Author’s response to reviews

Title: Shared decision making with oncologists and palliative care specialists effectively increases the documentation of the preferences for do not resuscitate and artificial nutrition and hydration in patients with advanced cancer: a model testing study

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Author’s response to reviews:

Dear Dr. LeBlanc

Greetings of peace!

Thank you for giving us the opportunity for a major revision! We have done our best to incorporate the excellent comments from the reviewers into the revised manuscript. The point-by-point response is presented following this letter. We sincerely hope you will find our manuscript suitable for publication in BMC Palliative Care.

Respectfully yours,

Tai-Yuan, Chiu, MD, MSci
Technical Comments:

Editor Comments:

The reviewers have expressed several very significant concerns, and are not in agreement on whether there should be revision or rejection of this manuscript. I am offering the opportunity to revise and resubmit this paper, to provide the benefit of the doubt, but there is no guarantee that the revised paper will be acceptable or publishable, in light of the significant reviewers' concerns. Please consider this when deciding about revising and resubmitting the manuscript.

Response:

Thank you for giving us the opportunity for a major revision! We have made great efforts to incorporate the excellent comments from the reviewers for the revision.

BMC Palliative Care operates a policy of open peer review, which means that you will be able to see the names of the reviewers who provided the reports via the online peer review system. We encourage you to also view the reports there, via the action links on the left-hand side of the page, to see the names of the reviewers.

Reviewer reports:

Ida Korfage, PhD (Reviewer 1): Review bmc care
15 september 2019

The authors describe how involving oncologists and palliative care specialists in shared decision making with patients with advanced cancer resulted in increased documentation on DNR preferences. I think structuring this involvement of both type of clinicians can indeed be very supportive for patients who may have to make difficult decisions about prolonging treatment or opting for comfort care.

My questions and suggestions are the following:
ACP is a process, as the authors indicate too. So, completion of ACP of DNR sounds strange. The outcome measures as described suggest a narrow interpretation of ACP, namely documentation of DNR or ANH. So, to which extent was this ACP?

Related to this, ACP has been defined in many ways. I ask the authors to indicate in the first paragraph of the background which definition(s) of ACP they are referring to when they indicated that ACP is essential for patients to honor their autonomy or that the aim of ACP is to preserve dignity at the end of life.

Response:

Thanks for your important suggestions. Indeed, advance care planning is a process of open discussion including a durable power of attorney assignment, living wills, personal values and preferences for end-of-life care. We defined ACP for patients with advanced cancer mainly based on the guidelines of the National Comprehensive Cancer Network (NCCN) and American Society of Clinical Oncology (ASCO). The definition was added in the first paragraph of the background at line 78 – 84 with references. From the definition, ACP is believed to be essential for patients to honor their autonomy and the aim of ACP is to preserve dignity at the end of life. Accordingly, we have revised the outcome measures to “documentation of DNR and ANH”. The outcome description in the title was revised from “completion of advance care planning” to “the documentation of the preferences for do not resuscitate and artificial nutrition and hydration”. In the manuscript, we clarified the concept mainly in the Abstract and Background sections, lines 123 – 130 and 140 – 142, respectively. Other minor revisions are highlighted in the Methods and Discussion sections.

Another remark considers the numbers as reported: they relate to completion rates after option talk and decision talk, but not to numbers after choice talk, i.e. the conversation with oncologist. Without those numbers we cannot evaluate the contribution of both type of clinicians in the SDM process. Also a comparison of documentation for groups of patients who did not participate in the SDM process would be useful.

Response:

Thank you for your comments. The completion rates for DNR documentation were zero for both groups after the choice talk. However, this result was because our model design was the initiation of choice talk by oncologists through providing treatment choices and preferences exploration without documentation. On the other hand, there were 120 eligible patients who did not participate in the model. Most of these patients visited oncologists in other hospitals for second opinions of treatments without following up at our hospital, and no information was available on their preferences in DNR and ANH.
The study showed that documentation increased. However, we do not know how this impacted what happened in practice: were preferences as documented followed? Did actual situations occur in which one had to decide about resuscitation?

Response:

Thanks for the comments. The questions raised are indeed essential parts of ACP outcomes. The actual situations and whether patients’ preferences followed after the documentation need further follow-ups, which is included as a limitation of the present study. However, since the DNR documentation form was uploaded to the national electronic health record, the preferences of these patients should be enforced according to Taiwan’s laws. Moreover, we believe the current results through the SOP model already presented evidence for a practice change and potential benefit on better end-of-life care for patients with advanced cancer.

Methods: inclusion criteria included ‘were recommended by oncologists that the integration of palliative care was optimal’. I am not sure what this means?

Response:

Thank you for the comment. Based on the criteria of NCCN and from the article by Quill et al. in the New England Journal of Medicine, we revised this description to “were recommended by oncologists that the integration of palliative care was needed for the management of refractory pain or other symptoms, management of more complex psycho-spiritual distress, and assistance with conflict resolution of treatment goals”, and added the description with references in the Methods section, lines 219 - 221.

Statistical analysis relate to two-sample tests. Which two samples are these? Those with DNR documentation versus those without?

