Author’s response to reviews

Title: Patient experiences of nurse-facilitated Advance Care Planning in a general practice setting: a qualitative study

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Dear Dr Pasman,

We thank you and the reviewers for reviewing our manuscript "Patient experiences of nurse-facilitated Advance Care Planning in a general practice setting: a qualitative study" (PCAR-D-18-00131), and for the considered feedback.

We have addressed the reviewer comments below (it might be easier to refer to the attached document 'Response Letter BMC.docx'). We hope that our responses and the changes to the manuscript are sufficient to allow the paper to be published.

Please let me know if you have any queries. I look forward to your response.

Yours sincerely,

Joel Rhee

Corresponding author
Amy Tan (Reviewer 1):

1) I would appreciate knowing what the training background of GPNs in Australia is, to provide context for this manuscript, as well as for readers internationally to understand the skill-set for GPNs used in this study.

GPNs in Australia are Enrolled Nurses (EN) or Registered Nurses (RN) who work in the general practice clinical setting. There is no formal training required to become a GPN but many receive additional training in skills that are relevant in community practice. National Practice Standards apply: https://www.anmf.org.au/documents/National_Practice_Standards_for_Nurses_in_General_Practice.pdf

The manuscript has been updated to reflect this (page 4, line 25).

2) There is an abbreviation in the Background paragraph 4 -NSW- I'm assuming this is New South Wales- please define in your paper?

Yes this is New South Wales. This has been changed in the background of the manuscript (page 4, line 28).

3) I find it very surprising that 83% of all Australians went to a GP office within the one cited year. Are these 83% of rostered patients within one year, or the entire Australian population? I would recommend confirming this statistic and what the denominator is, as it seems very high for any one year.

This figure comes from the Australian Bureau of Statistics (ABS) 2014–15 Patient Experience Survey. The survey found “more than 4 in 5 people (83%) had consulted a GP at least once in the previous 12 months”. The survey was based on a sample of 27,341 Australia residents (aged 15 years or over, living in private dwellings, excluding members of the Australian permanent defence force, certain diplomatic personnel of overseas governments, customarily excluded from Census and estimated population counts, overseas residents in Australia, members of non-Australian defence forces (and their dependants), persons living in non-private dwellings such as hotels, university residences, boarding schools, hospitals, nursing homes, homes for people with disabilities, and prisons, persons resident in the Indigenous Community Strata (ICS)). Full details are available here: http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4839.02014-15?OpenDocument

Revisions suggested:

This definition and citation has been incorporated into the manuscript (page 4, line 3-5).

5) How were the GPN's recruited? Was it voluntary, within the practices recruited, or was there an expectation by the employer? As well, what was the relationship between the GPNs in the practice with the GPs in the clinic (assuming that the GPs were the owners of the practices)? Was there any compensation other than their employment wages/salaries for being part of this study for the GPNs? What criteria existed for the GPNs to be selected for them to participate or just by virtue of working in a GP office?

GPNs working in the eligible practices were recruited by invitation letter, followed up with a telephone call from the chief investigator. In other cases, the study was promoted to GPs and GPN participants of an educational workshop on ACP. One of the eligibility criteria for the practice was having a GPN who is willing to lead ACP; therefore their interest and capacity to lead ACP was canvassed before the practice was formally recruited. The GPNs were not compensated by the investigators for participating in the study beyond their existing employment wages / salaries. There were no other exclusion criteria for GPNs. These clarifications and details have been added to the manuscript (page 6, lines 1-13).

6) For the selection of patients, you detail that you used SPICT vs opportunistically. Can you comment on whether you found that these two methods of selection may have caused selection of 2 divergent populations in general practice because SPICT would likely lead to a more symptomatic or more frail population to be selected, vs. likely a more healthy/functionally able population via opportunistic selection by presenting to a GP practice. How did this affect your results and analysis and conclusions?

We left the selection of the patients up to the practice, and the GPs and GPNs and their professional judgment of ‘patients who were likely to benefit from ACP’. The clinicians were given the option of identifying patients opportunistically or using the ‘Surprise Question” and / or SPICT systematically. As you pointed out, it is possible that the systematic use of the Surprise Question and SPICT may lead to the selection of a different cohort of patients compared to the opportunistic approach.

