Author's response to reviews

Title: Canada's Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care?

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Author's response to reviews: see over
To the editors of BMC Public Health:

Thank you very much for your comments and willingness to include this manuscript in your journal as an article relevant to the field. We have revised the manuscript based on the reviewers’ comments, and respond to their remarks specifically below.

In response to Nils Schneider, ordered based on his numbered points:

1. Given the Canadian context of this study, we have adopted the definition of palliative and end of life care provided in Health Canada’s Strategy on Palliative and End of Life Care (2007), and this definition encompasses both the terms “palliative” and “end of life”. We have clarified this definition in the revised manuscript, and acknowledge the existence of other terminologies (p. 2-3).

2. As authors, we acknowledge that the introduction to the article is lengthy, yet we believe the information provided is crucial in order to fully address our research question: how does the CCB operate as a public health response in sustaining informal caregivers providing P/EOL care, and how can the CCB become part of a ‘healthy public policy’ that adequately addresses caregiver burden? (p.4) We feel that it is necessary to explain the PHP model and the health determinants as they relate to caregiver burden and issues surrounding palliative and end of life care, in order to set the stage for the remainder of the manuscript and to address the question of interest within a public health framework that is central to our analysis.

3. We have clearly stated our research question both in the preliminary “Background” section (first paragraph on p. 4) and have enhanced the question that was written in the original manuscript just before going into the “Methods” section (on p.7): “is the CCB an adequate public health response to addressing the issue of burden among Canada’s informal P/EOL caregivers?”

4. We have added in the manuscript that the sample size was pre-defined based on a pilot study which helped define the required sample size (p.9).

5. Regarding the interview guide and development, we have mentioned the pilot project in the revised manuscript, and we have also attached some sample interview questions in the Appendix, Table 2. In response to the disease category of the patient, we have now included this information in the Results section (p.9), recognizing that the nature of the caregiving is impacted by the nature of the illness.

6. We have addressed the issue of data analysis by adding to the Methods section, to describe the initial inductive analysis with Nvivo software as well as the deductive stage (this paper), a secondary analysis which enabled us to specifically address the CCB from
a public health perspective using the health determinants as themes and the PHP model as a guiding framework.

7. We have made an effort to include caregiver support programs from around the world, including financial support provided in different countries as it relates most directly to the CCB; this has been added to part of the introduction (p.3,6) as well as to the Discussion section (p.15, 16). Hopefully this will be beneficial to the international community and strengthen the international Public Health perspective.

8. Regarding the unequal representation of participants across the provinces, we have expanded on this in our Study Limitations section (p.17). The high amount of participants in British Columbia and Ontario reflect their larger populations. We did have some difficulty recruiting participants in Quebec, a challenge which is also common in other Canadian studies. We have still obtained a great richness of data and have conducted an analysis from a spatial perspective (see Giesbrecht et al 2009 in references) that highlights the importance of scale and local context in the implementation of the CCB and other supports for family caregivers.

In response to Raisa Deber, based on the points made in order by paragraph:

1. It is true that this paper takes an advocacy standpoint, and we strongly support the premise of the PHP model and the importance of the social determinants of health. Although the PHP model and social determinants framework is not necessarily adhered to by all stakeholders in Canadian society, it is espoused by the Public Health Agency of Canada. Further, the Canadian Senate Committee on Population Health released a report in 2009 advocating the social determinants approach. The PHP model provides a framework that includes the social determinants of health, as well as the “how” and the “who” needed to address these determinants for improved health, occurring across scales and from the individual to the policy level. We have used this as the lens through which to evaluate the CCB, and thus felt it necessary to provide this background on the PHP model as a guiding framework for our research article.

