Author’s response to reviews

Title: An examination of home-based end-of-life care for cancer patients: A qualitative study

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Author’s response to reviews:

Response letter

Thanks for all your valuable comments on our manuscript. These comments make it much better. Here are our responses to all the comments.

To editor,

Besides the revisions made according to the reviews’ comments, the following revisions have been made:

λ. The first two sentences of the first paragraph in the section of Background (Line 32-35, page 2) have been revised, aiming to have a better introduction.

λ. The first sentence of the second paragraph in the section of Background (Line 2-3, page 3) has been revised, aiming to express the meaning in fewer words.

λ. The sentence between line 6-7, page 4, “purposive sampling and snowball sampling were adopted to approach possibly eligible community health care centers”, has been revised to have a better meaning.

λ. The second sentence in the first paragraph of the discussion section (line 16-17, page 11) has been deleted to avoid repetition.
The reference number of the ethical approval has been double checked and revised (Line 32, page 4; line 27, page 14).

The reference list has been updated.

The abbreviation “PhD” has been deleted in the section of List of abbreviation (Line 20, page 14).

To Daisy Ermers, MD MSc (Reviewer 1)

Thanks for your comments. We have tried to respond all the comments and revised the manuscript accordingly. However, about some minor comments, I am not sure if you want us to add the contents into the manuscript or just explain in the response letter. We can make revision according to your further comments.

- The research question exists out of two parts, the second part is about identifying factors associated with its delivery (page 2 line 4-5, page 3 line 17). To me, it is not entirely clear what the authors mean by that. Is it about examining the difficulties/barriers why home-based end-of-life care services in Shanghai is not delivered frequently? When looking at the four themes in the result section the final theme is "difficulties in delivering care" and as far as I know this is the part where the second research question is answered, so maybe the question needs a little bit more clarification.

The second objective of the study has been revised as “to examine the difficulties during the delivery of such care (Method section, line 27-28, page 3)”. Meanwhile, the second research question in the Background section (Line 21-22, page 3) and in the Abstract section (Line 4-5, page 2) have been revised accordingly.

- In the discussion section a lot of new information is provided which may be better off in the introduction sections. For example, in the first paragraph of the introduction, the authors state that many patients prefer to stay at home during their last months of life until death. Then they enumerate (page 2 line 33-39) how this is for several countries (sometimes they mention percentages sometimes not) except for China. In the discussion section (page 10 line 28-35) this information is provided.

The first paragraph in the introduction section has been revised accordingly. The situation in China has been added in the introduction section (Line 41-43, page 2). The missing percentage numbers of the reference articles (Line 37 and 39, page 2) have been added.
- Can the authors explain why data collection ceased when no further centers could be approached within the researchers' capability instead of saturation? And what consequences does this have for the results and conclusion of this paper?

We started data collection from a few eligible community health care centers where we either have formal collaboration or acquaintance there (not particular in the end-of-life specialty). With their help, we got approval from the management of the centers to conduct the study. And the managers of the centers helped us to invite eligible health care providers in their centers to join our study. Then we asked these managers and the informants who had finished the interviews to recommend other community health care centers to us. With their help, a few more community health care centers joined the study. We continued approaching community health care centers and recruiting informants in this way. However, things did not happen smoothly. Some managers and informants said they did not have contact with other centers. Others tried, but were refused. Those centers did not want to be interviewed. So the data collection was stopped when we could not find any community health care centers joined the study by all means. This might affect the data saturation of the study. The consequence has been added in the Limitation section as follows (Line 24-29, page 13).

“In Shanghai, there are more than 50 community health care centers providing home-based end-of-life care. Yet only 12 eligible centers joined this study. Some centers refused our invitation. This phenomenon suggests that the development of local home-based end-of-life service might be less optimistic. Meanwhile, it may affect the data saturation of the study. However, most contents of the interviews were repeatedly mentioned by the informants from different centers during the interviews.”

- The data were mainly coded by the first author and reviewed by the other three authors. Mainly implies that there was another coder, is that correct? Who? Can the authors please be so kind to explain why they did not use a second coder? What are the consequences of using this research method?