We have therefore modified the last paragraph of the Discussion section (page 16, line 23-25):

“Our findings may have been influenced by our sample, mostly comprising of long-term patients of the practices with chronic conditions but largely independent and in stable health. It is possible that the use of both an opportunistic approach to identifying patients in addition to a systematic approach in this study may have led to the selection of patients with these characteristics.”

7) I would have liked to know more details on the actual content of training sessions and subsequent visits by the GPNs- were the GPN visits standardized to some degree- through the EMR templates mentioned?
As explained in the Methods / Education and training to practices section, The GPNs attended a one-day intensive educational workshop, which was supplemented by online educational activities and mentoring by a senior nurse. We have added the following sentence to provide more detail:

“The educational resources covered: the practical aspects of discussing ACP with patients including the use of an ACP workbook and an Advance Care Directive template; communicating effectively regarding end-of-life issues; the legality of ACP in NSW; and the determination of decision-making capacity.” (page 6, lines 19-23)

As discussed in the following sentence in the Methods section, the ACP sessions conducted by the GPNs were guided by an Advance Care Planning workbook and Advance Care Directive template:

“An Advance Care Planning workbook and Advance Care Directive template was used to guide discussions and to record the patient’s wishes if required.” (page 8, line 8)

How did you mitigate differences in the skill level of each of the GPNs in facilitating these conversations with patients?

We conducted a knowledge questionnaire pre- and post-training to identify any remaining knowledge deficits. This assisted the senior nurse in providing ongoing mentoring and educational support to the GPNs throughout the study. We have modified the relevant sentence as below:

“A pre- and post-training knowledge questionnaire on ACP was administered to the GPNs and this assisted one of the investigators (AM), a clinical nurse consultant with expertise in ACP, to provide telephone support and mentoring throughout the study period.” (page 6, line 24 – page 7, line 3)

How long were the visits with the GPN and what was the actual interface with the GPs after the GPNs visit?

We have added this information to the Results section:

“All patients attended at least one ACP visit with the GPN, lasting a mean of 32.2 minutes (10-75). The mean number of visits to discuss ACP was 2.4 (range 1-4). The GP was present during 35% of the first visit, 5% of the second visit, and 71% of the third visit, and 33% of the fourth visit.” (page 9, line 22-23)

There is mention that the patients were referred back to the GPs to sign forms, but I would like to know the GP perspective as to whether they found the discussions and conclusions re ACP to be medically appropriate for the specific medical context at hand for each patient. In general terms—was this acceptable to the GPs and the GPNs as well, (fully acknowledging that it was the patients who were the focus of your study). I feel that to ensure that this model was clinically useful and relevant to the GP practice, that the perceived appropriateness of these discussions
with GPNs by the GPs would be important information to understand, in addition to the patient perspectives (ie: did not having enough medical information about the patient cause an ACP conversation to veer off tangentially to decisions that were not medically feasible or possible?)

We agree that the perspectives of the GPNs and GPs are very important. To explore this in detail, we conducted post-intervention interviews with the GPNs and GPs. We are currently preparing a separate paper discussing those results in detail.

8) How did you decide on the use of GPNs- did you consider having GPs involved explicitly too in your training and model suggested in your study?

As mentioned above, we have added detail on the training of GPNs. With this addition, we believe that the rationale for involving GPNs is sufficiently covered in the Background section:

“These barriers apply to Australian general practice settings, especially the general practitioners (GPs) who are time-poor. In response, it has been suggested that General Practices Nurses (GPNs), registered nurses with training specific to the general practice setting, could address common barriers to accessing ACP and address patients’ psychosocial concerns. GPNs appear to be enthusiastic about their involvement in ACP. In a recent survey of general practice nurses conducted in New South Wales (NSW), 84% (n=152) agreed or strongly agreed with the statement ‘Practice nurses should be involved in initiating and conducting ACP discussions with patients’ (12). While there are many examples of nurses successfully completing ACP in varied settings such as intensive care and acute care settings(8, 9), there is lack of studies conducted to date that examined the feasibility and acceptability of general practice nurse involvement in ACP.” (page 4 line 23 – page 5 line 2).

