Author’s response to reviews

Title: How to Come to Terms with Facing Death: A Qualitative Study Examining the Experiences of Patients with Terminal Cancer

Authors:

Ayumi Kyota (akyota@gunma-u.ac.jp)
Kiyoko Kanda (kkanda@gunma-u.ac.jp)

Version: 2 Date: 25 Dec 2018

Author’s response to reviews:

12/25/2018

Dr Maria Zalm and Dr Robin L. Cassady-Cain

Editor

BMC Palliative Care

Dear Dr. Zalm and Dr. Cassady-Cain:

I, along with my coauthors, would like to thank you for inviting us to revise our manuscript titled “How to Come to Terms with Facing Death: A Qualitative Study Examining the Experiences of Patients with Terminal Cancer” for consideration in BMC Palliative Care.

Please find our revised manuscript with changes included based on yours and the reviewers’ comments. A point-by-point response to each comment is appended below. Again, thank you for providing this opportunity to revise our manuscript, and we hope that our paper is now suitable for publication in your esteemed journal.

I would like to take internal review as a doctoral thesis in my university if could you accept it. The deadline is January 6th 2019. I would appreciate it very much if you could reply to me by
January 6. Even if your reply is not an official document, there is no problem with e-mail. If you have any questions or concerns, please let me know.

We look forward to hearing back from you.

Sincerely,

Ayumi Kyota
Department of Nursing
Gunma University Graduate School of Health Services
3-39-22 Showa-machi, Maebashi
Gunma 371-8514, Japan
akyota@gunma-u.ac.jp

RESPONSE TO REVIEWERS

We wish to express our strong appreciation to the Reviewer for their insightful comments on our study. We feel the comments have helped us significantly improve the study.

Responses to the comments of Dr. Melissa J Bloomer, PhD, RN (Reviewer 1)

1. A number of statements throughout the manuscript are not referenced. Examples include Page 3, Line 3 'It is estimated...' and the subsequent sentence 'In higher-income countries...' Another example is on page 4, line 36 'Not surprisingly...' Another example, page 5, line 18 'The number of'

Response: In accordance with your comment, we have changed the following text in the Background from:
It is estimated that 37.4% of all-cause deaths worldwide need palliative care. In higher-income countries with substantial older adult populations, this percentage may exceed 60%. Additionally, more than 34% of adults receiving palliative care eventually die due to cancer [1].

Palliative care is required in 37.4% of all-cause deaths worldwide, especially over 60% of the adult deaths in high-income countries where the population of elderly people [1]. Additionally, more than 34% of adults receiving palliative care eventually die due to cancer [1].

Not surprisingly, it is rather difficult to achieve mental stability in such circumstances, and the need for specialized care is often hidden among these individuals.

The number of cancer patients who will spend the last days of their lives at home or in palliative care units is expected to increase, particularly within high-income countries. This is due to progressions in high-quality palliative care provided as a result of trends toward increasing patient needs and a demand for reductions in healthcare expenditures [16, 17].

The number of cancer patients who will spend their final days at home or in PCUs is expected to increase, particularly in high-income countries; this shift is due to advancements in high-quality palliative care provided as a result of the trends of increasing patient needs and demand for reductions in healthcare expenditures [6, 7].
2. Page 3, Line 11 to 21 is disjointed and lacks logical flow. The accepted writing convention is to present one idea or one key point per paragraph.

Response: We have changed the paragraph the following text in the Background:

Page 3, line 10-13

In 1967, for the first time in the world, Cicely Saunders founded the modern form of hospice, based on her view that it is important for terminally ill patients to be cared for by experts [2]. In the 1970s, thanatology and death studies spread widely, primarily in Europe and the USA. Since then, professionals providing end of life care have focused on what patients feel, think, and desire regarding their impending death [3].

To

Page 3, line 10-53

[…] The need for palliative care for terminal cancer patients is high worldwide.

In 1967, for the first time in the world, Cicely Saunders founded the modern form of hospice, based on her view that it is important for terminally ill patients to be cared for by experts [2]. In the 1970s, thanatology and death studies spread widely, primarily in Europe and the USA. […]

Professionals providing end of life care have focused on what patients feel, think, and desire regarding their impending death [8].

