Author’s response to reviews

Title: Multidimensional needs of patients living and dying with heart failure in Kenya: a serial interview study

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Author’s response to reviews:

Dr Sara Booth
Editor
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Dear Dr Booth,

Re: Manuscript PCAR-D-17-00150R1 – Response to reviewers’ comments

Multidimensional needs of patients living and dying with heart failure in Kenya: a serial interview study

We thank the reviewers for their helpful comments on this manuscript and have addressed their concerns below.

Reviewer 1: Elizabeth Walker

1. This paper is a resubmission in which the authors indicate that they addressed the corrections raised. I did not review the initial submission and I am sure if is appropriate to raise additional issues at this point. However, I did want to identify an important finding
from this research which can be further developed. The authors suggest that there is a lack of patient understanding and knowledge of non-communicable diseases thus impacting on their experience and management of health failure. This points to a wider epidemiological shift taking place in Sub Saharan Africa, a shift from communicable to non-communicable diseases (or the complex coexistence of both). Yet, patient experience and popular/lay knowledge of illness is only almost exclusively of communicable disease and acute illness. Living with Long Term Conditions for a host of epidemiological, socio-economic, and other factors is not as widely experienced or researched - a situation which is rapidly changing. What this means for patient understanding of symptoms and this seeking treatment is an area for development. The discussion did tend to reiterate the findings rather than further develop the themes identified earlier (P16 lines 1-41). In the methods section bereavement interviews are mentioned but not explored in the paper. It is not clear if the patients were asked about their perceptions/understandings of palliative care?

Response

(i) An initial resubmission of this manuscript was made in response to the Editor’s request to exclude participants gender in the quotations and in Table 1 to protect their anonymity. The Editor also suggested we place Table 1 at the end of the manuscript and report participants age by range.

(ii) We have included a paragraph (line 391-395, page 17) to reflect the reviewer’s comment on the epidemiological shift from communicable and non-communicable disease and implications for patients’ understanding of symptom and seeking treatment

(iii) The aim of the discussion was to place the findings in context with regards to previous findings and the setting in which this study was conducted. We have discussed the implications of these findings and intend to explore these further in a subsequent publication on how services can be improved.

(iv) Bereavement interview: Three patients died before the end of the study period and we were able to trace two carers for interviewing. The aim of the bereavement interview was to explore patients’ experiences in their last days of life. We have included a quote from a bereavement interview (line 276-278, page 12) to illustrate little social support in last days of life and included a small comment in the discussion (line 380-382, page 16).

(v) Although we did not aim to ask patients about their understanding of palliative care, we asked about their multidimensional needs and experiences which reflected the philosophy of palliative care. We were careful not to use the word ‘palliative’ which tends to be associated with care for dying especially for those with cancer. By doing so, we would have introduced an implicit bias causing patients to perhaps view their illness as terminal which would be in
contrast to our findings that show patients had poor understanding of their illness and prognosis. Additionally, it would have been unethical and insensitive to discuss palliative care when majority were yet to discuss their prognosis with a health care provider.

Reviewer 2: Julie Burkin

1. I have reviewed the article "Multidimensional needs of patients living and dying with heart failure in Kenya: a serial interview study" and have the following comments:

A really interesting study and very important piece of research into patients living with heart failure and their carers in SSA.

2. Abstract

(i) In results section - what does "information needs" refer to specifically?

Response

We have amended this section and included the following sentence to describe information needs:

Abstract, line 57-58, page 2: They also had unmet needs for information about their illness, how it would affect them and how they could get better.

(ii) It may be worth putting here what percentage / proportion of patients expected to be cured or valued info, etc, to give an idea of whether this was a global theme or just stated by a few participants.

Response

We have included the following sentence to show that expectation of cure was a major theme.

Line 61-63, page 2: Nearly all patients expected to be cured and were frustrated by a progressive illness poorly responsive to treatment.

(iii) The conclusion states that "Patients would benefit from holistic care" and "A palliative approach to services should be provided" which I don't disagree with but I think it would be
better worded to say "this study suggests / supports the view that patients would benefit from holistic care..." etc.

Response

We have included the word ‘suggest’ to reflect the reviewer’s comment.

Line 69, page 3: This study suggests that patients would benefit from holistic care, such as a palliative approach, that is aimed at providing multidimensional symptom management.

(iv) As this is the first Kenyan study would it be worth recommending further research in the conclusion?

Response

We have included the following sentence in response to the reviewer’s suggestion

Line 73-74, page 3: Further research is needed to determine best practice for integrating palliative care for people living and dying with heart failure.

3. Background - p.5 line 2 (4th paragraph)

The authors state that they wanted to understand from patients their needs and what it is like for them to live with their illness - it would also be useful to state how this could inform / impact on healthcare practice.

Response

We have amended this section to state how understanding patients’ needs could inform services.

Line 122-124, page 5: We wanted to understand from patients, in their own words, what it is like for them to live with their illness. This type of research supports patients to share their experiences and become active participants in suggesting how services can be better improved to help them.

4. Setting - p6 line 36

Explain a little more what New York Association Grade is?

Response
We have included the following sentence to explain New York Heart Association grading.

Line 152-154, page 6: We approached patients who were breathless with less than ordinary physical activity or breathless at rest (New York Association Grade III or IV).

5. Data Analysis - p8

First sentence needs expanding on. Also might be preferable to state professional roles rather than initials?

Response

We have amended the first sentence to enhance clarity of this section

Line 188, page 8: We were guided by Braun and Clark’s [25] multi staged approach to thematic analysis.

We stated professional roles in line with the reviewer’s comment

Line 192-195, page 8: Multidisciplinary team meetings were held regularly with experienced palliative care researchers (LG, SAM) to consider emerging codes, themes and data saturation.

6. Results - p9 line 8

(i) Expand on what information needs means exactly.

Response

We have explained information needs as follows:

Line 207-208, page 9: They also had little access to information on their illness including prognosis and treatment.

(ii) Physical Symptoms - p9 - I like the use of patient quotes and this is very effective.

Response

We appreciate the reviewer’s comment
(iii) Information Needs - p14 line 54 - It would be good to know what proportion of people were interested in lifestyle changes of managing their condition as it states earlier in the article that most people think the condition is curative and are seeking cure rather than management.

Response

We note that nearly all patients understood their condition as short term illness and expected a cure. Interest in lifestyle changes was to prevent a similar episode of illness from occurring in the future. We have included this statement in line 340-342, page 14.

(iv) Implications for Practice - p18 - might be worth more explicitly stating the opportunity for education, health promotion and facilitating self-management.

Response

We have included a statement reflecting this comment in line 427-429, page 18.

Thank you.

With very best wishes,

Dr Kellen Kimani