Author's response to reviews

Title: Current advance care planning practice in the Australian community: a survey of Home Care Package case managers and service managers

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Ms Catia Cornacchia

Executive Editor

BMC Palliative Care

Re: Current advance care planning practice in the Australian community: a survey of Home Care Package case managers and service managers.

Dear Ms Cornacchia,

We would like to re-submit the above article for consideration for publication in BMC Palliative Care on behalf of all of the authors.

Please note the following changes have been made to the manuscript with consideration to comments received on the 20th of January 2015:

On behalf of the authorship team, I address the comments as follows.

Reviewer 1.

1. Please provide more information on response rate and the extent to which the data may be generalizable to the larger pool of case and service managers. What was the total size of the sampling frame? That is, how many were on the “contact list provided by the CDH”? Were particularly types of communities omitted, such as poorer or more ethnically diverse ones?

Thank you for your comment. We did not omit any communities. We have amended the manuscript by including the total number of services the surveys were sent to and the response rates at the beginning of the results accordingly.

“The invitation was sent to 481 valid email addresses and, in response 120 service managers and 178 case managers completed the survey. This would suggest a response rate of 25% for service managers and 18% for case managers.”
2. Given the international readership of BMC Palliative Care, it would be instructive to learn a bit more about the larger context of ACP in Australia. Are there national policies to encourage ACP, such as the Patient Self-Determination Act in the United States? Or other macrosocial factors that may enhance/impede ACP, such as religious beliefs regarding end-of-life decision making. Even a short paragraph would be sufficient, to help situate the study findings in the larger social/political/economic context.

We agree. Thank you for your suggestion. We have inserted the following sentences in the revised manuscript at the beginning of the introduction.

“Australia is constitutionally a federation with each state and territory having their own legislation regarding ACP. In the past 10 years, ACP has gained prominence in Australia because of emergence of legislation supporting ACP in each state and territory,[1] through government support and funding and through promotion by health professionals and organisations.[2] Most ACP services within Australia at present are provided within hospitals, rehabilitation services and Residential Aged Care Facilities (RACFs).”

3. The sample size may preclude more fine-grained multivariate analysis, but I would be curious to see sources of variation in some of the responses (e.g., confidence levels, etc.). Might these responses vary based on characteristics of the service provide or their clients?

Thank you for your suggestion. We agree that multivariate analysis is not possible given the sample sizes, however, we have now included additional chi square analyses to examine the relationship between having a nurse training (versus no nurse training background) and confidence levels on the 8 separate ACP domains.

Reviewer 2.

1. It may be useful to ahve further clarification on the difference between service manager and case manager - are case managers accountable to service managers?

Thank you for your suggestion. We have attempted to greater distinguish the role of case managers versus services managers in the third paragraph of the introduction.

“The service manager, who supervises the case managers, ensures that HCPs are delivered to clients in accordance with government guidelines. HCP clients are assigned a case manager who, in collaboration with the client and family, coordinates and reviews the care services that clients receive under the funding allocated to the HCP.”

2. The client profile is described as 'complex care needs and are at risk of sudden or less gradual deterioration', it may help to give an example e.g. dementia
Thank you for your suggestion. We have edited the client profile to give greater clarity to the fifth paragraph.

“Persons receiving HCPs, by definition are frail or have multiple medical problems with complex care needs. Such people are at risk of deterioration in their health status. Generally elderly people in their own homes are less likely to have significant dementia than people in RACFs and, therefore, are able to participate in ACP.”

3. The results were clear. Would it be useful to include the (n= ) by each %. I appreciate this is in the table.

We agree. Thank you for your suggestion.

4. The lack of response from the Australian Capital Territory - is this significant to the findings - this is not clear.

The ACT is very small part of the Australian population (1.6%) and this finding is therefore not unexpected. We have made reference to this in the results section.

5. Funding sources for ACP training (page 5 line 30) are there other sources of funding - is this related to the different regions of Australia or do people self fund?

The survey did not ask the case managers to identify the source of funding other than by service. However, we do know if it was funded by the service (n=25) it was provided in the following ways:

70% in-service training, 33% external workshop, 12% online training

6. Page 6 Line 11 - referral to an ACP service - it is not clear what this is or consists of?

Thank you for your comment. We have now made reference to what ACP services in Australia are in the introduction and discussion.

“Most ACP services within Australia at present are provided within hospitals, rehabilitation services and Residential Aged Care Facilities (RACFs).”

7. Was there any difference in responses depending on the qualification and background e.g. nursing. This would have been interesting to read if qualified nurses or people with a nursing background had more success generally with or without additional training - could this be included in the descriptive statistics?

