PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

Title (Provisional)

Exploring the quality of end-of-life care in the intensive care unit: a qualitative multiple case study approach with family members of Muslim patients

Authors

Nayfeh, Ayah; Conn, Lesley Gotlib; Dale, Craig; Fowler, Robert

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VERSION 1 - REVIEW

Reviewer	**1**
Name	**Walsh, Timothy**
Affiliation	**Edinburgh University, Critical Care Medicine; Centre for Inflammation Research**
Date	**24-Jul-2024**
COI	**None**

This qualitative/mixed methods study aimed to explore how family member substitute decision makers of recently deceased Muslim patients describe the quality and experience of end-of-life care in ICU? This is a topical and relevant area. It is under-researched.

The methodology appears to be robust, and the reporting complies generally well to COREQ recommendations. It is clearly written.

I have the following comments and suggestions:

Methods

1. Context. It would useful to give an outline of Toronto's ethnic make-up and diversity? Also, any context around socioeconomic deprivation status etc?

2. Relating to context, an indication of the approximate proportion of case mix in this ICU that is Muslim, and also the staffing representation from Muslim healthcare workers.

3. It would be useful to understand the detail of the outcome of purposive sampling against the sampling framework. The framework has multiple areas as stated but it looks more like the recruited family members were a 'convenience sample' based on respondents rather than purposively sampled? This is important to risk of bias etc?

4. The language abilities of the respondents are stated, but it is unclear what language with/without translators the interviews were undertaken for each case. Can this detail be added?

5. The timing from end-of-life care and approach to family member and the subsequent interview is not recorded but seem very relevant. Can this be provided?

6. Can the authors clarify if interviews were recorded.

7. Was ethical approval obtained and formal consent obtained from family members? This is not stated neither the ethical committee approving the study.

8. Was there any cross checking or double analysis between researchers? Similarly, was there any checking of coding of emerging themes from the interviews by a second researcher? This would be best practice.

9. Was there any review of findings by the interviewees for comment or confirmation?

10. The study used mixed methods in the sense that interview data were triangulated with case note data. This is a strength. Can the authors provide some additional detail on exactly how this was done, and how they sought to minimise bias either in data extraction or interpretation by the researcher? There are frameworks for this in terms of relative importance given to the different forms of data, and the order that analysis and integration were done. Can the authors describe in more detail how this was done?

Results

11. I note there were 20 eligible family members. How did purposive sampling work in relation to these or were all approached? This related to my earlier comment in methods.

12. Was data saturation considered to be reached and if so how was this assessed? Five interviewees is quite a small number for this type of study for data saturation given the complexity of the issue.

13. I note that two of the patients actually died in a palliative care setting? Are these truly representative of the question set, in terms of end-of-life care in the ICU. Some comment on this would be relevant as I assume this was with a different clinical team?

14. In relation to the themes, was there any reflection or comparison with other ethnic groups to provide data on 'what may be different' for Muslim families?

15. The research method was noted to include an element of reflexivity, ie the potential relevance and impact of the researcher on the emerging data and inductive interpretation. It would be helpful to see a short section on reflexivity, and the researcher's reflection on its potential importance.

16. I note that 4/5 decedents were Male. Also most appeared highly educated. Given gender and educational level could be relevant to end-of life experience for family members I think some comment on this, even to note it clearly, may be useful? Or example it was noted that

there were family members who were medical in some cases, which may not represent the general Muslim population.

17. The relationship and age of the interviewees seems relevant to the study. Was this available? It is not included in appendix C.

18. I think a figure summarising the themes that emerged, ie some form of infographic, would be very useful.

Discussion

19. The discussion notes the researcher's background as a strength, as a Muslim. I agree with this, but as above would like to see some data and consideration of reflexivity in terms of whether this might have introduced bias?

20. The authors state that 'theoretical saturation was achieved' but provide no evidence for this in the results (page 42; line 23-24).

21. The impact of COVID on care is known to have been substantial in terms of family visiting, staffing pressures, and other factors that might have made end-of-life care different from pre- or post-pandemic. I was not quite clear how the cases mapped on to different stages of the pandemic, and also the local pressures this hospital faced in terms of workload etc. Also, what were the visiting practices etc that might have been relevant?

