Author's response to reviews

Title: Psychological process from hospitalization to death among uninformed terminal liver cancer patients in Japan

Authors:

- Yuko Maeda (maeda@path1.med.kyoto-u.ac.jp)
- Akihito Hagihara (hagihara@hsmp.med.kyushu-u.ac.jp)
- Eiko Kobori (kobori@pbh.med.kyoto-u.ac.jp)
- Taro Shirakawa (shirakawa@pbh.med.kyoto-u.ac.jp)

Version: 5 Date: 28 June 2006

Author's response to reviews: see over
Responses to the comments by Reviewer Dr. Christine McPherson

From authors to reviewers
Before replying each comment from reviewers, we would like to make some points clear and share our latest discussion on the article and the revision with the reviewers.

Taking the reviewers’ latest comments, version 3, as an opportunity, we extensively rewrote almost whole part of the article, including both the part the reviewers mentioned and did not. It was done in terms of appropriate interpretation and expression of the data and logical and accessible presentation, including English corrections, as the comment by reviewer. Some replies that we mentioned to each comment may, therefore, seem meaningless; since we changed most of paragraphs, sentences, or points of discussion despite mentioned by reviewers or not.

Nevertheless, we replied reviewers’ comments point by point; so that we can present that every comment by the reviewers was never ignored. We carefully interpreted them and turned them to advantage for the article improvement. For some replies, therefore, it might not be helpful for reviewers to identify how the points were improved or not improved. The reviewers see this revised article as which almost newly rewritten.

Background
Major revisions:
1. The authors make reference to the attitudes of doctors toward informing patients of their disease but do not put this within the context of the prevailing societal norms in Japan regarding self-determination and disclosure of medical information.
(This has been addressed)

Based on the previous article, we understand your comments means that we did not discuss why doctor hesitated informing patients of their disease in the context of uncommon self-determination in Japan. In this revision, however, we removed mentioning the part of the self-determination. In our previous version, we raised this topic in the first paragraph of the background section, since we expected to discuss whether to inform a patient of his/her disease in Japan. However, as we considered the primary objective (to identify psychological process of undisclosed patients) and the
limitation (uniformity of the population) of this study, we thought discussing such topic based on the result this time seemed premature. We, therefore, removed the part.

If our understanding of this comment is not correct, please kindly let us know.

2. There is scant reference to the psychological literature relating to the reactions of individuals to diagnosis and impending death. There is also a literature on death anxiety, which would fit with the results of the study.

We organized reviewed literatures again and used them as references of this article. A literature on death anxiety that the reviewer mentioned was “Awareness of death” by Glaser and Strauss? We cited it in the introduction section, however did not use for discussion, since whereas the authors has been discussing context awareness of death based on the relationship between patients and the people around them, what we focused on in this article was only the patients’ side, which resulted in difficulty in comparing for discussion.

Minor revisions:

3. The authors state the purpose of the study is “to examine the psychological processes of uniformed terminal cancer patients until death”. However, the significance of this purpose is not clearly stated.

This was stated in the last two paragraphs.

4. In paragraph 2- the sentence regarding a survey from the Statistics and Information Department (references 9 & 10), is not clear.

This was revised at the end of in the first paragraph.

Methods

Major revisions:

5. Given the nature of the research participants were not made aware of the
actual reason for the study. This brings many ethical issues regarding the
research that are not addressed by the authors. For example, how did the
interviewers deal with this ethical dilemma within the context of the interview,
particularly given the rapport over the study period?
(The authors have adequately explained the necessity for not informing
participants as to the nature of the research, given the aims of the study.
However, they have not addressed the ethical dilemma of being asked directly
by participants about their condition, as the excerpt given as a “typical
conversation” on page 19 illustrates. This is not a major revision but the authors
might consider addressing it in the discussion).

Concerning the comment of the necessity for not informing participants the
exact study purpose for building the rapport or for obtaining informed
consent, our addressed description in the previous revision (page 8, 2.2 Data
collection method; 1st paragraph, line 22-29) was further improved in the
first paragraph of the participants section). Regarding how the interviewer
addressed when asked directly by patients, we described it in the 4th
paragraph in the discussion section, and further mentioned the ethical
dilemma at the last of the same paragraph.

6. The interviewers did not ask questions but listened. How did the interviewers
explore issues raised by participants in more detail or clarify their understanding
of what participants were saying?
(My understanding from the article is that this was not part of the interview
process).

We made effort not to influence the psychological flow of the patients as much as
possible during the interview. Clarification of patients’ understanding is believed to be
secured through long term interview. The details were described in the 4th paragraph of
the data collection section.

7. The authors talk of theoretical sampling but it is not clear whether and how this
was carried out.
(Reference to theoretical sampling has been removed).