The participating GPs received a brief educational session as discussed in the Methods section. We have added further detail regarding its content:

“The participating GPs attended a brief educational session with a GP investigator (JR) on ACP. This session covered important aspects of ACP, especially issues that are likely to arise when completing and signing the ACP documents such as the law around substitute decision-making, and assessing the capacity of the person signing legally-binding Advance Care Directives.” (page 7, lines 4-8)

8) IN your analysis of the transcripts, how did you determine the subset of interviews that JT coded- how can you be sure that this was representative of the other ones not coded by JT given that this was the main secondary comparison of the coding tree that was developed by the primary coder HM? How was saturation acheived and ensured? Were you able to triangulate this analysis with any other sources? I would like some more details to ensure the reader can be confident in the rigour of your analysis methods.

JR read all transcripts and selected 3 based on diversity in content for HM and JT to respectively code. HM and JT read 3 transcripts and noted emerging themes, developed initial coding trees
(HM using Nvivo, JT using Microsoft Word). HM, JT, JR and OH then met to discuss emerging themes. Overall there was a high convergence of coding by HM and JT. Diverse codes were discussed within the research team and either incorporated or refined.

The remaining transcripts were read by HM and JT. HM continued to code the remaining transcripts and to develop the coding tree. JT noted any emerging themes from transcripts they observed. Meetings with the research team were held regularly to discuss coding tree and preliminary themes. Thematic saturation occurred when no new concepts were emerging from the data. Triangulation of other data sources was not possible but most of the themes were consistent with the qualitative literature on ACP. Additional details of the analysis process have been added to the manuscript (page 8, line 12-19)

Marike De Boer (Reviewer 2):

Background

The focus of the intervention is to address common barriers in the uptake of ACP, which is well explained. However, many healthcare providers also struggle with how to provide adequate ACP. Despite the fact that this is not the focus of the article, it would be good to address this issue.

We agree with the reviewer on the importance of improving the quality of ACP. We have actually conducted post-intervention interviews with the GPNs and GPs, and these explored in-depth their experience of conducting ACP discussions. It was not possible to include those results into this paper, so that will be submitted as a separate paper.

- Note: The data this study is based on is rather 'old' (2014-2015). Hasn't ACP changed significantly since then?

We feel that this study is still highly relevant as the practice and laws regarding ACP in New South Wales (NSW) and most of Australia have not undergone significant change since 2015.

Method- ACP intervention/Data collection As noticed before limited information is provided about the experience of the participating nurses prior to the intervention, nor on the content of the one-day training which was provided.

As such the article misses information on the content of ACP in this intervention.

We have added the following information on the characteristics of the nurses prior to the intervention:

“All the GPNs were Registered Nurses with a mean of 6 years experience in the general practice setting (range 2-13 years). None of the nurses had formal training in ACP or palliative care.” (page 6, line 16-18)
As explained in the Methods / Education and training to practices section, the GPNs attended a one-day intensive educational workshop, which was supplemented by online educational activities and mentoring by a senior nurse. We have added the following sentence to provide more detail:

“The educational resources covered: the practical aspects of discussing ACP with patients including the use of an ACP workbook and an Advance Care Directive template; communicating effectively regarding end-of-life issues; the legality of ACP in NSW; and the determination of decision-making capacity.” (page 6, line 19-23)

On page 7 it is said that patients that completed ACP were approached. What is meant by completing ACP? It suggests that advance directives is an important outcome of ACP; the template suggests this too. It should be stressed that ACP is much broader that just advance directives, and that ACP should be a continuous process.

To be eligible for interview, the patient needed to have attended a minimum of one session with a GPN and have no future sessions planned. The manuscript has been amended from reflect that all patients that participated in the intervention were “approached” (page 7, line 21). Advance Directives were not a requirement of the ACP process and only around one third of participants had an Advanced Directive. We have added a paragraph in Methods section of the manuscript to describe the differences between ACP and AD, and to reflect that ACP is not the same as AD (page 5, line 19-24).

