Author's response to reviews

Title: Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies

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Author's response to reviews: see over
To Associate Editor,

Thank you for the opportunity to considerably revise this paper in accordance with your advice and the comments from the four reviewers. We are very grateful for these comments and our detailed response is laid out below. We feel the paper is much stronger now, and thank yourself and the reviewers for their very helpful comments.

Letter of responses to reviewers

Responses to request for revision by the Associate Editor

1. We have included a statement within the text that clarifies that consent was sought and obtained for all photographs, which included permission to print these photographs in public documents.

2. We have made the introduction more accessible and informative for those who have limited knowledge of the African context. The following two sentences have been inserted: “With minimal resources, huge shortages of health workers, national health systems in a number of African countries have focussed primarily on preventive, curative and maternal health services, responding to a set of immediate (and development agency identified “best buys” in healthcare through their Essential (or Basic) health packages. In many countries minimal or no resources have been dedicated to supportive or palliative care”. (see track changes)

3. We have reviewed the RATS guideline for qualitative research, and have strengthened the methods section accordingly, giving a fuller description of the study design, sampling and analysis (see track-changes)

4. Full ethical permission was not applied for as this was not a piece of experimental research. We report an in depth “service evaluation” rather than formal research, evaluating the effect of the three community based palliative care interventions in sub-Saharan Africa. Guidance from our SE Scotland Ethics committee was that such “service evaluations” do not require ethical
The hospitals involved all individually consented to the evaluation. We however, as we have done in Africa for over 10 years took great care to fully consent all participants, and make every effort to ensure that no harm was done.

Response to reviewers
Below we have responded to the comments by each of the reviewers in turn. Where similar comments were made we have fully addressed the issue the first time it is raised and referenced it in the following reviewer responses:

Reviewer 1
1. **Reference to two abstracts.** We were unsure of the reference that the reviewer makes to the “two abstracts” as we have only provided one abstract in the paper.

2. **Inclusion of reference to Non HIV palliative care programmes predating the HIV programmes.** We recognise that the sentence on page 14 fails to justly describe the earlier non HIV palliative care interventions and have corrected this in the paper with the following sentences (see pg XX)

   While initial palliative care services were developed specifically for cancer such as Island Hospice founded in 1979 in Zimbabwe and Nairobi Hospice in Kenya in 1990, HIV pandemic pushed forward a new wave of palliative care in the 1990s which was very much focussed on home based care. Thus the more recent constructions of palliative care became very much associated with terminal AIDS care.

3. **Definition of palliative care.** We contend that the more comprehensive definition of palliative care that the reviewer urges us to use is indeed the definition that we do use and on which we have based our evaluation. We have clarified this in the text (p_.)

4. **Reviewer 1 comments that our conclusion that new models of palliative care need to be made for cancer is erroneous.** We note that our conclusion states that “those living with other life limiting illnesses such as cancers have less access to help” which we still believe to be the case. We clarify that models must be dynamic.

5. **Use of Charcoal.** Reviewer 1 notes that she is not aware of the use of charcoal. We respect this reviewer who has worked in Africa for many years, but the use of charcoal was a finding, and reported as such.

Reviewer 2

1. **Recording of interviews.** We do recognise the value in recording interviews, and planning for the evaluation we did discuss this option. We finally chose not to tape interviews so as not to disturb the relationships
between the providers and their patients and service users. Our interest was in capturing, as closely as possible, the nature of this relationship. Also a major tenet of the rapid evaluation technique is “proportional accuracy”, which means using a method that effectively gathers the data you need, but does not take too long to carry out. The researchers in the field carried out initial analysis of interviews on the day they were carried out, which interviewing would have prevented.

2. Exploring Commonalities and differences. We recognise the importance of highlighting commonalities and indeed differences across the three countries. The summary paragraph that introduces the discussion section already tries to illustrate the commonalities. We have added in areas of difference. “National differences in how health systems were established and managed affected local difference in programme delivery. This was most evident in the different ways that HIV treatment, patient management and palliative care were delivered, with Malawi’s very effective HIV programme functioning through a silo system. P

3. Reviewer 2 notes that there is insufficient information on deficits and failures. We admit that in our attempt to keep within the word count we reduced the range of quotations from patients, and in doing so have few examples of more negative responses. We did encourage patients and staff within the different programmes to talk about their problems, and challenges, and we did seek patients who might be more likely to have issues with the services, rather than “their favourite patients”. Patients and staff were almost always positive constantly comparing the situation to what it had been like before the palliative care projects began. Some patients, such as the patient in Malawi, did speak critically of the team and we have added a comment to provide more substance to the quotation that is already in the paper. Some patients were critical of the failure of teams to provide comprehensive care, “My house leaks when it rains, and the bedding is not enough. I am very cold in the evenings, especially this month. I wish the team could help mend my house” said Zora, a patient in Malawi.

