Reviewer's report

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?

Version: 1 Date: 4 February 2011

Reviewer: Raisa Deber

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Major Compulsory Revisions

The paper includes some valuable data, but often places it within a context that this reviewer finds less than helpful.

The paper takes an advocacy position, assuming that the perspective of family caregivers is the appropriate policy goal, and that the population health promotion (PHP) model is universally accepted. One might also view this as a question where there are multiple policy goals, and recognize that Canada (like many countries) is faced with an ideological dispute as to the appropriate goal of various stakeholders, including government, families, and voluntary charities. The approach taken in this paper assumes that "the PHP model operates as a central tenet of public health in Canada, evident by its inclusion in the framework of the Public Health Agency of Canada." It is replete with talk of rights and entitlements, and equity. Others (including this reviewer) see little evidence that the broader determinants of health framework has been widely accepted, and some evidence that it has been rejected, particularly by the current federal government. (Similar questions arise when looking at poverty, or at child care.)

This reviewer is accordingly unconvinced that the extensive material on the PHP model adds much to the analysis.

The paper also appears to assume that home care is the same as palliative care. Many of the references about caregiver burden relate to ongoing needs, not to end-of-life care. The discussion under the heading Introducing the Determinants of Caregiver Burden about restructuring the health care system is misleading, and takes the references out of context. (In some cases, these papers do not say what the paper implies they do.) For example, the authors write that "responsibility for many public services was downloaded onto communities" without indicating where it had initially rested. In the case of palliative care, people still can (and do) die in hospitals. The issue being dealt with here would seem less to be "downloading" than improving end-of-life care. There are another, important, set of issues about supporting caregivers for ongoing care, but it is unclear which of them are related specifically to palliative care.

The paper then reports on the views of 57 participants. It is unclear how representative these individuals were. Only 5 had been unsuccessful CCB applicants. Although 22 had been successful, and 30 had not applied, this
variable was not used in the analysis, which seems odd given the focus of the paper was said to be evaluating the CCB. In addition, the sampling method used was most likely to select strong advocates. This reader did wonder, for example, the extent to which having the yacht club members bringing flowers, however thoughtful, fit into a determinants of health framework, particularly for vulnerable populations. Neither is there any effort to assess how realistic their expectations were (e.g., the expectation that there would be immediate response from home support when someone “just peed the bed”), or why the CCB should have been expected to alleviate them. How, for example, would the CCB be expected to make dealing with a dying loved one unstressful? To create a new social network for people who “had no family close to where she lived to assist in providing care”? The paper blurs a discussion of the CCB with the literature (touched on) on best practices in end-of-life care.

The paper also does not discuss the impact of features of the CCB (e.g., dealing with the ongoing problem of identifying when people will die), although this is again touched on. The various headings did not seem to match the data provided. For example, the heading Income and Social Status mentioned the importance of fiscal support, but did not appear to link this to characteristics of respondents. Given the earlier discussion of the PHP model, readers might expect the analysis to deal with the differential implications for differing caregivers, whereas the authors appear to just be indicating that income replacement could be important. (Here again, were there differences between the respondents who did or did not make use of the CCB?)

As written, the paper contains some interesting qualitative excerpts from interviews regarding views of caregivers and sources of stress, but does not bring data to bear on the question it purports to deal with. A clearer understanding of what the CCB might or might not be expected to do, and how it might relate to other policies, might be helpful in clarifying this paper.

Discretionary Revisions
The paper as written is primarily of interest to Canadian readers; the authors may or may not wish to place them into a broader international context.

**Level of interest:** An article whose findings are important to those with closely related research interests

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**
I declare that I have no competing interests.