The coding process of the study as follows: The transcripts were coded by the first author and all the authors reviewed and discussed the codes. The first author coded the data second round and all the authors reviewed and discussed the codes again. All confirmed the final codes and themes.

The sentence has been revised as follows: “The data were coded by the first author and reviewed by the other three authors” (line 43, page 4 to line 1, page 5).
The way by which we coded the data was decided after careful discussions within the research team. According the book, the coding manual for qualitative researchers, written by Johnny Saldana, there are several ways to code the data within a research team. One of the methods is that one researcher is the ‘lone wolf coder’ and the other members of the team are given copies of the coding data to review the coding process at all stages, and function as rigorous examiners and auditors of the analysis (Saldana 2015, page 37). We thought it was the most suitable way for us. One reason was that the first author had plenty experience of using this method. Another reason was that the first author had more time to analyze the data to make sure the implementation of the study is on schedule.

One possible disadvantage of this way is the codes generated in the analysis might not be as rich as those coded by multiple coders. The possible consequence has been added in the section of limitation as follows (Line 34-39, page 13).

“Second, the way the authors coded the data may also lead to the limitations. In this study, the data was coded by the first author and reviewed by the other three authors. Although it is a feasible way to analyze the data [47], the codes generated in the analysis might not be as rich as those coded by multiple coders [47]. In addition, it may impair the credibility of the study, since the credibility of a study could be increased through triangulating analyses [46].”

- Some sentences in the discussion section seem to lack evidence, for example line 28-31 page 11, and line 11-13 page 12, line 15 page 12, line 17 page 12.

Relevant references have been added in the discussion section (Line 18 and 19, page 12; line 4, page 13). Meanwhile, the sentence “Psycho-spiritual care is an indispensable part of end-of-life care. However, it is very difficult to practice among Chinese populations” has been rewritten as “However, the lack of training on psychological and spiritual care makes it difficult for health care providers to practice in clinical settings [44] (Line 5-7, page 13).

- The limitation section seems to be limited to generalizability. I believe there are also some limitations in the research method as mentioned in my earlier comments.

The limitations mentioned above have been added in the section accordingly (1st and 2nd paragraph of the limitation section, page 24-39, page 13).
Minor comments

- In the method section (page 3, line 38-39) a definition of end-of-life care has been given, namely when there was a life expectancy of 6 to 12 months. The reason why this is mentioned is because eligible informants were frontline health care providers of home-based end-of-life care, or those in charge of the end-of-life care in the community health care center. To me it is not clear who determined the life expectancy, and when this happened in the research process.

The sentence “the end-of-life was defined as a life expectancy of 6 to 12 months” has been deleted (Informants section, line 43, page 3 to line 1, page 4).

- Can the authors clarify how many community health centers there are in total who provide home-based end-of-life care, and in how many districts?

Shanghai is consisted of 16 districts. In each district, there is at least one community health care center provides home-based end-of-life care. According to the unpublished report from the city health authority in 2017, there are totally 56 community health care centers providing home-based end-of-life care. Among the 56 centers, there are 41 (73%) community health care centers in which the total number of patients who received home-based end-of-life care in 2017 was less than 10 patients.

- What do the authors mean by line 15-16 (page 4): "Three interviews were conducted with two informants, respectively."

We usually invited one physician/team leader and one nurse from one community health care center to participate the study. They were interviewed separately, so that they could share their opinion freely. However, in three community health care centers, the physician and the nurse from the same community health care center preferred to be interviewed together. Therefore, in these three centers, we conducted three interviews. In each interview, the physician and the nurse were interviewed together.

- Can the authors explain when follow-up telephone calls were made for clarification?

The telephone calls were made within one week after the interviews. Each interview was transcribed verbatim immediately after the interview. We usually spent 2-3 days to transcribe the interviews and then spend 2-3days to double check the transcripts. We found the informants’ reply was not very clear when we double checked the transcript. So we called them for clarification. This happened a few times at the beginning of data collections when we were not familiar with how the patients were managed in the community.
- In line 26-27 (page 4) the authors are transparent about the fact that one informant gave oral consent and was interviewed without begin recorded. To me it is not clear if field notes were made and if the interviewer was included in the study. Can the authors explain if this has consequences for the results?