3. Page 3, Line 23, Kubler-Ross is very outdated. There are multiple newer theories that could be used here to explain the process of grieving and anticipatory grief.

Response: We agree with your assessment. We have changed the following text in the Background from:

Page 3, line 23

3. Page 3, Line 23, Kubler-Ross is very outdated. There are multiple newer theories that could be used here to explain the process of grieving and anticipatory grief.
To date, several investigators, such as Kübler-Ross [4] and Buckman [5], have proposed hypotheses regarding the way in which terminally ill patients accept death. For instance, Kübler-Ross [4] demonstrated, via analyses of patient narratives, that acceptance of death involves five stages (denial, anger, bargaining, depression, and acceptance), and individual patients alternate between these stages. This multi-stage theory has received various criticisms. Backer [6] stated that the path to death can produce many emotions, such as anger, sadness, depression, and assuredness, but these emotions do not occur in a particular sequence. Buckman [5] proposed a three-stage theory that included fear, a sense of sin, desire and despair, and humor, which are often seen in near-death situations. Overall, several models of death acceptance have been proposed; however, terminally ill patients do not always accept death, and many require mental healthcare in order to manage the negative emotions generated by the awareness of their imminent mortality.

Professionals providing end of life care have focused on what patients feel, think, and desire regarding their impending death [8]. Theories have been proposed regarding the way in which terminally ill patients accept death. Acceptance is an active process where the patient becomes open to and acknowledges all aspects of his or her current situation, whether physical or emotional, so as to make the most of the time he or she has left [9]. For instance, Buckman [10] proposed a three-stage theory that included fear, a sense of sin, desire and despair, and humor, which are often seen in near-death situations. The Patient Health Engagement model not only describes the patient’s emotional adjustment to the disease and diagnosis, but also tries to describe how the self-concept is reconfigured [11]. Acceptance-based interventions, from approaches such as Acceptance and Commitment Therapy, are also being applied to patients in palliative care [12]. However, terminally ill patients do not always accept death, and many require mental healthcare in order to manage the negative emotions generated by the awareness of their imminent mortality.

4. Page 3, Line 52 the terminology 'strong anxiety' and 'spiritual pains' is not explained. Spiritual pains is not a term used in English-speaking countries. Also what is meant by 'various sufferings' (line 57)?

Response: We have changed “the strong anxiety and spiritual pains” to “the anxiety and spiritual suffering.” “Various sufferings” means “physical pain, loss of meaning, loss of autonomy, being
a burden, fear of future suffering, and worry” in the following sentences. We have deleted the sentence which was included so that it is easy to understand.

Page 3, line 51

Healthcare professionals are keenly interested in assisting with the strong anxiety and spiritual pains experienced by terminal cancer patients. Cancer patients who have reached a terminal stage despite attempts at treatment have various sufferings. They are realizing the approaching of death by increasing difficulty in doing what they were previously able to do easily. Physical pain, loss of meaning, loss of autonomy, being a burden, fear of future suffering, and worry occur frequently among patients with terminal cancer [7].

To

Page 4, line 25

Healthcare professionals are keenly interested in assisting with the anxiety and spiritual suffering experienced by terminal cancer patients. Cancer patients who have reached a terminal stage despite attempts at treatment suffer in various ways. Physical pain, loss of meaning, loss of autonomy, being a burden, fear of future suffering, and worry occur frequently among patients with terminal cancer [13].

5. Page 4, line 9 the authors refer to psychiatrists. Yet I would assume a terminal patient would be more likely to see a grief and bereavement counselor, social worker or psychologist, BEFORE seeing a psychiatrist. The authors also fail to acknowledged that to some extent, grief, sorrow, anxiety and feelings of depression are also a normal and logical response to a terminal diagnosis. This is important because a clinician's aim should not be to remove or suppress all negative feelings, but rather to manage them so that other aspects of living are not unduly impacted.

