Author's response to reviews

Title: Knowing and Being Known: A Qualitative Ethical Analysis of Social Values in Rural Palliative Care

Authors:

Barbara Pesut (barb.pesut@ubc.ca)
Joan L. Bottorff (joan.bottorff@ubc.ca)
Carole Robinson (carole.robinson@ubc.ca)

Version: 3 Date: 1 September 2011

Author's response to reviews: see over
August 31, 2011

Adrian Aldcroft

In-house Editor BMC Medical Ethics

Attached you will find the revised manuscript entitled Knowing and Being Known: A Qualitative Ethical Analysis of Social Values in Rural Palliative Care for publication in BMC Medical Ethics.

As requested we have highlighted all our revisions with track changes. Here is a synopsis of our changes in response to the reviewer feedback:

Reviewer: D.M. Wilson

1. the title now focuses on one of the themes arising from the qualitative analysis, and although it is the "main" theme, I am concerned with its use in the title - as there is much more than "Knowing and Being Known." The title has been changed.

2. in the abstract and later on, I am concerned on page 6 with the words - worked alongside - when this should perhaps be "shadowed" or "accompanied" or "observed" rural healthcare providers. Research observation is hard work in itself, without the observer working to provide home care! This has been changed to accompanied as recommended.

3. The abstract's results are very clearly outlined as such - "this study illuminated the core values of knowing and being known, being present and available, and community and mutuality that provide the foundation for ethically good rural palliative care." It is unfortunate that these 3 themes are not more clearly outlined in the case study description and discussion and conclusion. In addition, on p. 18 these are described as "ethical tensions", and on page 17 - "highest values" are mentioned instead. What we are trying to illustrate in this paper are not only the values that are upheld but also how those values can be violated – hence leading to lower perceived quality of care. Good qualitative research will show variability in the data and so we have purposely chosen not to simply focus on the beneficial effects of these values but also to illustrate how these same values can have negative effects and how the politics of care come to bear when these values are perceived to be violated – hence the language of ethical tensions and highest values are used concurrently. This is why the case study is particularly important and why we have chosen to include certain points in the discussion. Please note we have not disregarded the values in the discussion. We do discuss them further in paragraphs on page 20 and 21. However, we have chosen to extend the discussion to the politics of care and resulting ethical tensions as they relate to the values. This line of discussion is particularly important in light of Kelly’s work as outlined on page 4 in the introduction. Ethical issues in rural health must “pay attention to the lived experiences of individuals that are formed by the complex political, economic, and social realities...” This is not just a qualitative study about values but an ethnography that looks at the interplay of values and politics that create ethical tensions for rural residents.
The authors must be cautioned that NOT all rural people will share the same core values. In the bottom paragraph on page 17 - it is stated that "they are required to go to a strange place to die." Does this mean that NO one dies at home now because of this shift in health care from a small rural to city hospital? This is a very dramatic statement that does not add to the professional tone and information of this manuscript, it does not appear that funds for local homecare were increased with the rural hospital closing. We have added a qualifier and the limitations clearly caution against any sweeping generalizations of rural values. See e.g. Further, we are conscious that simply by writing about rural values we run the risk of reifying the idea that rural culture is homogenous [14]. In describing these values our intent is not to suggest that they characterize all of rural life but rather to show how they play into building rural capacity for palliative care and how initiatives that disrupt these values also disrupt care. P. 23.

4. Another issue is that burnout among homecare nurses is not mentioned. It would seem to me that one issue with working 24/7 is burnout. Shift work, broken sleep, long daily work hours, and caring for dying neighbours and other local community people - could all lead to burnout. It is not just family members who burn out, but also paid caregivers. Thank you for this point. It is interesting to note in our data that there was only one suggestion of a caregiver burning out and it was difficult to use this example because we also interviewed this caregiver and she did not see herself as burning out. Rather, she saw the loss of her position in relation to the politics of palliative care. We agree that we expected to see more about burnout but it was not born out in our interviews.

5. Some wording changes are needed:
- p 4 - euthanasia is illegal - why mention it here?
- p 4 - reference 13 is a report of Toronto bioethicists' opinions - it would be appropriate to tell readers this. Changed as recommended.
- p. 5 do you mean contradiction and not contradistinction? No we do mean contradistinction which is "distinction by contrast" not contradiction which is a logical incompatibility.
- p. 6 do you mean acute care hospital? As acute is vague and may not be understood by all readers. In addition on this page - what is the difference between field work and direct observation? Clarification made.
- p. 12 needed presence - could instead be phrased "on-site" On-site was added but we have kept presence in keeping with the theme.
- please start the section on page 16 with the word - "Some" healthcare facilities are older (as some are brand new)...rephrased.
- p. 21 presents information that goes beyond the findings - which again are outlined nicely by this statement in the abstract - this study illuminated the core values of knowing and being known, being present and available, and community and mutuality that provide the foundation for ethically good rural palliative care. I would recommend deleting page 21. The findings which support this section arise from the findings on community and mutuality (see para on ownership on p 15) and the case study. We do not bring these findings into the discussion except on this page so omitting the entire page would be problematic.
- similarly the last half of the paragraph on P 24 goes beyond the findings. I
would suggest deleting this section of the paragraph. See comment above. Again, there were important tensions around mutuality and decision making that c
* there are a few typos and editing corrections needed throughout the manuscript - such as 11 and 31 references in reference list – Corrected.

Thank you once again for considering this article. We will look forward to your decision.

Sincerely,

Barbara Pesut PhD, RN
Canada Research Chair (Tier 2), Health, Ethics and Diversity
Assistant Professor of Nursing
University of British Columbia