Thank you for your suggestion. We agree that multivariate analysis is not possible given the sample sizes, however, we have now included additional chi square analyses to examine the relationship between having a nurse training (versus no nurse training background) and confidence levels on the 8 separate ACP domains.
Reviewer 3.

1. Definition of ACP

The authors, therefore, are encouraged to revise their definition of ACP given in the background, clarifying that ACP is a planning process that is facilitated by a trained health care person, so that the definition is in line with the obvious meaning of the notion in the survey and in the Results section.

Thank you for identifying this issue and we agree to change the definition of ACP in accordance with your suggestion in the background and the abstract. Furthermore, in line 6 of the first paragraph of the introduction accordingly to reflect ACP as a planning process.

“A desirable outcome of the ACP conversation is the completion of a written Advance Care Directive (ACD) that documents the person’s wishes and/or the appointment of a substitute decision-maker.”

2. Online Survey

Methods (P2, L10ff; P4, L13ff)

It is a crucial information that these are the results of an ONLINE survey, because online surveys differ methodologically substantially from other surveys, for example postal surveys, with regard to response rates (often much lower) and typical response populations (for example older versus younger, more vs. less educated). This information should appear in the abstract, and in my opinion should also become part of the title (“an online survey of …”)

In its current formulation, the methods section in the abstracts gives the wrong impression to the reader that this was a postal survey: “A cross-sectional survey was distributed…” – why not “An invitation to take part in a cross-sectional online-survey was sent by email”?!

Thank you for identifying this issue. We agree with your suggestion and have amended the manuscript in the abstract, title and methodology to more clearly reflect that this was an online survey.

3. Response Rate

Limitations (page 8, 20ff)

With regard to reporting the response rate, the authors write:

A second limitation is that it is not possible to report the response rate of the survey because, out of convenience, each service was requested to forward the survey to the target sample; however, it was not possible...
to determine whether services acted in accordance with this request. 

Thus, the denominator of the total sample is unknown.

I have difficulties both understanding and accepting this explanation. In the Methods section, the authors write:

All HCP services across Australia were identified through a contact list provided by the Commonwealth Department of Health and invited them to complete an online survey.

This sentence clearly informs the reader that there must be a total number of HCP services which then is the denominator of the response rate, while the number of services who responded is the nominator.

Results

Correspondingly, for the report (and interpretation) of any survey results, it is crucial to inform about the response rate. The authors need to report in their Methods how many HCP services were contacted via the contact list (p4, line 13), and in their Results (both in the abstract and the text) the response rate for service managers (120 divided by number of HCP organisations), and the response rate for case managers (178 divided by 2x the number of HCP organisations; see p4, line 18).

Thank you for identifying this issue. We agree with your suggestion and have amended the manuscript in the abstract and results to include the response rate based on the total number of services contacted through the contact list provided by the Commonwealth Department of Health.

Discussion (page 6, 32ff)

The authors can not simply state representativity when they have not reported response rates (see above). The information provided in lines 33-35 is of interest, and should be included in a separate results or discussion section that transparently discusses response rate and representativity. The quoted reference [22] is also of interest, but it refers to NSW and can therefore be used only as an indication (estimation) of the “manager of population of Australia”.

Thank you for identifying this issue. We agree with your suggestion and have amended the manuscript in the discussion accordingly.

“A second limitation is that the response rate was relatively low; this is a recognised limitation of the online survey format.[30] In order to ensure anonymity, we did not link the survey responses to the services provided in the contact list. We were not, therefore, able to determine the characteristics of services that not respond to the survey. Although this potential limitation is a deliberate trade-off to ensure anonymity, the characteristics of services and the profiles of case managers were similar to past surveys suggesting that the characteristics of the services and staff that did not respond to our survey would be similar to Australian HCP services.[11, 23]”
4. HCPs and the international literature (P7, L 1)

I haven’t looked up the quoted literature [15-18]. However, it seems to me that HCPs are a national (Australian) phenomenon, so it sounds awkward to compare HCPs with the “international literature” even though there may be very similar structures internationally only that they are likely to be named differently. I would suggest to use a more generic term than “state of ACP within HCPs”, for example “state of ACP within home care service providers”. This is better transferable for an international readership.

Thank you for identifying this issue. We agree with your suggestion and have amended the manuscript in the discussion accordingly.

Minor Comments
Loc. Comment

Thank you for your thorough suggestions. We have attempted to address all of the minor comments in the table below.