Field note was made during the interview without recording. After the interview, the researcher wrote down the content of the interview and the reflection as much as possible immediately after the interview. This has been added in the section of data collection (Line 23-24, page 4).

Meanwhile, this interview was included for data analysis. One sentence, “All the 16 interviews were included for analysis,” has been added in the section of data analysis (Line 38, page 4)

Without recording, part of the information provided by the informant may be missed. However, according to the field note, we found that the key contents mentioned by this informant were repeatedly mentioned by other informants. The possible consequence of the interview without recording has been added to the limitation section as follows (Line 31-34, page 13):

“Meanwhile, there are some possible limitations associated with data collection and analysis. First, one interview was not recorded. Although the interviewer took notes during the interview and wrote down the interview content as much as possible after the interview [46], some information may be missed. It could affect the richness of the data.”

- In the paragraph "The management of the patients" (page 6 line 19-30) the authors explain that there are two ways of managing the services 1) inpatients = hospitalized at home, 2) another way, with the service being provided for free. Can the authors please be so kind to explain what that means? And each method has its own advantages and disadvantages. Can the authors explain which these are?

Under the first way of management, the patient receiving the home-based end-of-life care was treated like an inpatient who was admitted into a hospital ward. That means the medical expense, including the consultation fee of health care providers, drugs, medical consumables, etc, could be covered by the medical insurance. The main advantages of this method include: (i) The patient only need pay little money by themselves because most of the medical expense is covered by the medical insurance; (ii) The physicians could prescribe drugs for the patient if needed. But one main disadvantage of this method is that the patient could not go to other hospitals because their medical insurance is locked in the community health care center. If the patient goes to another hospital, his/her medical insurance cannot be used. He/she has to pay all medical expense in another hospital by themselves. It is an important reason that the health care providers in some communities do not adopt this method.
Because of the disadvantage of the first method, the patients in other centers are cared for in another way, i.e., receiving the home-based end-of-life cares for free. The patient does not need to pay any fee for the home visits or telephone calls from the health care providers. So, free service is the biggest advantage of this method. Another advantage is that the medical insurance of the patient could be used in other hospitals. It is not locked in the community health care center. But it also has prominent shortcoming, which is that the physicians cannot prescribe any drugs for the patients. The main job of the health care providers is to check the patient’s condition and “verbal” care, such as home care instruction and comfort patients verbally. If the patient has symptoms, the health care providers can only do very limited things for the patient.

- In the paragraph: "The outcomes of the patients" (page 6 line 32-36) the authors present that a proportion of the patients of whom the condition deteriorated were admitted into the hospice wards. I am wondering if the authors can tell a bit more about why patients were admitted instead of continuing home-based care?

The reason why the patients were sent to the hospice wards has been added in the manuscript, in the section of “The outcomes of the patients” (Line 3-13, page 7).

- I am not sure if I completely understand the following section: "In most centers, it was the physicians and nurses who would deliver the home-based end-of-life care. In some centers, the care was delivered by health care providers with a certificate in end-of-life care, regardless of whether they were from the general practice team or from the hospice care team of the centers. In the other centers, the care was provided by health care staff who might or might not have a certificate in end-of-life care (page 6 line 40-43, page 7 line 1). Which kind of health care providers? What are the exact differences between these 3 groups?"

This part has been revised. The first sentence, “In most centers, it was the physicians and nurses who would deliver the home-based end-of-life care”, has been rewrote as follows, “In all study centers, both the physicians and the nurses involved in delivering the home-based end-of-life care. They are the main hospice care providers. In most centers, staff with other professional backgrounds, such as social workers, volunteers, or psychologists, seldom involved in the home-based end-of-life care (Line 19-23, page 7)". 
The following sentences, “In some centers, the care was delivered by the health care providers with a certificate in end-of-life care, regardless of whether they were from the general practice team or from the hospice care team of the centers. In the other centers, the care was provided by health care staff who might or might not have a certificate in end-of-life care”, was indeed quite confused and complicated. Therefore, we has been revised this sentence as follows, “According to the informants, not all the health care providers who deliver the home-based end-of-life care had a certificate in end-of-life care in the study centers no matter which department they came from.” A quotation has been added as well (Line 23-34, page 7).