2. The paper does not assume that home care is the same as palliative care and the authors did not intend to imply this. The reality is that there is a documented trend towards a greater number of deaths occurring out of hospital, and much of the burden of care is felt both at home and in other care facilities. We have highlighted health care restructuring in the introductory section of the manuscript to provide a context that helps explain the demands that are placed on communities and families regarding P/EOL care; we have eliminated one reference (Deber 2003) and added one reference (Wilson et al 2002) to better reflect that message. Most of the informal caregivers who participated in our studies were providing care in the home and this is reflected in their comments. In the Background section of the manuscript, we acknowledged that many issues that P/EOL caregivers experience are common to all informal caregivers, but that certain aspects of caregiver burden are exacerbated in the end of life stage (p.6).
3. Regarding the representativeness of the study, this is a qualitative study, and thus the sampling is purposive rather than proportional. We do not claim that this information is representative, though many strong themes emerged from a rich data set. We gathered data that captured the voices of a diversity of informal caregivers across Canada. We are hopeful that this research may create an impetus for more in-depth research into caregiving at end of life.

For this article, we have decided not to analyze the data separately by participant group (successful applicants, non-applicants and denied applicants). Several publications have been released by the research team that address specific features of the CCB and provide detailed recommendations for improvement, based on the perspective of the research participants (see numbers 53 to 56 in the References); this article focuses on the CCB as it relates to caregiver burden and caregiver health more broadly, and it also speaks to the larger caregiving experience and the challenges caregivers face. We have therefore included the perspective of all of the caregiver participant groups, as each group had something to contribute to the thematic results. In order to identify the participants in this paper when presenting direct quotations, we have added the participant group as a descriptor to accompany the quotations in the Results.

We acknowledge that our expectations of the CCB in the manuscript may have been confused with what are, in reality, our expectations for a more comprehensive policy around P/EOL care and support for informal caregivers, of which the CCB would be a part. We believe that the CCB has a vital role to play in providing the best P/EOL care for patients and their families, but by no means do we expect the CCB to address all issues related to caregiver burden. The CCB itself cannot create a social support network or resolve crises for caregivers. Regarding the participant who talked about the care recipient who “just peed the bed”, and how they needed a home care worker to show up, the quotation was meant to emphasize caregivers’ need for more frequent home support and their feelings of helplessness in times of crisis, which can apply to a variety of incidents. We have made a significant effort in the revised manuscript to clarify that we do not expect the CCB alone to address the determinants of caregiver burden and thus improve caregiver health; we see it as a key component of a more comprehensive policy that supports all P/EOL informal caregivers, beyond those working full time, through a variety of mediums, including the provision of improved health and social services such as home care support, and health promotion efforts that educate informal caregivers about available supports and educate the public around issues of death and dying. We thus include broader end of life issues in the Discussion, as the CCB cannot be isolated from them. Our Discussion is framed by the PHP model action strategies in order to discuss the different avenues by which policy and initiatives from the individual to societal scale can support caregivers and improve their quality of life, as well as improve the quality of death of those they are caring for.

4. Rather than go into a detailed explanation of the impact of specific features of the CCB, for the purposes of this paper we have placed the CCB in a broader public health framework to illustrate that an improved CCB is needed alongside multiple other
supports that address the social determinants of health as they relate to caregiver burden. Specific comments and recommendations that different family caregivers provided about the features of the CCB (from all three participant groups) are already provided in several publications, mentioned above, including the widely disseminated lay report that can be accessed here: 
http://www.coag.uvic.ca/eolcare/evaluation_compassionate_care.htm

5. In response to the comment about the need for a clearer understanding of what the CCB might be expected to do and how it might relate to other policies, we have addressed this comment above in point number 3, and have revised the Discussion to make our vision of the CCB’s role more clear, specific to the action strategies of the PHP model.

To the reviewers, we thank you for the time and effort you have put into considering and reviewing our manuscript. We are confident that these revisions will improve the quality and clarity of the research article, which we believe is an important contribution to the international public health literature. We look forward to hearing from you.

Sincerely,

Jeanette Eby (corresponding author) and Dr. Allison Williams, on behalf of all of the authors