<table>
<thead>
<tr>
<th>P2, L13</th>
<th>The response rate should already become visible in the abstract, i.e. brackets with percentages behind 120 and 178, rsp.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Thank you. We have amended the manuscript accordingly.</td>
</tr>
<tr>
<td>P2,</td>
<td>Comma instead of semicolon (?)</td>
</tr>
<tr>
<td>L16</td>
<td>Thank you. We have amended the manuscript accordingly.</td>
</tr>
<tr>
<td>P2,</td>
<td>I don’t understand the opposition (as indicated by “although”) between the fact that most case managers had initiated ACP conversations on the one hand, and that “the majority of the conversations did result in documentation of the client’s wishes…”. “did not result” would seem to better meet the intention of the construction applied to this sentence – could the missing “not” here be an error?</td>
</tr>
<tr>
<td>L16ff</td>
<td>Thank you. We have amended the manuscript accordingly. This was an error.</td>
</tr>
<tr>
<td>P3,</td>
<td>When service providers tender to government for the right to provide HCP, they are at this point not yet HCP service providers, so perhaps better delete first word (HCP) in this sentence</td>
</tr>
<tr>
<td>L18f</td>
<td>Thank you. As above in response to reviewer 2, we have amended the manuscript accordingly.</td>
</tr>
<tr>
<td>P3,</td>
<td>Don’t understand: “sudden or less gradual” – please clarify.</td>
</tr>
<tr>
<td>L30</td>
<td>Thank you. We have amended the manuscript accordingly.</td>
</tr>
<tr>
<td>P3,</td>
<td>The paragraph / the factors describing why ACP makes sense in this subpopulation could be structured somewhat clearer / more</td>
</tr>
<tr>
<td>L29ff</td>
<td></td>
</tr>
</tbody>
</table>
1. They are more prone to sudden or slow deterioration due to medical complications rendering them incapacitated and requiring critical decisions because they are requiring nursing support, i.e., already frail. 2. They are less likely to suffer from dementia than the average RACF population (because dementia is a frequent reason why people are moved from the community to RACFs), meaning that they are more likely to actively participate in the ACP process, and articulate their individual preferences. 3. They have regular contact with various qualified health care staff who would be eligible as ACP facilitators.

The sentence in line 34f, however, is confusing and does not belong in this argument because it denotes nothing that is particular for this group of HCP clients as opposed to other elderly people. Delete.

Thank you. We agree with the above, however, we could not identify which sentence is quote 34f. We would be grateful if you could please clarify so we can respond.

P6, L22  The last sentence (from “However”) is partly redundant to what was reported above, and it certainly does not belong into this section but into the above sections, for example ACP and support. Thank you. We have amended the manuscript accordingly.

“The majority of case managers were not satisfied with the level of support from their service to complete ACP with clients. Specifically, 65% (n=116) were not satisfied with time allowed to undertake ACP, 60% (n=107) with lack of support from senior staff to discuss the issues, 67% (n=119) with lack of appropriate documentation for recording outcomes of discussions, 78% (n=139) with lack of training to facilitate ACP discussions and 72% (n=128) with absence of written information to give to services users and their family about ACP. In addition, only 36% (n=64) of case managers believed they had sufficient time in their workload to complete ACP, only 27% (n=48) believed that the majority of clients were interested in ACP, and only 15% (n=27) of case managers believed ACP was done well within their service. Case managers were mostly (56%, n=100) satisfied with support from peers to discuss ACP with clients.”

P7, L14  “having had 1-12”

Thank you. We have amended the manuscript accordingly.

P7, L15  “progressed to a documentation of wishes [or rather: treatment preferences]”.

Thank you. We have amended the manuscript accordingly.

P8, L16  This is the first time that I find the statement that this was a “preliminary study”. That could only be correct if the same survey was planned to occur subsequently with similar methods, but at a larger scale. I don’t have the impression that this was a preliminary study in the correct sense, and then this statement should be deleted. It is...
immanent to surveys that the surveyed population self-reports its practices, so it is fine to describe this here (also without denoting this study “preliminary”).

Thank you. We have amended the manuscript accordingly.

“There are several limitations to the generalisability of these findings to HCP services across Australia. Firstly, as the survey relied on self reporting by the respondents regarding their practices and experiences with ACP, this may have resulted in over or underestimating prevalence of practices and in socially desirable responding.”

Personally, I am relatively tolerant towards thoughts and conclusions developed from a study in the Discussion section. Therefore, although the discussion is already quite long and includes a number of paragraphs that are not directly derived from the results, I have the impression that these considerations are of interest to the reader of this article; perhaps the authors can try and shorten these paragraphs. However, with regard to the paragraph beginning with “Furthermore” down below on page 8, I cannot recognise any connection with the core paper, therefore I would suggest to delete it.

Thank you for your suggestion. These 2 paragraphs were included at the request of the editor based on the following sentence:

“Given that you identify this research as a ‘preliminary study’, please provide a paragraph or two outlining your vision for future research that should be conducted in light of what you have discovered in this study.”

Again, I would use a more generic term than “HCP services”.

Thank you. We have amended the manuscript accordingly.

Yours Sincerely,

Assoc. Prof. W. Silvester