According to our careful review and discussion on the sampling method in this study,
we concluded that the method was NOT theoretical sampling, since all of patients hospitalized during the recruiting period were asked to participate in the study. Therefore, all references to the theoretical sampling were removed. We apologize making reviewers confuse.

**8.** The methodological procedures are not clear and need to be rewritten to improve clarity. The sentence at the end of the third paragraph of this section “Taking correlation..” does not make sense within the context of the analysis. (“Taking correlation..” has been deleted from this passage

The authors have improved the methods section but it still requires work to structure and make it clearer to the reader. Perhaps the authors might consider putting ethical approval before data collection. There is also repetition between the data collection and analysis, while acknowledging that the approach taken by the investigators is one where data collection and analysis are an on-going process. For instance, the sample is stated twice on page 7 and again on 8. On page 7 the sample are liver cancer patients, whereas on page 8 they are lung cancer patients).

The methodological procedure, including participants, data collection, and analysis sections, was almost completely rewritten for clear clarification. We moved the description of ethical approval at the last of the participants section before data collection. All the repetitions between data collection and analysis were removed. A word of lung was replaced by a word of liver throughout the article.

**Minor revisions:**

**9.** The fourth paragraph in the methods section is contains the findings before the reader had reached the Results section. This is confusing for the reader. (This has been addressed)

The findings described in the method section were moved to the result section.

**10.** There needs to be more transparency in the methods section in relation to the interviewers/researchers backgrounds and how this might influence their interpretations. (There is no reference in the methods section to the background of the interviewer or those involved in the interpretations. This does not acknowledge
the role of the interviewer as a part of the research, or those involved in the interpretations. For example were the researchers from different disciplines or the same? This has a bearing on how one interprets and explicates meaning and should be stated in relation to the validity of the findings).

We described the backgrounds of the interviewer and other study members, and its aim to contribute to ensure the validity of the result in the 2nd paragraph of the analysis section.

Results
Major revisions
11. The findings are presented in a stepwise way, where all participants progressed in exactly the same way with the same emotions at particular times since their hospitalization. If there was variability in the process, this would be of interest to the reader. Was there any overlap in concerns? (This has been addressed).

As the reviewer mentioned, what none of the study patients moved back and forth between stages or skipped a stage seems quite unusual, since we empirically know that our psychological condition is not change unidirectionally. We therefore concluded that the interview process itself might have provided an opportunity for patients to understand or reorganize themselves, pushing them forward psychologically.

Uniformity of the population, that is, all was males in their 50 or 60 with high education, could be another reason. The details were described in the 5th paragraph in the discussion section.

Overlap was found in the duration of each stage presented in Table 2. This time we did not mention the unidirectional of steps, though mentioned in the previous version; since it would make the discussion further complicated.

12. The authors suggest that as participants went through one gate into another gate the psychological conditions (feelings and behaviours) in the preceding gate came to an end. Yet on reading the data presented participants were clearly demonstrating certain feelings such as anxiety throughout the periods. (This has been addressed)

We had to say that the psychological “stage,” not “condition,” came to end, as revised
this time, shown in the 2nd paragraph in the model development section. Taking this reviewer’s comment as an opportunity, we reconsidered if the naming of each stage and gate were appropriate. As a result, we found some of the names were not well responded the psychological conditions of the patients, so we chose names as much as representative of each stage and gate as possible, as shown in Table 3. We believe these revisions would not cause any confusion for readers. This revision is related to the next comment and the reply.

13. Analyzing the data, the authors make interpretations that are not supported by the data presented. For instance, section 3.2.1 the comment “We suggest that while they had vague feelings that death might arrive sometime in the near future, they were not clearly conscious of it”. Again, in section 3.5 the authors discuss the finding that the participants no longer talked about death and looked active and lively. The authors state that “Based on this evidence, the interviewer found that patients had come to terms with their own death at this stage”. (This has been addressed. However, the authors state that given the rapport with the patient the “interviewer can grasp various states of patients’ mind accurately”. This may need rewording but it is not a major revision).

We had intensive discussion on the interpretation of the data again. As a result, we we reached the agreement to avoid the description, “We suggest that while they had vague feelings that death might arrive sometime in the near future, they were not clearly conscious of it,” and then we interpreted that “They clearly expressed their recognition that they were suffering from cancer and conveyed to the interviewer their fear that they might no longer be able to escape death,” in which the feeling of fear of approaching death was not “vague” or “not clearly conscious” any more. Please refer to the 3rd to 5th line in the paragraph of stage 3 in the results section.