22. The authors do not make clear comment on whether they think their work highlights issues that are potentially 'specific' or 'especially important' to Muslim families compared to other ethnic groups (or even the dominant local population – presumably white Canadians?). I think this is a key question in the minds of the readers. I think it would be helpful to consider this in the discussion, even if with qualification. As the authors note, the researcher was of Muslim background, and this was very much the research question.

I congratulate the authors on a challenging and interesting study.

Reviewer	**2**
Name	**Walsh, Timothy**
Affiliation	**The University of Edinburgh**
Date	**05-Sep-2024**
COI	**None**

This qualitative/mixed methods study aimed to explore how family member substitute decision makers of recently deceased Muslim patients describe the quality and experience of end-of-life care in ICU? This is a topical and relevant area. It is under-researched.

The methodology appears to be robust, and the reporting complies generally well to COREQ recommendations. It is clearly written.

I have the following comments and suggestions:

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1. Context. It would useful to give an outline of Toronto's ethnic make-up and diversity? Also, any context around socioeconomic deprivation status etc?

2. Relating to context, an indication of the approximate proportion of case mix in this ICU that is Muslim, and also the staffing representation from Muslim healthcare workers.

3. It would be useful to understand the detail of the outcome of purposive sampling against the sampling framework. The framework has multiple areas as stated but it looks more like the recruited family members were a 'convenience sample' based on respondents rather than purposively sampled? This is important to risk of bias etc?

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8. Was there any cross checking or double analysis between researchers? Similarly, was there any checking of coding of emerging themes from the interviews by a second researcher? This would be best practice.

9. Was there any review of findings by the interviewees for comment or confirmation?

10. The study used mixed methods in the sense that interview data were triangulated with case note data. This is a strength. Can the authors provide some additional detail on exactly how this was done, and how they sought to minimise bias either in data extraction or interpretation by the researcher? There are frameworks for this in terms of relative importance given to the different forms of data, and the order that analysis and integration were done. Can the authors describe in more detail how this was done?

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22. The authors do not make clear comment on whether they think their work highlights issues that are potentially 'specific' or 'especially important' to Muslim families compared to other ethnic groups (or even the dominant local population – presumably white Canadians?). I think this is a key question in the minds of the readers. I think it would be

helpful to consider this in the discussion, even if with qualification. As the authors note, the researcher was of Muslim background, and this was very much the research question.

I congratulate the authors on a challenging and interesting study.

Reviewer	**3**
Name	**Crooks, Jodie**
Affiliation	**Marie Curie, Policy and Research**
Date	**16-Sep-2024**
COI	**I declare I have no competing interests.**

This is an important area of research. I like the use of case study methodology, and feel the interview guide in the supplementary material demonstrates the depth of information discussed and gathered to inform your analysis. I have only a few, minor feedback points:

- Could you provide more justification for the ICU setting for the research? Though this is touched upon briefly in the background section, it would be good to see expansion on this, and addition of justification / explanation in the 'Research Setting' section of the methodology.

- Please report the ethical approval number and institution in the methodology section. If approval wasn't sought, please justify why

- It is good that cultural humility is mentioned throughout. It would be good to see this drawn upon more, for example in the discussion / as a recommendation from this research

- In the first paragraph of the discussion (page 12, line 9), you have said "Culture, religion and religiosity did not appear to have a major influence on the medical decision-making process." Though this is true from your data for the decision making process, it does not appear true for the care process / preferences for care received (i.e., personal care etc). It would be good to make this distinction here

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VERSION 1 - AUTHOR RESPONSE

REVIEWER 1 COMMENTS:

9. It would useful to give an outline of Toronto's ethnic make-up and diversity? Also, any context around socioeconomic deprivation status etc.?

Response: Thank you for this helpful suggestion. The multicultural and demographic make-up of our research setting is described on page 4 as follows: In terms of demographic make-up, foreign-born immigrants (46.6%) and visible minorities (55.7%) comprised nearly half of the Toronto population. South Asian (14%), Chinese (10.7%) and Black (9.6%) were the three largest visible minority groups in Toronto. After Christianity (46.2%), Muslim (9.6%), Hindu (6.2%) and Jewish (3.6%) were the three largest religious groups in Toronto.

We did not include details around the socioeconomic status of Torontonians as we did not have ability to explore this concept more deeply in this study.

10. Relating to context, an indication of the approximate proportion of case mix in this ICU that is Muslim, and also the staffing representation from Muslim healthcare workers.