Response: We agree with you and have incorporated this suggestion throughout our paper. We wanted to say that there are few patients who are diagnosed with anxiety or depression, have a major obstacle to their lives, and referre specialized treatment by psychiatrists. As your points out, various people such as a grief and bereavement counselor, social worker or psychologist support them. Moreover, we fully agree with the opinion that some extent, grief, sorrow, anxiety and feelings of depression are also a normal and logical response to a terminal diagnosis. We want to say that patients who are not receiving care of counselors, social workers, psychotherapists, psychiatrists, etc. manage their various emotions such as grief, anxiety,
depressed emotion and send their daily lives. For that reason, we wanted to clarify how they are managing their feelings. We changed the following text in the Background from:

Page 4, line 9

[...] For this reason, some patients are often referred to mental healthcare specialists such as psychiatrists. One of the most challenging roles for the psychiatrist is to help guide terminally ill patients physically, psychologically and spiritually through the dying process [8]. Close attention has recently been paid to cognitive behavioral therapy [9] and Mean-Centered Psychotherapy-Palliative Care [10] to help patients to deal with spiritual pain (e.g., despair and the loss of the meaning in living).

However, not all patients with terminal cancer are referred for specialized mental healthcare. Approximately 24% of terminal cancer patients have been diagnosed with an anxiety or depressive disorder [11]. Therefore, it is likely that many more patients with terminal cancer attempt to attain mental stability, individually, while managing the stresses of impending death. Here, mental stability is defined by patients managing their daily life without expressing anxiety or depressive symptoms to a diagnostic level.

To

Page 4, line 37

[...] Nurses also have the important task of screening patients for specialized mental healthcare that may be necessary. Thereby, some patients are referred to mental healthcare professionals, such as grief and bereavement counselors, social workers, psychologists, and psychiatrists.

However, not all patients with terminal cancer are referred for specialized mental healthcare; approximately, only 24% of terminal cancer patients have been diagnosed with an anxiety or depressive disorder [14]. Patients who do not receive professional mental healthcare must manage various emotions such as, sorrow, anxiety, and depression, only with the help of their daily care nurses. However, no studies have focused on how terminal cancer patients manage their feelings associated with anxiety and depression at this stage of life, and no methods have been established to provide nursing support for patients' attempts in this regard.

6. Page 4 'spiritual pain' and 'mental stability' are not adequately explained to an international audience. Neither of these terms are familiar to me at all, and are not used in clinical practice.
Response: We have changed “spiritual pains” to “spiritual suffering” and “mental stability” to “mental well-being.”

7. The purpose statement, found on page 4, line 43 does not make sense due to the grammar. The sentence reads 'The purpose of this study is to clarify that patients who exhibited anxiety or depressive disorder how recognize the terminal stages and are trying to stabilize their mental health' After reading this several times for clarity, I am not sure, but I think you mean 'The purpose of this study is to explore how patients with a terminal illness manage feelings of anxiety or depression' But I am not sure from the purpose statement. The subsequent sentence is much clearer.

Response: Thank you for rectifying the difficult-to-read sentences. We have fixed according to your comment.

Page 4, line 43

The purpose of this study is to clarify that patients who not exhibited anxiety or depressive disorder how recognize the terminal stages and are trying to stabilize their mental health.

To

Page 5, line 30

The purpose of this study is to explore how patients with a terminal illness manage feelings associated with anxiety and depression.

8. In the previous review, the authors were asked to remove references to 'we' in their writing and use third person convention. Yet there are still instances of 'we' throughout the body of the manuscript.

Response: We are sorry, that we had misunderstood that remove the word “we” only in the analysis section. We have fixed it in all sessions.
9. The first mention of nurses is on line 50, of page 4. Reflecting on this, I am left wondering why nurses are not identified earlier as healthcare professional integral to assessing and supporting the person with a terminal illness, identify and manage negative emotions such as symptoms of anxiety and depression. Most certainly, nurses are most often the most likely to interact with patients, often responsible for coordinating multidisciplinary care teams, so this is peculiar that they are not mentioned earlier.

Response: We have added the role of the nurse to the 4th paragraph according to your comment.