- Page 7 line 21-22 the authors document that in one center free pain drugs were distributed. Could the authors please be so kind to explain how this was distributed in other centers?

The free pain drug is a special case in the study. It is donated by a charity organization. Such kind of free pain drug is only provided in the community health care centers in one specific district. As far as I know, it may be because there is a cooperative agreement between the charity organization and the district health authority. Actually, only one specific pain drug could be provided. It can be regarded as a pain drug supply outside of the health care system.

In other districts, since there is no such cooperative between the charity organization and the district health authority, there are no free drugs. All pain drugs are supplied in the health care system. The patients have to pay for the pain drugs. However, their medical insurance could cover the cost of pain drugs to certain extent.

However, no matter where the pain drugs come from, the physicians would assess the severity of the patient’s pain first and prescribe the pain drugs for the patients according to the severity of the pain. It is strictly followed the clinical guideline.

- In the section service duration (page 7) the authors state that patients received the service for a period of two weeks to three months. Do the others perhaps know how long before death how long before death the services were delivered?

We are not sure if we get the meaning. We try to answer it. One of the patient criteria for the service was that the life expectancy of a patient is within one year, which is mentioned on the section of “patient criteria for the service”, line 38, page 5. Although the patients may not know how much time they have, but usually the families knew the life expectancy of the patient.
- On page 8 line 6 it is stated that the services consisted of multiple components e.g., giving psychological support. However on the same page in line 26-27 it is stated it was limited to chatting about daily matters. Could it be the case that the authors mean that when interviewees were asked which components the service had they mentioned psychological support but when interviewees were asked what they provided it was limited to chatting about daily matters?

I try to answer this question. Your understanding may be right. When I raised the question, “What do you do for the patients when you visit the patient or call the patient?” Some informants mentioned the term “psychological support”. Then I invited the informants share more about their “psychological support”. Most of them answered that “I would chat with them.” It may not limit to chatting daily matters. But they could not share more information in depth.

- Page 9 line 11-12, the authors state that informants could only provide limited interventions to deal with patient discomfort. A poor drug supply was a prominent obstacle. What are the other obstacles and is it common that there is poor drug supply? This poor drug supply is also mentioned on page 12 line 6-7.

It is common that the drug supply, especially the pain drug supply is not satisfactory for patients at home. Several factors are associated with the poor drug supply. First, some community health care centers do not have narcotic drugs in their OPD pharmacy (all the drugs the patients needed, who stay at home, are picked up from the OPD pharmacy). According to the relevant regulation, the narcotic drug for community OPD patients should be stored and kept by specific staff using specific cabinet in the community health care centers. It will cost more human resource and material resource. Some community health care centers do not want to spend extra resource on the management of OPD narcotic drugs. So in these centers, there is no pain drug supply for OPD patients.

Second, only tablets and patches of morphine can be prescribed for patients at home. It is a city-wide regulation. If the severity of the pain could not be controlled well using tablets or patches, the patients have to go to the hospitals or the hospice ward of the community health care center because intravenous morphine could be only used in inpatient settings. These are the main reasons for the poor drug supply.

About other drugs, the drug supply in the community health care centers is not as good as that in tertiary/secondary hospitals. The health authority of the city made a basic drug list for all the community health care centers in the city. So the staff in community health care centers has fewer choices of drugs.

Other obstacles mentioned by the informants included, the management of some symptoms is beyond their ability and the condition of the center, and they could not perform intravenous nutritional support at home.
I hope I answer the question.

- A few typographical errors are made (page 2 line 42 countries, page 4 line 12 staff member with a Phd?, page 8 line 35 they refers to …?, page 10 line 15-16 this sentence is not fluent, page 11, line 23 the study = this/our study?, appendix service process ◊ care components ◊ must- do's? instead of must dos)

The typo “counties” has been corrected (Line 4, page 3).

The work “PhD” has been changed to “a doctoral degree” (line 18, page 4).