Response: Thank you for this comment. A limitation of this study is that patient race/ethnicity and patient religion is not routinely documented in the patient medical record. We therefore did not have access to a reliable estimate of case mix in our ICU setting. This limitation is noted on page 14. We also do not have access to the demographic make-up of healthcare staff, which we have now included as an additional limitation on page 14: We also did not have access to healthcare worker demographics or staffing information before or after the emergence of COVID-19 to help describe the ICU context during specific points in time.

11. It would be useful to understand the detail of the outcome of purposive sampling against the sampling framework. The framework has multiple areas as stated but it looks more like the recruited family members were a 'convenience sample' based on respondents rather than purposively sampled? This is important to risk of bias etc?

Response: Thank you for requesting further clarification on the sampling approach. We identified two lists of Muslim patients; those who were admitted to ICU before COVID-19 and those admitted to ICU after the emergence of COVID-19. Each list was arranged in reverse chronological order according to date of patient death. This enabled the research team to purposively select patient cases based on characteristics of interest in a logical order. We followed this approach until theoretical saturation was reached against the theoretical framework using deductive analysis.

Despite our best efforts, we acknowledge that there is some homogeneity in our sample population, particularly for patient race/ethnicity and immigration status. Limitations in the screening and identification process may have contributed to these results (noted on page 14). While we note that our sample population is representative of Toronto's immigrant and visible minority population (as referenced on page 4), the manuscript points to the need for further research using more inductive designs with targeted sampling of recent immigrants and Muslims from other regions of the world.

12. The language abilities of the respondents are stated, but it is unclear what language with/without translators the interviews were undertaken for each case. Can this detail be added?

Response: All interviews were conducted in English (noted on page 5) and language translation was not required for any of the cases.

13. The timing from end-of-life care and approach to family member and the subsequent interview is not recorded but seem very relevant. Can this be provided?

Response: Thank you for this comment. The manuscript currently notes that (page 6): Three patients died in 2021 and two died in 2019. We have added the following text to help the reader contextualize the timing of interviews as it relates to date of patient death (on page 5): Interviews took place between August and November 2022.

14. Can the authors clarify if interviews were recorded.

Response: Yes, interviews were audio-recorded (noted on page 5).

15. Was ethical approval obtained and formal consent obtained from family members? This is not stated neither the ethical committee approving the study.

Response: Verbal informed consent was obtained from each participant prior to research participation (noted on page 5). An ethics approval statement is now included in the Methods section of the manuscript (on page 6).

16. Was there any cross checking or double analysis between researchers? Similarly, was there any checking of coding of emerging themes from the interviews by a second researcher? This would be best practice.

Response: Thank you for the opportunity to clarify this part of the research process. The evolving analysis was recorded through a codebook with supportive quotes and extensive analytic memos were recorded throughout the data analysis process in order to document analytic thinking and the interpretation process (noted on page 6). The research team met several times throughout the analytical process to discuss emerging themes in full detail. We have added the following text in the manuscript to document best practice (on page 6): Feedback from the research team helped to expand the analytical process.

17. Was there any review of findings by the interviewees for comment or confirmation?

Response: While the research team was prepared to conduct follow-up interviews with participants to clarify information and/or gather new reflections, this was not required as there was alignment across themes and sufficient data to assess how these ideas converged/diverged. We did not include explicit mention of 'member checking' in the manuscript as this process was not required.

18. The study used mixed methods in the sense that interview data were triangulated with case note data. This is a strength. Can the authors provide some additional detail on exactly how this was done, and how they sought to minimise bias either in data extraction or interpretation by the researcher? There are frameworks for this in terms of relative importance given to the different forms of data, and the order that analysis and integration were done. Can the authors describe in more detail how this was done?

Response: We appreciate the opportunity to clarify this process further. We have included additional text in the manuscript to provide more detail on the order and importance of different sources of data (on page 6): Data obtained from healthcare providers' notes were also coded and categorized according to the matrix. These lines of data were used to expand upon and provide complementary insight into the patient care journey and healthcare experience gathered during the interview process.

Following each interview, data were extracted from the patient medical record using a template to gather key details around the patient care journey, such as discourse around treatment decision-making, prognostication, resuscitation status, patient goals-of-care, and other patient and family interactions

19. I note there were 20 eligible family members. How did purposive sampling work in relation to these or were all approached? This related to my earlier comment in methods.