Page 4, line 34

[...]Nurses have a responsibility to understand this suffering and the impact it has on their patients’ lives. Nurses also have the important task of screening patients for specialized mental healthcare that may be necessary. Thereby, some patients are referred to mental healthcare professionals, such as grief and bereavement counselors, social workers, psychologists, and psychiatrists.

10. What is meant by 'latent mental needs', page 4, line 55?

Response: “latent mental needs” are described in this case as there are some cases that can not be caught when understanding the suffering of end-of-life patients by general nurses. For example, if a patient does not express his / her emotions much, and there is no appeal of suffering, the nurse will possibly judge instantaneous as “This patient has no mental and psychological problems” in daily busy work. However, when nurses carefully listen to the patient’s story, there are cases in which various sorrow, anxiety and anguish are held in his / her heart. This research will clarify how manage patients’ own feelings who judged that “there is no problem on the surface” by nurses. Thereby, it can deepen nurses understanding of the patient's mental, and judge “whether there really is no problem.” We have changed the following text in the Background from:

Page 4, line 55

[...]It was conducted the present study with the expectation that this findings could help nurses better assess patients’ mental health and capture latent mental needs.
[...]For example, if a patient does not express his or her emotions well, and there is no obvious suffering, the nurse could possibly assume that the patient has no mental or psychological problems. However, if nurses carefully listen to patients’ personal stories, it can become clear that some patients are harboring sorrow, anxiety, or depression. Symptom assessment scales are used by general nurses to identify the need for special interventions such as by palliative care teams.

11. It is not clear how the data commencing on page 4, line 57, through to page 5 relates to the present study. If this is background information, then it should be moved earlier, prior to the purpose statement. Furthermore reference to STAS-J on line 14, page 6 is not helpful. I don’t know what this is, and I doubt most readers would not.

Response: We have deleted these to clear the sentences. We have changed the following text in the Methods from:

Page 4, line 57

[...]In Japan, 80.2% of palliative care teams include at least one certified nurse (CN) or certified nurse specialist (CNS) [12]. The most common symptoms treated include pain (63%) and anxiety/depression/grief/emotional burden (22%) [13]. However, only 0.34% of all nurses qualify as a CN or CNS for palliative care and cancer nursing [14]. Therefore, it is often necessary for a general nurse to assess patients’ mental health and consult with doctors in order to request relevant care. It is also necessary to assess mental situation not only from tools, such as STAS-J [15] but also from patients’ narration. This study are expected to lead to the provision of appropriate nursing assistance and advances in palliative nursing skills.

To

Page 5, line 8

It is necessary for a general nurse to assess patients’ mental health and consult with doctors in order to request relevant care, but it is not easy. For example, if a patient does not express his or her emotions well, and there is no obvious suffering, the nurse could possibly assume that the
patient has no mental or psychological problems. However, if nurses carefully listen to patients’ personal stories, it can become clear that some patients are harboring sorrow, anxiety, or depression. Symptom assessment scales are used by general nurses to identify the need for special interventions such as by palliative care teams. However, it is necessary to assess the mental state of patients not only on a scale but also based on the patients’ own narration.

12. Page 5, there is no description of or justification for the study design. The authors need to briefly describe the methodology and justify why it was chosen.

Response: We have added the following text in the Study design:

Page 5, line 54

[…]This research design can reflect the essence of feeling, thinking, and ideas which are conscious or unconscious in participants, through the analysis of intensive and extensive interviews [15]. This research design was adopted because it aims to clarify the dynamics of psychological functioning in participants who do not communicate about their depressed mood or intense grief.

13. It is not until the 'Participants and Setting' section that the authors state that this study relates to Japan. As detailed in the previous review comments, some information is needed on the background to explain the influence of the Japanese culture of perspectives of death and dying, the hospice/palliative care movement and cultural influences. It cannot be assumed that the readership will understand this. How is hospice care provided in Japan? Who can access hospice care? At what point in the disease trajectory is hospice care available? Is it multidisciplinary? Is inpatient or outpatient hospice care provided?