The typo “they refers to” has not been found.

The sentence, “This is because the staffs only visit the patients once a week even longer, and they felt that such limited contact was insufficient to establish the kind of strong rapport that would be needed to discuss subjects concerning life and death has been rewritten as follows: “The health care providers usually could only spent less than one hour with the patients and their family every 1-2 weeks. They did not think they could establish strong rapport that would be needed to discuss subjects concerning life and death in such limited time (Line 2-7, page 11).

“The study” has been changed to “this study” (Line 12, page 12).

The “must-dos” on the appendix file has been changed to “must-do’s (page 2).

Christantie Effendy, PhD (Reviewer 2):

1. The title is about experiences in caring for cancer patients at the end of life stage at home. It is not mentioned yet in the title who is the subjects (HCP or Family caregiver) on caring for the patient at home. The authors need to add 'HCP' in the title. With the title "The experience of caring for cancer patients at the end-of-life stage at home: A qualitative study". It seems that the aim of study will be focusing on how the HCP explore their experiences during they addressed caring for the patient. But the aim of study in this manuscripts was to explore how home-based end-of-life care is being delivered in community health care centers. When the aim is to explore how the caring was delivered, in my opinion, its meant not talking about the HCP experiences but more focus on monitoring and evaluation the program of caring (in this case was end of life care). It is different between experience of the HCP and exploring how the caring being delivered. When we look at the interview guideline, it is more focus on exploring how the caring was delivered. Therefore, It should be clear. The authors need to re thinking about the better title.

The title of this manuscript has been revised as follows, “The examination of the home-based end-of-life care: A qualitative study”.
2. In the methodology, it is unclear about:

- how the snowball process was done.

We started data collection from a few eligible community health care centers where we either had formal collaboration or acquaintance there (not particular in the end-of-life specialty). With their help, we got approval from the management of the centers to conduct the study. And the managers of the centers helped us to invite eligible health care providers in their centers to join our study. Then we asked these managers and the informants who had finished the interviews to recommend other community health care centers to us. With their help, a few more community health care centers joined the study. We continued approaching community health care centers and recruiting informants in this way. However, things did not happen smoothly all along. Some managers and informants said they did not have contact with other centers. Others tried, but were refused. Those centers did not want to be interviewed. So the data collection was stopped when we could not find any community health care centers joined the study by all means.

- What kind of follow up? Is it kind of member checking? Please explain more detail

The telephone calls were not member checking. We usually transcribed the interviews immediately after the interview and then double check the transcripts. We found the informants’ reply was not very clear when we double checked the transcript. So we called them for clarification. This situation happened a few times at the beginning of data collections when we were not familiar with how the patients were managed in the community.

- The reason that 3 interviews perform to 2 informants

We usually invited one physician/team leader and one nurse from one community health care center to participate the study. They were interviewed separately, so that they could share their opinion freely. However, in three community health care centers, the physician and the nurse from the same community health care center preferred to be interviewed together. So we respected their decision. Therefore, in these three centers, we conducted three interviews. In each interview, the physician and the nurse were interviewed together.

- How the authors doing the interviews? Explain more detail in page 5 line 3

The way we coded the interviews has been added in the section of rigor (Line 12-16, page 5).
How the authors use the personal journal? Is it mentioned in the results presentation?

The personal journal was used when the first author was coding the interviews and writing the manuscript. And it was not mentioned in the result sections.

3. Regarding one interview was not recorded, how the authors use the interview data (please explain more in detail). Did these data analyzed?

Field note was made during this unrecorded interview. After the interview, the researcher wrote down the content of the interview and the reflection as much as possible immediately after the interview. This has been added in the section of data collection (Line 23-24, page 4). Meanwhile, this interview was included for data analysis. A sentence, “All the 16 interviews were included for analysis”, has been added (Line 38, page 4).

4. Only one citation of BMC Palliative care in this manuscripts. The authors need to add some references using BMC Palliative Care. The words account also need to be the authors' concern.

Some articles published in BMC Palliative Care has been cited in the manuscript (No. 24, 26, 40).

The word account can be reduced in the future once the revisions made this time are confirmed by the reviewers.