Response: We appreciate the opportunity to prove further clarification on the sampling approach. We identified two lists of Muslim patients; those who were admitted to ICU before COVID-19 and those admitted to ICU after the emergence of COVID-19. Each list was arranged in reverse chronological order according to date of patient death. This enabled the research team to purposively select patient cases based on characteristics of interest in a logical order. We followed this approach until theoretical saturation was reached; we did not approach all eligible patients.

20. Was data saturation considered to be reached and if so how was this assessed? Five interviewees is quite a small number for this type of study for data saturation given the complexity of the issue.

Response: Thank you for this important comment. In using a deductive approach and existing theoretical framework, our aim with this study was to validate and exemplify existing theory with Muslim patients/families rather than to develop new theory. Had we used an inductive approach (like Grounded Theory), we likely would have required more cases and participants to develop any new theory. For the purposes of our study, we note on page 5 that the addition of more data beyond five patient cases would likely not provide new insights about the theoretical framework which was the overarching aim. This sample size is in accordance with case study methodology (Stake 2006). However, we also acknowledge growing debate about the concept of theoretical saturation and point to the importance of conducting further research (using inductive approaches) to more deeply explore this phenomenon (noted on page 13, 14).

21. I note that two of the patients actually died in a palliative care setting? Are these truly representative of the question set, in terms of end-of-life care in the ICU. Some comment on this would be relevant as I assume this was with a different clinical team?

Response: We appreciate recognition of this point. The interview questions were specific to the end-of-

life decision-making process and experience of care in the ICU (Appendix A). There were instances where reference to quality-of-care in the palliative care unit were made by participants, and this was distinguished in the analysis and clearly noted in the manuscript, where relevant.

22. In relation to the themes, was there any reflection or comparison with other ethnic groups to provide data on 'what may be different' for Muslim families?

Response: This manuscript highlights several findings that are consistent with prior research around the quality and experience of end-of-life care for the general patient population (i.e., predominant Caucasian/Christian sample) (noted in the Results section on page 11-12). We further highlight two specific areas that are unique to the Muslim patient population in the Discussion section (page 13): Language barriers were identified as an additional element of quality end-of-life care for Muslim patients that was not previously defined in the existing framework.

Respect for cultural and religious values was identified as an important element of quality care for Muslim patients and families.

23. The research method was noted to include an element of reflexivity, ie the potential relevance and impact of the researcher on the emerging data and inductive interpretation. It would be helpful to see a short section on reflexivity, and the researcher's reflection on its potential importance.

Response: Reflexive details were used as additional source of data to help surface personal biases that could impact data analysis and interpretation. We have added the following text in the manuscript (on page 13): Practicing reflexivity was particularly important for surfacing personal experience, values and beliefs and acknowledging areas where responses could be interpreted in a certain way.

24. I note that 4/5 decedents were Male. Also most appeared highly educated. Given gender and educational level could be relevant to end-of life experience for family members I think some comment on this, even to note it clearly, may be useful? Or example it was noted that there were family members who were medical in some cases, which may not represent the general Muslim population.

Response: Thank you for this comment. We have added the following text in the manuscript (on page 14): Most participants were also male and most were highly educated which may have also had an impact on the end-of-life care experience and delivery of care.

25. The relationship and age of the interviewees seems relevant to the study. Was this available? It is not included in appendix C.

Response: We have included 'relationship to patient' in Appendix C.

26. I think a figure summarising the themes that emerged, ie some form of infographic, would be very useful.

Response: Thank you very much for this feedback. We would be happy to include an infographic if the editors permit the addition of more appendices in the manuscript.

27. The discussion notes the researcher's background as a strength, as a Muslim. I agree with this, but as above would like to see some data and consideration of reflexivity in terms of whether this might have introduced bias?

Response: Thank you for prompting reflection on this. Practicing reflexivity was important for surfacing personal experience, values and beliefs and acknowledging areas where bias could be introduced and where responses could be interpreted in a certain way. To manage this, topics that resonated or triggered emotional reactions by the interviewer/data analyst were clearly noted. For example, hearing participant testimony regarding seeing a sick parent in a dishevelled state was a personal experience that evoked an emotional reaction by the interviewer/data analyst and prompted the labelling of this experience.

