and indeed this seems to be what is presented. However the methods section states that thematic analysis "using principles of Grounded Theory..." is employed, The authors do not seem to be employing GT principles in the development of their study, nor in the theorising following analysis. For example, a theory of 'balancing beliefs' could be considered as emergent in these data whereby the sample seem to try to fit their lay models of illness and alternative therapies within a dominant medicalised culture. How does this fit with the CS-SRM model appropriately described for the quantitative study.

Response: Thank you for your comments. We did not use a full grounded theory approach in the qualitative study as the whole research programme had a priori assumptions which were influenced by theoretical assumptions and ideas from the literature. The a priori assumptions were used to develop the research questions and interview topic guide for this study. We used the principles of the grounded theory approach as suggested by Charmaz (2006): 'the flexibility and legitimacy of grounded theory methods continues to appeal to qualitative researchers with varied theoretical and substantive interests (p. 9). Charmaz (2006) views grounded theory methods as a set of principles and practices which can complement other approaches to qualitative data analysis, rather than stand in opposition to them p.9. For example, in our study, an iterative approach to data collection and analysis was used and this approach enabled the qualitative study to evolve and this enabled us to gain a deeper understanding into the beliefs about diabetes.

The constant comparative approach allowed us to compare different codes across transcripts, developing categories, refining categories and exploring patterns across categories simultaneously. Our aim was not to theorise our findings based on grounded theory but to use the emerging themes to better understand diabetes management in this population, as well as explore how the themes fit in with the CS-SRM and the findings of the quantitative study. We have included the relevant references and information about the a priori assumption on lines 242-244.

3. I feel the authors 'triangulation' of findings, and theoretical considerations are underplayed and thus the contribution of the data to current understanding is currently limited. Greater consideration needs to be given to the 'grounded theory' principles.

Response: Our study used a sequential embedded mixed methods design as outline in the methods (lines 130-133) and our findings and contributions of the data have been discussed in the context of the study aims and design. As described above, we did not use a full grounded theory approach.
4. In terms of the sample and potential confounds there is an issue regarding comorbidity - 84% of the sample have 2 or more conditions! Although this is considered in the quantitative analyses it is not clear how the assessments used were worded and thus how the data are to be interpreted. Was the IPQ-R worded so that participants responded solely in relation to their diabetes (as the extra fatalism items were)? Line 258 in Results suggests that 'diabetes' was used in the fatalism items but I don't think this is the case for B-IPQ. If true then what you may have are generic 'illness' beliefs e.g. illness concerns, associating with health outcomes or social network variables, and NOT diabetes beliefs per se. The discussion of these data and the qualitative data need to reflect more on the challenges of comorbidity, and be clear as to the wording of measures used. Without this it is hard to judge what the findings mean.

Response: We used the generic version of the BIPQ, and although we cannot be entirely sure that the participants prioritised diabetes when completing the questionnaire, but we made every effort (through the participant information sheet, consent form) to ensure that they knew the study was focused on diabetes. As mentioned above, our primary aim was to explore the role of illness beliefs, social network and the sociocultural context and self-management of diabetes; including additional analysis and data on comorbidity would have detracted from the aims of the study. We have highlighted and now described our approach in the paper and these weaknesses together with the impact of comorbidity in the discussion section – lines 165-169 and 602-604.

5. Are multivariate analyses sufficiently powered? Was comorbidity controlled for in the first or second step (after age, time since diagnosis etc)? Given other significant correlates how were the regressions constructed? These data are not presented/reported in a standard manner.

The multivariate analyses undoubtedly have low power, due to sample size, in the sense that they are only able to detect fairly strong relationships between patient and social network factors and beliefs, and not weak ones. However, given the shortage of research data on this population we still feel that they make a worthwhile contribution. We have added more detail about the regression method, which was forward stepwise in which variables with a significant univariate relationship were added to the regression model in order of predictive ability until no further variables reached the entry criteria (p<0.05). Because of document length we have necessarily described the regression results in the text as briefly as we can and hence have forgone presenting any table of regression results.