Response: We added to the Background about the influence of the Japanese culture of perspectives of death and dying, the hospice / palliative care movement and cultural influences. We have added the following text in the Background:

Page 3, line 20
There were 357 palliative care units (PCUs) and 7,184 beds to serve Japan’s population of 127 million [3]. More than 80% of cancer deaths occur in general wards; home hospice and PCUs account for less than 20% of cancer deaths [4]. PCUs have beds for cancer and acquired immune-deficiency syndrome patients with the average length of stay of 33 days, and the average deceased patient discharge rate is 84% [3]. Meanwhile, only 991 hospitals (or 13.3%) have palliative care teams for hospitalized patients and outpatients with cancer [5]. Patients who can receive professional palliative care are limited to large hospitals and few home hospice clinics. To solve this problem, the policy of the Japanese government is promoting palliative care and home hospice.

14. Why only cancer patients? Why not patients with other terminal illnesses?

Response: Thank you for providing these insights. This study is targeted at home hospice and PCUs patients. PCUs are targeted for only cancer or AIDS patients in Japan. We think that there is adaptability in the results of this study for “end-of-life patients who realized that can not be escaped from own death,” but that is uncertain. Because, cancer is characterized by abrupt increase in physical symptoms and ADL is sharply decreased within 1 month before death, but the cognitive ability is kept relatively. It follows a different process from other chronic diseases such as chronic cardiac insufficiency, chronic kidney failure, cerebrovascular disorder, intractable disease, and dementia. Therefore, in this study, we identified as “cancer patients.”

15. Page 6, how many potentiality participants were approached? How were potential participants identified?

Response: We have added the following text in the Participants and Setting:

Page 6

The study purpose was presented in a detailed document, wherein 16 respondents who provided formal written consent were selected as participants.
The candidates for this research were selected by the nurse manager. The nurse manager explained to them the outline of the research and asked whether the researcher could visit to give a more detailed explanation. If consent was obtained, the researcher visited the candidate and explained the research.

Researchers used detailed documents to explain the research content to 21 candidates, and 16 participants submitted formal written consent form.

16. Given the concerns already raised, I cannot endorse this manuscript for publication. It does not meet the needs or interests of an international audience, nor is it self-explanatory enough in terms of language and terminology that it could be of use to an international audience.

Response: Thank you for your suggestion. However, we targeted the Japanese people, but our focus is not “to characterize the Japanese people” but “to deeply read the feeling, emotions, and ideas of terminal cancer patients.” The result, which is derived as “I have to accept it” and “it can not be helped,” is a character of “the end period where death can not escape” more than the characteristics of the Japanese. Therefore, we think that there is universality that applies not only to Japanese patients but also to patients all over the world. To make our intention easier to convey, we have reduced the description of the characteristics of the Japanese from the Discussion and added the universality in multicultural. Research on patients who are in front of death is extremely valuable and we believe that the results of this study will be widely applied in the international community. We have added the following text in the Discussion:

Discussion

This study demonstrated that patients told themselves that “I have to accept it” to manage their feelings when facing death. Thus, they felt thankful for being alive and around people, and they were finding positive meaning even in such a serious situation. […]

It is not only Japanese patients who tell themselves “I have to accept it” in a difficult situation that cannot be controlled. This is one of the cognitive reinterpretation and adaptive coping skills, which involves “reinterpreting adverse experiences to find meaning and benefit” [26]. Thereby, the patient maintains self-efficacy for coping with cancer [27]. The results of this research have universality and thus are applicable to patients with terminal cancer globally regardless of culture or race.
Facing cancer and their own deaths, which they had been trying to avoid

This is consistent with spiritual suffering resulting from a sense of unfairness and wondering, “Why was it me who developed such a disease?” [28]. Cancer is a major cause of death in many countries including Japan [29].

The unsatisfactory body and circumstances

[…] Close attention has recently been paid to cognitive behavioral therapy [30] and Mean-Centered Psychotherapy-Palliative Care [31] to help patients deal with spiritual suffering (e.g., despair and the loss of meaning in their lives). By accepting themselves with reduced independence, patients notice that “It is important to maintain self-determination ability if they cannot engage in self-care.”