We have thus added the following text in the manuscript to reflect the process of reflexivity (on page 13): Practicing reflexivity was particularly important for surfacing personal experience, values and beliefs and acknowledging areas where responses could be interpreted in a certain way. For example, topics that resonated or triggered emotional reactions were noted and enabled labelling of experience (i.e.,

seeing sick parent in a disheveled state).

28. The authors state that 'theoretical saturation was achieved' but provide no evidence for this in the results (page 42; line 23-24).

Response: Thank you for this comment – in using deductive analysis, we relied on pre-specified codes and categories to organize emergent themes in accordance with an existing theoretical framework. The coding framework is presented in Appendix D and provides exemplar quotes to showcase how theoretical saturation was achieved for each theme. We further present our findings in the manuscript through cross-case analysis to highlight common experiences and divergent cases in an attempt to guide the reader through the analysis and saturation of themes. However, we do also acknowledge growing debate about the concept of theoretical saturation and point to the importance of conducting further research to more deeply explore this phenomenon (on page 13).

29. The impact of COVID on care is known to have been substantial in terms of family visiting, staffing pressures, and other factors that might have made end-of-life care different from pre- or post-pandemic. I was not quite clear how the cases mapped on to different stages of the pandemic, and also the local pressures this hospital faced in terms of workload etc. Also, what were the visiting practices etc that might have been relevant?

Response: Thank you for this comment. We agree that staffing information during the pandemic is a key factor that could have influenced the quality of care. We did not have access to staffing information before or after the emergence of COVID-19 to describe the ICU context during specific points in time for each case. We note this as a limitation on page 14. However, we do note that visitor restrictions and health human resource shortages may have impacted findings compared to pre-pandemic practices.

30. The authors do not make clear comment on whether they think their work highlights issues that are potentially 'specific' or 'especially important' to Muslim families compared to other ethnic groups (or even the dominant local population – presumably white Canadians?). I think this is a key question in the minds of the readers. I think it would be helpful to consider this in the discussion, even if with qualification. As the authors note, the researcher was of Muslim background, and this was very much the research question.

Response: This manuscript highlights two specific areas in the end-of-life care experience that are unique to the Muslim patient population. We note in the Discussion section (on page 13): Language barriers were identified as an additional element of quality end-of-life care for Muslim patients that was not previously defined in the existing framework.

Respect for cultural and religious values was identified as an important element of quality care for Muslim patients and families.

REVIEWER 3 COMMENTS:

31. Could you provide more justification for the ICU setting for the research? Though this is touched upon briefly in the background section, it would be good to see expansion on this, and addition of justification / explanation in the 'Research Setting' section of the methodology.

Response: Thank you for this suggestion. We have included the following justification in the manuscript on page 4: We deliberately focused on the ICU setting to explore end-of-life decision-making at its most pointed relevance. Patients admitted in ICU typically experience a more sudden or acute illness trajectory which often requires timely decision-making around life-prolonging measures such as CPR and mechanical ventilation.

32. Please report the ethical approval number and institution in the methodology section. If approval wasn't sought, please justify why

Response: An ethics approval statement was added to the Methods section of the manuscript (on page 6).

33. It is good that cultural humility is mentioned throughout. It would be good to see this drawn upon more, for example in the discussion / as a recommendation from this research

Response: Thank you for this suggestion. We have included two explicit references on cultural safety and humility (on page 13): There may be opportunities to enhance cultural safety and humility among healthcare staff to prompt for and document cultural considerations important to the patient and family while engaging in advance care planning or goals-of-care discussions.

Insights from this research can inform clinical processes and interventions to improve quality of care, enhance cultural safety and humility, and reduce psychological and emotional burden at the end of life.

34. In the first paragraph of the discussion (page 12, line 9), you have said "Culture, religion and religiosity did not appear to have a major influence on the medical decision-making process." Though this is true from your data for the decision making process, it does not appear true for the care process / preferences for care received (i.e., personal care etc). It would be good to make this distinction here

Response: We appreciate this excellent suggestion. We have added the following text in the manuscript on page 13: While culture, religion and religiosity did not appear to have a major influence on the medical decision-making process, respect for cultural and religious values was identified as an important element of quality care for Muslim patients and families. Perceived failure to acknowledge or address ethnocultural beliefs and values at the end of life appeared to have contributed to loss of trust and lower satisfaction with the quality and experience of care.