Before performing the multiple regressions, we checked for outliers using Mahalanobis distance for variable pairs where p value score was .1 or less to allow for the relationship becoming significant after removal of outliers (Tabachnick & Fidell, 2007) but no outliers were found for either of the variable pairs in the multiple regressions.

The primary aim of this analysis was to depict associations between data, however due to the small sample size of this study, we are aware that the significant associations between the variables have to be treated with caution and we have stated this in lines 589-591 in the discussion.
6. throughout the authors need to present summary as to the direction of effects

We have tried throughout to be clear on the direction of relationships between pairs of variables, as this is not always obvious from their labels. Following from this comment, we have been through the manuscript again and made some additional changes where we feel the direction was not entirely clear –lines 283, 285-287, 289, 297-298, 301-304, 308.

7. Information is needed as to the sampling frame- how many were approached in order to achieve the final sample i.e. what was the response rate? Although qualitative studies do not claim representativeness, this information is useful when considering the quantitative findings

Response: As this study was embedded within the larger CLAHRC study, it was not possible report the response rate of the number of South Asians recruited using random sampling as previously stated on lines 253-255 that “The response rate for the number of South Asian patients invited to take part in study from the GP practices is unknown, as not all GP practices routinely record the ethnicity of South Asian patients”.

8. The qualitative data present emergent themes relating to fatalism, behaviour change influences in the family, balancing different illness models/use of alternative therapies and are well supported by quoted material. However there is no sense of the commonality of the themes, i.e. did they exist in all/most/many/few transcripts; were there a few participants for whom the wives influence on eating, for example, was salient and others where they took more self-control? How did this fit with those participants own’ quantitative data ie their scores on the BIPQ for example? Did fatalism and behaviour change co-exist within a family unit and create conflict or was the incongruence accepted?

Response: It was not within the scope of this study to relate/quantify each theme back to the individual BIPQ scores due to the design (sequentially embedded) used. As mentioned earlier, the aim of this design is to use the qualitative findings to elaborate on and complement the quantitative findings.

We have, however, outlined the commonality of themes by making distinctions between first and second generation British Asians (e.g. lines 342-344), men and women (lines 394, 415-416, 432-433), and where necessary used phases such as minority, majority, some (e.g. lines 443, 415) to further distinguish the commonality of the themes. Our findings suggest that fatalism existed within a family unit, and we have distinguished between fatalistic beliefs in British born South Asians and British migrant South Asians (lines 357-358, 363-364). We did not specifically explore behaviour change in the interviews.
The discussion is generally appropriate to the findings and makes a good effort to consider implications without over-stating them. Perhaps I was expecting greater reflection on the two data type- greater triangulation, and certainly more explicit consideration of what these findings ‘mean’ for the CSM SRT, and also perhaps greater sociocultural analysis of the immediate context of where participants resided (ratio of Asian: Caucasian population, local culturally appropriate services etc).

Response: Thank you for your comments. As this study did not include data from the Caucasian population, it is not possible for us to provide a sociocultural analysis of the differences between the two groups; however, this is an important area for future research. We have now included this suggestion in the discussion (lines 623-625).

Our findings highlight the need for additional cognitive and emotional constructs to be included within the CS-SRM and BIPQ measure which target specific items related to illness beliefs of the South Asian population. We have, therefore, revised the sentence in the discussion (lines 628-629) on theoretical implications to also include information on the BIPQ measure and future behaviour change interventions.

MINOR REVISIONS

1. the language and sentencing needs attention; there are many errors/omissions, repetitions e.g. line 105 "...has also been reported to management practices."

Response: - This error has now been corrected and the word ‘impede’ has been included before the word management to improve the flow of this sentence (line 106).

line 365-367, has "..the quantitative study" twice; line

Response: - This error has now been corrected (lines 384-385)

397-8 reads "...for instance their such as..." etc.

Response: - This error has now been corrected (line 415)

Proof reading and also considering sentence structure/flow, is essential

Response: Thank you. The typos and grammatical errors have now been corrected (highlighted in green on lines 283, 285-289, 297-298, 301, 522, 550, 560, 582-584). The manuscript has also been proof read thoroughly.