Regarding the description, “the participants no longer talked about death and looked active and lively,” and “Based on this evidence, the interviewer found that patients had come to terms with their own death at this stage,” we changed them to “the patients talked about their wishes in a warmhearted atmosphere with their families. In this stage, the patients made no references to death;” which is believed to be more adequately interpreted the patients’ psychological conditions in this stage.

The sentence, was deleted, since it was not correctly expressed our interpretation.
Minor revisions

14. The results section is too long and will lose the reader.
(The authors have stated the need for retaining the length of the results section)

Although we stated the need for retaining the length of the results; as a result of our further discussion, we improved the results section, including its length, as shown in the result section. All conversations, previously described in the text, were listed in Table 2.

Discussion

Major revisions

15. The discussion would be strengthened by basing the work in current theory (as mentioned in the introduction revisions)
(This has been addressed)

We understand this comment as saying that the discussion would be strengthened by basing the background of self decision-making in Japan. However, we removed the description of the self-decision making in Japan. Please refer to the reply to the comment No. 1 for that reason.
If our understanding of this comment is not correct, please kindly let us know.

16. What are the implications of the findings?
(This has been addressed)

We mentioned the implications of the findings in the 3rd to the last line in the last paragraph of the discussion section.

Minor revisions

17. The authors suggest that the interviewer might have pushed participants through the stages. This needs to be elaborated.
(This has been addressed on page 29, line 9)

The sentence was improved and explained in the 3rd to 7th line in the 4th paragraph.

18. In paragraph 4 of this section who are the informed patients that the authors are comparing their uninformed participants with? Also in this paragraph the sentence referring to attitudes to death- the source is not identified.
(This has been addressed)
The informed patients whom we compared with the uninformed patients in the previous revision were the patients described in previous studies by Kubler-Ross, and so on. For the sentence referring to attitudes to death, the reference should have been identified as the reviewer made comment. However, we removed these descriptions this time, since we did not make discussion on whether to inform a patient of his/her disease or not, due to the same reason replied to the comment No.1 and 15.

(Additional comments that require revision:

19. In the Results section if saturation was reached at 38 participants why did the investigators continue interviewing all 59 participants?)

Please kindly refer to the reply to the comment No.7.
Response to the comments by Reviewer Dr. Linda Emanuel

1. Description of the cohort: Why is it described first as liver cancer patients and later as lung cancer? Why do these patients appear to be hospitalized from diagnosis till death? Why was data from patients who were informed of their diagnosis discarded? If possible the authors should retrieve that data and include it. It may provide only preliminary data but even that would be very interesting.

A word of lung was replaced by a word of liver throughout the article. Concerning the reason why patients were hospitalized till death, we understand that you are asking why these patients did not end their lives at home or somewhere outside a hospital. We would like to reply this by explaining that most of people in Japan end their lives in a hospital, rather than home, hospice, or any other place. Especially for terminal cancer patients who are not informed, most cases stay and continue to have treatment and care at the hospital. According to the population vital statistics in 2001 (Ministry of Health, Labor and Welfare), 81% of all of the death died in the hospital. In case of uninformed patients, they never think of leaving a hospital, because they think they need to have treatment and care; and families or doctors do not, or cannot, speak out for leaving, since it might lead patients misunderstanding that doctors give up their treatment because their disease is incurable. If our understanding of your question is not correct, please kindly let us know.

We did not include the data from patients who were informed, because comparing patients who were informed with those who were not informed was not the purpose of this study. Suppose we mention it, it seems difficult to discuss the results in the context of this article without disturbing logical description. We would like to find another opportunity for that.

2. How can content analysis give rise to the concept of gates and an entire conceptual model? As I understand content analysis, it can identify areas, not build a model. The model is, nonetheless, interesting, and the data is an important addition to an important topic. The author should present the content analysis as the findings and offer a conceptual model (stages and gates) as a second
matter. The conceptual model should be offered as consistent with but not the only possibility driven by the data in this study.

In the results section, we presented several areas identified as parts of the patients’ psychological process as the results of content analysis. We further presented the psychological model apart from the result section.

3. Explain more about the interviews. In what sense did the interviewer only listen? Later the process is described as supportive. What exactly was the interviewer allowed to say or convey in non-verbal ways? Why were the transcripts translated into English before content analysis? What was the process - eg was back translation used?

We think in what sense the interviewer did only listen could be explained that we made effort not to influence the psychological flow of the patients as much as possible during the interview. Please refer to the last paragraph in the data collection in the methods section. We removed the description mentioning that the process is supportive; instead, we explained our expectation which might be able to obtain through that process in the last paragraph in the data collection, in the method section.

What the interviewer was allowed during the interview was also described in details in the same paragraph. We moved the description of the English translation at the last of the method section, since it was translated after all of the data and content analysis were completed. The process of the translation was also mentioned together.