VERSION 2 - REVIEW

Reviewer **1**

Name **Walsh, Timothy**

Affiliation **Edinburgh University, Critical Care Medicine; Centre for Inflammation Research**

Date **19-Nov-2024**

COI

Thank you for the opportunity to review the revision of this manuscript. The authors have made a comprehensive response to my previous comments and suggestions and I will focus on these.

My only additional or outstanding suggestions/comments are:

1. In relation to point 13, it would be clearer if the range of times (in months?) from end-og-life care to the interviews were included. The inclusion of a range of dates for the deaths and the interviews does not allow the reader to gauge the time delay between the events in the five case studies. This seems an important detail given the impact of recall bias and also grieving processes etc.

2. In relation to data saturation and also purposive sampling (points 20 and 28, and also 19 and 24). I accept the argument about this being ‘case study’ deductive work rather than inductive thematic analysis. However, the purposive sampling underpins protecting against bias (alongside the reflexivity). I’d still be concerned that the numbers were small, 4/5 were male, generally highly educated and/or medical, and they may not have been representative of the community. This does not detract from the work or findings, but i think it merits a little more in the discussion on limitations than the additions with the revision.

3. In relation to their response 26, I would suggest an infographic summarising the findings is included in the main paper. It will provide the 'take home' message in an accessible form to readers. Currently there is only one table and no figures.

Reviewer	**3**
Name	**Crooks, Jodie**
Affiliation	**Marie Curie, Policy and Research**
Date	**10-Dec-2024**
COI	

This is an important research area with clearly defined objectives. The methodology is clearly outlined to be appropriate for meeting the research objectives, and is thoroughly reported in the manuscript. The authors have comprehensively addressed the reviewers comments in this amended manuscript.

Although it is not possible for the current manuscript, I would suggest, in future work, considering ways to generate Patient and Public Involvement in your research. Whether this is full co-production of research, or holding focus groups with people with lived experience to review and gather feedback on the study materials, results of your study etc., it can add great value to your research.

VERSION 2 - AUTHOR RESPONSE

REVIEWER 1 COMMENTS:

1. In relation to point 13, it would be clearer if the range of times (in months?) from end-of-life care to the interviews were included. The inclusion of a range of dates for the deaths and the interviews does not allow the reader to gauge the time delay between the events in the five case studies. This seems an important detail given the impact of recall bias and also grieving processes etc.

   Response: Thank you for this comment. We have updated the text to read (on page 5): *Interviews took place between August and November 2022 (ranging from nine to 36 months after patient death).*

2. In relation to data saturation and also purposive sampling (points 20 and 28, and also 19 and 24). I accept the argument about this being 'case study' deductive work rather than inductive thematic analysis. However, the purposive sampling underpins protecting against bias (alongside the reflexivity). I'd still be concerned that the numbers were small, 4/5 were male, generally highly educated and/or medical, and they may not have been representative of the community. This does not detract

from the work or findings, but i think it merits a little more in the discussion on limitations than the additions with the revision.

Response: We agree with this comment and have added a more detailed description around the concept of saturation in the text and the need for further inductive research (page 14): ***Our aim with this initial study was to validate and exemplify existing theory with Muslim patients/families rather than to develop new theory; however, there is importance in conducting further research (using inductive approaches and more demographic variability) to explore how the end-of-life care experience is influenced by region or country of origin, racial/ethnic background, or level or religiosity/spirituality.***

3. In relation to their response 26, I would suggest an infographic summarising the findings is included in the main paper. It will provide the 'take home' message in an accessible form to readers. Currently there is only one table and no figures.

   Response: Thank you for this suggestion. We have included an infographic in the manuscript on page 18 to display the key themes.

REVIEWER 3 COMMENTS:

1. This is an important research area with clearly defined objectives. The methodology is clearly outlined to be appropriate for meeting the research objectives, and is thoroughly reported in the manuscript. The authors have comprehensively addressed the reviewers comments in this amended manuscript.

   Although it is not possible for the current manuscript, I would suggest, in future work, considering ways to generate Patient and Public Involvement in your research. Whether this is full co-production of research, or holding focus groups with people with lived experience to review and gather feedback on the study materials, results of your study etc., it can add great value to your research.

   Response: Thank you for this important comment. We are in full agreement with the importance of patient involvement in research and will seek to further engage this group from the outset of research in future studies.