Response:

Yes, the participants were divided into those with and without DNR documentation for the analysis of demographics data presentation in Table 1. We also revise the “two-sample independent t-tests” to “the independent t-tests” in the Methods section, lines 242.
Results: 255 patients met the eligibility criteria and participated. Not clear if any patients refused?

Response:

There were 120 patients who refused to participate. We added this information to the Results section, lines 268 – 270. However, most of these patients visited oncologists in other hospitals for second opinions of treatments without following up at our hospital, and the information on their DNR and ANH preferences were not available.

I suggest to refer to patients with advanced cancer than advanced cancer patients.

Also suggest to have language checked.

Numbers of decimals for e.g. percentages need to be reduced.

Response:

Thank you for the suggestions. We have changed all of the phrase “advanced cancer patients” to “patients with advanced cancer” including in the title. The manuscript was revised after reviewing the fluency and style of the whole article, and the numbers of decimals were reduced.

Amy Tan (Reviewer 2): I have global philosophical concerns with the general approach to the purpose of ACP and how this study shows how to improve it for patients. For example, there was a lack of clarity as to the outcome of the study- is it to have any EOL preference documented, or to have patients agree to an actual "Do Not Resuscitate" order? The focus on the documentation as the endpoint of an SDM intervention for ACP is overall concerning, as it should be on the process for the patient in being able to effectively reflect upon and elicit their preferences, whatever they may be.
Response:

Thanks for your comments, and we have made our efforts to clarify the purpose of the SOP model testing. First, the outcome of the study was clarified to have end-of-life preferences documented. Thus, we revised the title accordingly from “completion of advance care planning” to “the documentation of the preferences for do not resuscitate and artificial nutrition and hydration”. In the manuscript, we clarified the concept mainly in the Abstract, and Background sections, lines 123 – 130 and 140 – 142. Other minor revisions are highlighted in the Methods and Discussion sections.

Second, advance care planning is a process of open discussion including a durable power of attorney assignment, living wills, personal values and preferences for end-of-life care. We defined ACP for the advanced cancer patients in our study mainly according to the references of the National Comprehensive Cancer Network (NCCN) and American Society of Clinical Oncology (ASCO) guidelines. The definition was added in the first paragraph of the Background at lines 78 – 84 with references. The advantages that ACP could help patients with advanced cancer through the process of end-of-life treatment decisions are demonstrated in previous studies, and the performance of a goals-of-care discussion on realistic options about life-sustaining treatments and artificial nutrition and hydration at the end of life is the key components in ACP according to the guidelines for patients with advanced cancer. Also, the communication of preferences for DNR and ANH at the end of life as a part of ACP could assist cancer patients to receive the medical care that are concordant with their will. The clarification is provided in the Background section, lines 123 – 130.

Furthermore, Taiwan is the first in Asia to have the Patient Right to Autonomy Act enacted in 2019 which allows patients to have the documentation of their preferences on DNR and ANH through ACP. Therefore, the current results with outcome measures of the documentation of DNR and ANH through the SOP model already provide evidence for future research and model dissemination.

There was also almost interchangeable use of ACP and palliative care and they are not one in the same. There was a leap to how improved DNR documentation meant that there was an earlier palliative care approach to care as written in the paper.
Yes, we agree that ACP and palliative care are not the same. The value of early ACP as a key component of optimal palliative care is recognized in NCCN and ASCO cancer treatment guidelines, and the preference documentation about life-sustaining treatments for better end-of-life care is suggested in the ACP for cancer patients. The documentation of DNR and ANH through the SDM process symbolizes the benefits of earlier palliative care integration as the congruence of patients, family, and medical professionals on the choices of life-sustaining treatments at the end of life. We added the description in the Background section, lines 127 – 130. Also, the text in the Discussion section lines 327 – 330 was revised from “The coordination of oncologists and palliative care specialists in the SDM process demonstrated the early integration of palliative care could be an ideal strategy to improve the decision-making process for patients with advanced cancer” to “The coordination of oncologists and palliative care specialists in the SOP model demonstrated an ideal strategy to facilitate the decision-making process of the patients.”

In addition to the editing for English language, a major rework is required for clarity of methods, results and conclusions. Many of the conclusions made were not backed by the results of the study.

Response:

Thank you for the comments. We have reviewed the fluency and style of the whole article after revising the manuscript. Furthermore, the contents were extensively revised after incorporating the reviewers’ excellent suggestions in outcome measures, the concept of ACP, and the relationship between ACP and early palliative care throughout the manuscript. The conclusions were also modified to better reflect the findings of the present study. The statements that were not well supported by the results in the original version were deleted from the Discussion section, such as “The coordination and continued care of the team facilitated the documentation of end-of-life care preferences by establishing a better rapport through the SDM process. The benefits of improving satisfaction with care, better quality of life, and decreased economic burden in patients with advanced cancer by the integration of palliative care can be achieved through this process” and “The longitudinal and continuous involvement of palliative care specialists to help these difficult discussions as the SOP model is also a key hallmark for better patient care.” The revisions in the Discussion and Conclusion included lines 325 – 331, 340 – 342, 348 – 352, 356 – 358, and 401 – 403.