Results

- Page 8, lines 35-37: 13 patients consented to participate. What were reasons for the other 7 not to participate? It could be all patients dissatisfied with the intervention, which would lead to a selection bias in the results. This issue should be addressed in the discussion of the article.

All 20 patients receiving the ACP intervention provided consent for the study. Of these, 13 participated in the interviews. We did not capture reasons for the 7 participants who chose not to take part, but this could be due to lack of time, being away, disinterest, as well as dissatisfaction. However 13/20 (65%) did choose to take part in the interviews, and we feel that this is rate is quite acceptable. We have added in the following sentence in the final paragraph of the Discussion section on the limitations of the study:

“Not all patients who received the ACP intervention took part in an interview. However, nearly two-thirds of the patients did participate in the interviews and our findings are mostly consistent with other qualitative research on this topic, lending support to the transferability of the findings.”

- Page 9, line 1: why were two patients not offered the chance to invite family?
This was unclear. It is possible that there was a recall issue (patient could not remember having been offered the opportunity to invite family) or this may have been a limitation of GPN training. We have amended the sentence to read:

“Two patients stated they were not offered the chance to invite family” (page 10, line 11-13)

- Page 11, lines 7-17: For international readers it should also be clear what the status of AD's (and non-treatment directives) is from a legal perspective. This should be clarified in the article.

The law in Australia with regards to Advance Directives is different for each state and territory, with AD either being supported by statute law (determined by legislation), common law (determined by judges’ decisions from case law), or a combination of the two. In most states and territories ADs are supported by statutory law. In New South Wales (NSW) and Tasmania (TAS) ADs are supported by common law. We have added information on the legal status of ADs (Page 5, line 19-24).

Discussion: It is clear that the ACP process is highly dependent on individual preferences; this is also shown in the results. Most of the findings are in line with other literature on ACP. The main conclusion here is that GPN's are capable of initiating and facilitating ACP conversations, which is in itself a very important finding. However, the discussion does not address how the content of the ACP intervention could or should be adapted to the findings and other existing literature on ACP in practice.

We agree with the reviewer on the importance of improving the quality and content of ACP.

We feel the Discussion has addressed the implications of our findings for how ACP should be conducted in practice. For instance, based on our finding that ACP is seen as a two-stage process involving the patient-health professional discussions, followed by patient-family discussions, we recommended that patients should be supported in having discussions with their families. We also noted that the patients felt that financial, legal and spiritual aspects of end-of-life care could be better addressed, and recommended that clinicians should be prepared for these issues and be ready to provide referrals to external supports as appropriate.

We also noted an important finding in the Discussion section about the patients’ high level of satisfaction with nurses and how their satisfaction with ACP is not dependent on the professional role (e.g. as a doctor or a nurse) but rather through relational and psychosocial aspects of care. In order to make the clinical practice implications of this finding clear, we added the following sentence:

“All in all, our findings support the nurses having a central role in ACP in the general practice setting.”

- Page 15, line 5-6: financial, legal and spiritual aspects of end-of-life are found to be important for some patients. What is the authors opinion on whether these aspects should be part of the ACP interventions?
The ACP is a highly individualised process and the financial, legal and spiritual aspects of end of life care should ideally be considered within the scope on a case-by-case basis. Different patients may commit to different values when it comes to end-of-life care. The clinician should be prepared for issues and questions stemming from these and also consider referring the patient onto appropriate services if required (e.g. chaplain, social worker). We have made changes to the paragraph:

“In addition, there were some issues raised by patients that were not addressed in ACP including financial, legal and spiritual aspects of end-of-life. The variability in patient preferences for ACP demonstrates the need for ACP to be adaptable to patient preferences (11, 20). Therefore, the clinician should be prepared for issues and questions going beyond the biomedical aspects of care, and ensure appropriate referral to external supports are provided to ensure greater patient satisfaction (24).” (page 16, line 19-20)