Also patients did comment that the volunteers seemed to be doing much of the work, over and above the work that the team members did, and were critical of this, recognising that staff were paid and volunteers were not. We have referred to this criticism within the paper (p) but acknowledge that we could have expanded this more thoroughly.

Reviewer 3

1. Request for further description of the methods. We have included more detail on methods in the Methods section “The rapid evaluation method (REM) was developed by the WHO to provide a rapid assessment of the nature, performance and the effectiveness a health care service. It builds on a triad of data, observational data on what is actually happening in the system, who is doing what, how are things visibly organised, survey or interview based data from service, providers, users, or those engaged with
the service. The methodology is unique in its ability to bring together a series of data that can be internally validated.

Potential Participants were identified by staff and by a review of the casebook and case identifiers and we sampled the potential interviewees to ensure that we saw a range of patients who reflected the programme staff’s perspective on their caseload, and patient and community perspectives on who was being seen by the team.

Interviews were conducted by 2 researchers together, one interviewing and the other taking extensive notes, using a topic guide, which allowed for flexibility, enabling more sensitive interviewing and fluidity in the interview process. Each item in the topic guide functioned as a trigger for further more in-depth questions on the topic, that evolve in response to the person who is being interviewed. (topic guide included)

Data were analysed using standard qualitative interview analytical techniques, interrogating the data for thematic correlates, and dissonances, and capturing linguistic expressions to convey individual, and communal beliefs, attitudes, and feelings. All team members contributed to the analysis. A main analyser was identified for each set of materials. See track-changes in methods section)

2. Request for “a little more balance in interpretation”. As noted under responses to Reviewer 2 we have been more specific about the negative comments from those interviewed.

3. Request for a statement of ethics. Please see comment to Associate editor.

4. Typos. We have corrected the typos identified by Reviewer 3

5. Use of the word “indisputable”. We do accept reviewer 3’s opinion that the word is over-inclusive and have redrafted the sentence to remove the word.

6. Reviewer’s request for an anonymous identifier could be reported alongside quotes to give a sense of spread throughout the sample. Additional information has been added to each quotation to permit this.

MAJOR COMPULSORY REVISIONS
7. Too brief an introduction with limited information on programmes. We have extended the introductory section to provide a more systematic introduction to palliative care in Africa and referenced further information sources for the programmes.

8. Extension of Methods section: As noted earlier we have included a more comprehensive review of the rapid evaluation methodology and addressed the specific comments of Reviewer 3.
8.1. “Routine local information relevant to palliative care”; (as noted in the paragraph this was all reports, (published and unpublished, newspaper comments, and documentation about palliative care in the area).

8.2. How were patients families and staff recruited, interviewed etc and how were these data analysed; (discussed above)

8.3. In the direct observations how was a quality assessment made, against what criteria. The quality of the palliative care encounter and the counselling were assessed using a quality framework based on good practice which included the following domains: patient focussed, empathetic, provision of an holistic assessment (clinical, social, emotional, spiritual) appropriate listening skills and effective sensitive communication, confidentiality, and information giving.

9. Ethics. We have addressed this under our response to the Associate Editor.

10. Lack of “see web extra”. The web extras were included in the original submission, and are now re-appended.

11. To what interview category does Local politician fit? The quotation attributed to a “local politician” was captured during the interviews with local community leaders. The Local Politician regarded himself as a local community leader.

12. Response to reviewer’s comment that it would be very surprising if many patients didn’t continue to die in severe pain. We have changed this accordingly recognising the reviewer’s point. We have removed the sentence, "Before home based care was available in the region many patients died in severe pain" and added the sentence “At least now with the team presence many more people get good pain relief than previously was the case”

13. Response to sentence “the presence of the palliative care teams in the community had shifted attitudes towards those who are dying”. We have now prefaced this quotation to show that this was the perspective of those being interviewed, who included palliative care team members and patients, “Staff and patients spoke of how the presence of the palliative care team was changing community attitudes to death and dying."

14. Balance of negative and positive comments. As noted for reviewer 2 we have incorporated in a stronger way the negative messages that were heard.

15. The Contribution of the co-author’s photography to the paper. Some additional photographs which demonstrate the issues of poverty, technology, volunteer engagement are presented in the web extras.

Reviewer 4
MAJOR COMPULSORY REVISIONS

1. The focus of the paper is on end-of-life care. We do recognise that palliative care should be much more than terminal care, and have tried throughout the discussion to illustrate this. We have changed the first use of the term “end of life care” in paragraph one to the term “palliative care”. We do recognise that in the UK “end of life care” means much more than terminal care, and that it incorporates the staging between acceptance that illness is no longer curable but life limiting. We recognise that this understanding of the phrase is not so common in African countries where end of life is often only associated with last days. We have clarified this vocabulary.