In addition, a good death in Japan is characterized by an emphasis on interpersonal relationships with family members and loved ones [32]. A similar trend has been observed in Korea (a country in a cultural zone that is close to that of Japan) [33], and others [34, 35], where terminal cancer patients rate “not being a burden to the family” as very important. By believing that “I have to accept it” to receive care from others, patients reconsider themselves from the perspectives of others. Thus, they realize that there are still things they can do for their family and the others and find meaning in life.

Consciousness of the transcendental existence of destiny

Some participants stated that the “higher power” was Buddha, but for many, it was an inconclusive, vague concept that included “nature.” Numerous people from around the world including the Japanese have scientism-based worldviews. The rate of atheist, agnostic, and nonbeliever exceeds 80% in some countries, with the highest in the order of Sweden, Vietnam, Denmark, Norway, and Japan [40]. This perspective does not appear to be specific to Japanese people and is observed frequently in patients with terminal cancer from other cultural and racial backgrounds.

[…] In this way, these patients attempted to achieve mental well-being under difficult and severe circumstances. Thus, patients reinterpret the circumstances and life experiences. They experience
gratitude towards their life, self-determined, and families, and can thereby find meaning in their life.

Responses to the comments of Dr. Gianluca Catania, PhD, RN (Reviewer 2)

1. The psychophenomenological approach of 5 steps is detailed and so the fact that there is no saturation point with respect to deriving phenomenological meaning (Can this be clarified, as a saturation point is usually reached with qualitative research?)

Response: In accordance with your comment, we have changed the following text in the Analysis from:

Page 9, line 16
However, there is no saturation point with respect to deriving phenomenological meaning [20].

To
Page 9, line 42
There is no saturation point with respect to deriving phenomenological meaning, to clarify the essence using phenomenological reduction and free imaginative variation [17].

2. Also - the "Japanese have a fatalistic idea "Shouganai" towards they cannot change anything." Should a statement be added about how this may differ with other countries / cultures?

Response: Thank you for your suggestion. We think coping of "I have to accept it" or "it can not be helped" applies to other than Japanese people. We have changed the following text in the Discussion from:

Page 17, line 17
The Japanese expression, “Shouganai,” which is equivalent to “I have to accept it” or “it cannot be helped” in English, is used in situations in which there is no means of resolving an issue [23]. This term is used on a daily basis in Japan. The idea of "it cannot be helped" has been examined in various fields ranging from the extraordinary huge-scale disasters such as earthquakes [24, 25] and nuclear incident [26], economics [27], education [28], and individual identity [29]. Japanese have a fatalistic idea “Shouganai” towards they cannot change anything. This study demonstrated that patients told themselves that they had “to accept it” to achieve mental stability when facing death.

This study demonstrated that patients told themselves that “I have to accept it” to manage their feelings when facing death. Thus, they felt thankful for being alive and around people, and they were finding positive meaning even in such a serious situation. The Japanese expression, “Shouganai,” which is equivalent to “I have to accept it” or “it cannot be helped” in English, is used in situations in which there is no means of resolving an issue [20]. This term is used on a daily basis in Japan. The idea of "it cannot be helped" has been examined in various fields ranging from the extraordinary huge-scale disasters such as earthquakes [21] and nuclear incident [22], economics [23], education [24], and individual identity [25]. Japanese have a fatalistic idea “Shouganai” towards they cannot change anything.

It is not only Japanese patients who tell themselves “I have to accept it” in a difficult situation that cannot be controlled. This is one of the cognitive reinterpretation and adaptive coping skills, which involves “reinterpreting adverse experiences to find meaning and benefit” [26]. Thereby, the patient maintains self-efficacy for coping with cancer [27]. The results of this research have universality and thus are applicable to patients with terminal cancer globally regardless of culture or race.

3. Study Design needs a little more explanation - “The present study was based on a psychophenomenological approach, which is a descriptive phenomenology originating from Husserl's philosophy.”

Response: We have added the following text in the Study design:
This research design can reflect the essence of feeling, thinking, and ideas which are conscious or unconscious in participants, through the analysis of intensive and extensive

interviews [15]. This research design was adopted because it aims to clarify the dynamics of psychological functioning in participants who do not communicate about their depressed mood or intense grief.

4. