Author's response to reviews

Title: Recommendations to improve the end-of-life care system for homeless populations: A qualitative study of the views of Canadian health and social care professionals

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Author's response to reviews: see over
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Dear Dr. Jennifer Kryworuchko:

Re: Submission No. MS: 4517413806848520

Thank you for the opportunity to resubmit our manuscript following revision for possible publication in *BMC Palliative Care*. We also thank the reviewers, Drs. Isolde Daiski and Edward Ratner, for their thoughtful comments on our manuscript.

As requested, we have revised our manuscript based on the reviewers’ comments. Attached to this cover letter is a detailed description of changes to the manuscript (including page numbers). All authors have reviewed the reviewers’ comments and have approved the revised manuscript.

We hope that you find these revisions acceptable. Please do not hesitate to contact us if you have any questions regarding this manuscript. We look forward to hearing back from you.

Sincerely,
Ryan McNeil, PhD Candidate
on behalf of the authorship team
Response to the comments of Dr. Isolde Daiski

Minor Essential Revision
The method is appropriate but some comparison between 4 sites could be made, e.g. were they all the same or different? Were some more appropriate than others?

1. We thank Dr. Daiski for this comment. Barriers and recommendations reported across the cities included in this study were consistent, although the availability of low threshold services in two cities were perceived to minimize some barriers. We feel that our data does not therefore support comparison between cities and have added the following statement to the introduction to the Results section (p. 9):

“Barriers to and recommendations for improving the end-of-life care system were consistent across the cities included in this study, although the availability of low threshold services in two cities (Ottawa and Toronto) was perceived to minimize some barriers to care.”

Include a brief description of the palliative care system in Canada.

2. In the introduction, we have added information about the palliative care system in Canada (p. 4)

In Canada, where we conducted our research, hospice and palliative care services are underdeveloped [31] and are structured in ways that limit access for homeless populations. For example, existing service structures emphasize family caregivers and dying-in-place (i.e., the home) [31-32]. Accordingly, in many regions, end-of-life care services are oriented toward providing home care support and potentially limit access for homeless or precariously housed persons. Hospice and hospital-based end-of-life care services are also available to provide an additional source of care in many communities, especially in urban centres [31]. However, homeless populations are often unable to access hospice or hospital-based end-of-life care due to rules and regulations (e.g. anti-drug policies, codes of behaviour, etc.) that exclude substance-using populations [29-30].

Include a section on facilitators.

3. We thank Dr. Daiski for this suggestion. In the course of our study, we identified few facilitators to end-of-life care services for homeless populations. The main facilitator that we identified (harm reduction services) has been reported elsewhere in great depth. We have subsequently removed references to
facilitators throughout the article. Our other work is referenced in the text and can be easily accessed by interested parties (published in BMC Public Health).

Include your recommendations you draw from the discussion, literature and the recommendations of the participants, especially as this is stated in your title [in the Conclusion, according to embedded comments]

4. We thank you for this comment. We have reiterated these recommendations in the Conclusion by adding the following statement (p. 17):

These observations have the potential to be translated into policy and programmatic responses, notably the expansion of end-of-life care services, implementation of patient advocate programs, and adoption of harm reduction policies.

In-text comments embedded in the PDF

5. We have made changes to the manuscript based on comments embedded in the PDF version of our manuscript supplied by Dr. Daiski. Specifically, we added a statement to the limitations that increased work is needed to involve care recipients in developing recommendations to improve the end-of-life care system. We made a slight change to the labelling of Theme 1.1. We also expanded the first paragraph of Theme 2.2. to better account for the role of individuals in potentially mediating access to end-of-life care services (p. 12).

“Participants articulated how the trust developed between these agencies and homeless populations helped to mediate access to a range of other services (e.g., primary care, specialists, etc.) and could perform a similar function in the context of end-of-life care. Furthermore, participants reported that these agencies, and especially trusted staff, were able to monitor changes in health status over time due to their sustained contact with this population and mediate access to health and end-of-life care services.”

Response to the comments of Dr. Edward Ratner

Major Compulsory Revisions
Song et al research describes external factors that are of concern to homeless regarding end of life care…
6. We thank Dr. Ratner for this and other suggestions. We have referenced these articles and the first is briefly discussed in the background section.

**Need to describe how many interviewers there were? How trained?**

7. We have added a statement describing how many interviewers and how they were trained, as follows (p. 7):

“The majority of interviews were conducted by the lead author (RM), a qualitative health researcher, while the remaining interviews were conducted by the study principal investigator (MGY), a clinical psychologist.”

**Need to describe how many people involved in coding? What was process for collaboration between coders?**

8. We have added further information regarding our analytic process, who was involved, and the process for collaboration, as follows (p. 8)

Two of us (RM & LBD) independently coded the data by drawing on constant comparison methods, wherein preliminary categories were revised and emerging categories were identified and expanded through constant comparison to the data [42-43]. We regularly met to discuss emerging categories, with any revisions to the coding framework made by consensus. All authors discussed emerging themes to aid in framing the findings in relation to existing literature. Once the final categories were established, one of us (RM) re-coded sections of the data to ensure the credibility of these categories.

**Since dying patients most needing end of life care services typically can no longer access street drugs and often, regardless of housing status, have altered cognition, it is unclear how history of substance abuse or mental illness inhibits enrollment in end of life care programs. Article needs better description of the types of services homeless patients are denied.**

9. We thank Dr. Ratner for this comment. During the course of our study, substance use was continually identified as the most significant barrier to end-of-life care services for this population. We have reported on this elsewhere in much greater depth than is possible within the context of this article:

McNeil R & Guirguis-Younger M. Illicit drug use as a challenge to the delivery of end-of-life care services to homeless persons. *Palliative Medicine* 2012; 26: 350-359
McNeil R et al. Harm reduction services as a point-of-entry to and source of end-of-life care and support for homeless and marginally housed persons who use alcohol and/or illicit drugs. *BMC Public Health* 2012; 12: 312.

Citing this work, we have made minor changes to this article to better describe how substance use serves as a barrier to care. We added the following statement to the Background section (pp. 4-5):

“However, homeless populations are often unable to access hospice or hospital-based end-of-life care due to rules and regulations (e.g. anti-drug policies, codes of behaviour, etc.) that exclude substance-using populations [29-30]. For example, research suggests that, among those who continue to use alcohol or illicit drugs at end-of-life, abstinence-only policies and discrimination in hospice and palliative care settings serve as a significant barrier to care [29-30]. Furthermore, homeless persons who use alcohol or drugs may also refuse referrals to hospice and palliative care services due to a range of factors, including real or perceived discrimination in these settings or the preference to die in a familiar environment (e.g., emergency shelter, hostel, etc.) [30].”

We also added the following statement to Theme 1.2. (p. 10)

“In particular, anti-drug policies were identified as a barrier to care and, where formal policies did not exist, participants reported that substance-using homeless persons were identified by intake personnel as disruptive and, on the basis of this, denied services.”

A limitation to add is lack of interviews with mainstream end of life providers, who may have provided a different perspective on why they serve relatively few homeless individuals.

10. We have revised the limitations section as follows (pp. 16-17):

Participants were recruited largely from community settings and our findings only partly reflect changes necessary to improve mainstream end-of-life care services delivery to the homeless. Further research with mainstream end-of-life care providers is needed to get their perspective on end-of-life care services delivery to this population, and in particular why homeless populations are underserved by this system.
**Discretionary Revisions**

*Epidemiology of homelessness should be expanded beyond Canada, as there is an international audience of readers.*

11. We have made minor changes to the opening section of the Background section to extend this work to North America. Specifically, we have made a minor change to the opening two sentences. We have also included information about the aging of the homeless population in the US.

*Background section should describe end of life care system in Canada, such as eligibility and reimbursement and co-pays for hospice programs and whether communities studied had residential hospice facilities.*

12. As noted in our response to Dr. Daiski, we have added a brief section describing the end-of-life care system in Canada.

**Additional changes**

13. We added a statement in the acknowledgements section thanking Drs. Daiski and Ratner for this feedback on this manuscript.