2. Reviewer 4 comments: While none of the programmes focussed exclusively on care of patients who were terminally ill, there has been a tendency especially in HIV palliative programmes before the advent of ART to see the palliative stage as a final stage. In our discussion we have tried to emphasise that palliative care must be more than terminal care, and indeed this is an actual discussion heading in the paper. See p

3. Reviewer 4’s request for caution given there is no control group. Our Response: As this was an evaluation of service impact a control group was not appropriate. We have revised the conclusion section of the Abstract to include the word “reportedly” to indicate that the belief in success was shared by those interviewed – patients, staff and community leaders.

3.2. Pg 5, section 2: how were interviewees selected and how were the sample size determined (thematic saturation)? See information in detailing of methods under Reviewer 3 responses.

3.3. What are ‘question outlines’? Questions? Question outlines, otherwise known as topic guides are one of the standard tools within qualitative research and qualitative reviews to collect data.

4. Assessment of quality of PC and counselling provided. See response to Reviewer 3 comments above.

5. Ethical permission. See above.

6. Data analysis. Additional information on the methodology has been included under responses to Reviewer 2.

7. In the course of this paper, there appears to be no observational data reported. This could be outlined in the methods section so readers are not looking for it (i.e. say what you are presenting). The observational data collected included photography, aspects of poverty, broken houses, leaking roofs, beds with no sheets, food scrapings; it included use of mobile technology, - phones, and lists of phone numbers placed on clay walls which had no other adornment. We observed medications. We observed patients in pain, patients supported by volunteers, patients speaking with their family members, we observed school children running around the homes and compounds who should have been in school. These observations shaped the
discussion section, and strengthened the quotations from patients and from staff on the nature of care and the challenges to delivering good care.

8. Pg 3, In 20: ‘palliative care’ rather than ‘palliative project’? We are unsure what the reviewer is suggesting. If it is the final sentence of the abstract then we do wish to have the term “care” remain.

9. Pg 4, In 4: should be ‘Hospice Africa Uganda’. We have corrected this.

10. Pg 4, ref 4: could consider also citing the Cape Town declaration. We have now added the reviewer’s paper on the Capetown Declaration.

11. Pg 4, ref 6: is the UNAIDS citation appropriate? Yes.

12. Request for additional information with sub headings such as settings and precise information including km distances etc. If the word count were unrestricted then we would have included this material. Additional material on the sites can be found in a report to the Diana Princess of Wales palliative care initiative available on their website. We have inserted a reference to this so that readers can gain more knowledge of sites.

13. Additional references required. If references exist, they should be cited, even if they are official service provider publications. We have now included the reference.

14. Pg 5, In 6: request for definition of Multidisciplinary team. The multidisciplinary team consisted of a Medical anthropologist, a palliative care consultant, a palliative care researcher and trainer, and a primary palliative care consultant (please add to paper)

15. Extensiveness of the review of local information and published materials. The review was very extensive. We examined all of the grey literature and unpublished reports from all three sites. We have comprehensive summaries of all literature reviewed including all reports which the programme had previously sent to the Diana Princess of Wales palliative care initiative. Our summaries can be made available if needed.

16. Suggestion to include additional detail in Table 1. (The table has been supplemented with some additional information.

17. Malawi: there is talk of ‘most’ and ‘many suffered’, but the vast majority of quotes are presented as singular in nature, apparently recording individual narratives rather than a majority opinion etc. The nature of the interviews meant that we collected personal “narratives” from various patients and staff. This is the normal way of reporting and analysing qualitative data.

18. Use of thematic sub-headings. We have not added these headings so as not to break the flow.
19. ‘A Ugandan volunteer also noted …’ should not be in italics. Corrected.

20. What is the multi-tasking nature of Kitovu palliative care team? As noted earlier, the Kitovu team engage in holistic care, providing comprehensive services, and treating the needs of family members as well as patients whom they visit.


22. Should be ‘seeking health care’, not ‘seeking for health care’. We recognise the reviewer’s comment but believe in the context of the sentence that seeking “for” health care is more appropriate.

23-25. Discretionary Revisions. We have corrected/changed - studies; wife; WHO;

26. For all the results section, authors should try to keep the descriptive details of each site in the suggested settings sub-section, and only use this for thematic results. We recognise this as an alternative writing style, but have kept the original structure of the paper.

27. ‘You are a god …’, is a quote within a quote. Corrected.

28. Pg 11: There is repetition regarding the inability of the Maua programme to retain volunteers. Could be tightened. Noted and tightened.