Author's response to reviews

Title: The caregiving perspective in heart failure: a population based study.

Authors:

Patricia M Davidson (patriciamary.davidson@uts.edu.au)
Amy Abernethy (amy.abernethy@duke.edu)
Phillip J Newton (phillip.newton@uts.edu.au)
Katherine Clark (Katherine.Clark@calvarymater.org.au)
David C Currow (david.currow@flinders.edu.au)

Version: 3 Date: 29 July 2013

Author's response to reviews: see over
Thank you for the useful and constructive comments of the reviewers. Please find attached detailed comments for the reviewers and amended sections are highlighted in red in the manuscript.

**Response to Reviewers:**

1. General comments: The study deals with a topic of high priority in health care - family caregivers. The study is novel because it uses a population-based approach to examine characteristics of heart failure (HF) caregivers in comparison to caregivers of persons with other conditions.

   Thank you for this response.

2. Literature review: The literature review addresses the need to study caregivers of HF patients who are near death and compare their needs with needs of caregivers of non-HF patients. Please consider adding one or two more paragraphs about the current state of HF caregiving research given there are many clinical studies of HF caregivers’ needs and add how this study adds to the state of knowledge about HF caregiving.

   Response: This has been added to address issues identified in the literature review.

   Although there has been extensive research on caregivers in many other clinical setting, research is limited in CHF and there are sparse recommendations to address unmet needs for support 1. Available data suggests that caregiver burden increases if the caregiver experiences poor mental and/or physical health and has limited social and professional support 2. Patients who are enrolled in specialty disease management programs are likely to have a level of caregiver support whereas those in primary care settings are less likely to have this support underscoring the need to undertake a population based approach to assessing needs.

   Current guidelines recommendations suggest that interventions to reduce caregiver burden should focus on improving social support as well as control over their situation 3 4 5. A comparison of caregivers with cancer, chronic obstructive pulmonary disease and HF demonstrated that caregiver resources not patient diagnosis or illness severity were associated with caregiver burden 6.

1. Strömberg A. The situation of caregivers in heart failure and their role in improving patient outcomes. Current Heart Failure Reports. 2013;1-6
3. Methods: Although the Survey has been published, it would be helpful to add more information about the Survey and questionnaires used for readers unfamiliar with the larger Survey. Consider adding a figure of the design.

- An omnibus survey is a method of quantitative research using a stratified sample where data on a wide variety of subjects is collected during the same interview. Multiple researchers contribute individual questions while sharing the common demographic data collected from each respondent. We consider that a figure will not provide additional information.
- We have added additional information.
- For example caregiving was defined for the respondent as follows: “Care includes attention to any of the needs of the person, including hands-on care, overnight care, respite, shopping, collection of medications, taking to appointments, emotional support, bathing, etc.” To incorporate differing levels of caregiver burden into the analysis, respondents were asked if they provided: “day-to-day hands-on care” (care 5–7 days per week); “intermittent hands-on care” (care 2–4 days per week); or, “rare hands-on care” (care 1 or less days per week).

4. Design: The study used data from random population-based survey in Australia that is conducted annually. The methodology for the survey is described. Sample: Description of sampling method is described. Setting: Described. Measures: The measures consisted of descriptive questions designed to elicit responses, Statistical analysis: The first sentence states that the data were weighted by age group, sex, geographics, and birth country. Can you explain which data were weighted and give rationale? How did analyses account for unequal group sizes? In the analysis it says the dependent variable in the regression analyses was cause of death. Can you make sure this matches the purpose stated earlier of examining needs of caregivers?

Response:

- The survey respondents were standardized against the population of all South Australia for gender, 10-year age group, socioeconomic status, and region of residence according to the Australian census using direct standardization techniques. Each respondent was assigned a standardized weight and only weighted data were analyzed to ensure standardisation of the population.
- The model used cause of death (heart failure versus other causes) as the dependent variable to examine the caregiving needs specific to heart failure deaths.

5. Results: Results are important in that caregivers provided care for many years and the experience was worse than expected. What is difference between specialist palliative care and palliative care services – could this be added to the measures?
A description of the differences between specialist palliative care and palliative care services
In the statement the “model found 2 significant factors that helped explain the difference
between caregivers for people with HF and caregivers for people with other diagnoses” Was the dependent variable death as noted in the analysis section? Adding a sentence of interpretation here would be useful.

Response
Yes – sentence added. The model found two significant factors that helped to explain differences between caregivers for people with HF and caregivers for people with other diagnoses in unmet needs at the time of death – increasing age (OR 1.02; 95%CI 1.01 to 1.04; \( p = 0.005 \)) and not having access to palliative care services (OR 0.39; 95%CI 0.24 to 0.64; \( p=0.000 \)).

Discussion: On page 6 there is a note that the “questions could not be modified just
for questions relating to EOL” – how did this influence results of the study? Please consider expanding the discussion section to add how this study expands
on clinical studies of the HF caregiving experience. These processes apply to the whole survey,
are unchanged since the survey’s inception in 1991, and could not be modified just for the questions relating to the end of life due to the omnibus study methodology and the capacity to add limited items to the overall study structure. In spite of this limitation, the capacity to obtain a population based approach to caregiving at the end-of-life for individuals with HF is an important opportunity.

Conclusion: While it is true that “The need for assistance with physical care
has not been documented using a similar methodology before” there are many studies about HF caregiving and these population-based results provide further support about the complexities of HF caregiving.

Response:
Additional information provided and this caveat added.
These data and the work of others illustrates the complexity of the caregiving experience and the importance of assessing individuals’ needs and social circumstances.

Table 2: Why is sample size different than Table 1?

The differences in the sample sizes pertain to the variable responses to survey items over years and hence the denominator.

Table 1 provides data on all respondents who provided day-to-day or hands-on care for someone at the end of life. Table 2 explores a specific sub-group: those who provided this level of care and, additionally, were able to indicate their preference for ‘willingness to provided care’ again in similar circumstances. The difference between the two groups is those who are undecided about their willingness to care.

Reviewer 2

Minor Essential Revisions
There are a few areas where the reference number is before the period and at times the reference number follows the period. There is at least one occasion where a period was needed instead of a comma. Only minor editorial issues were found with this manuscript.
Editorial changes made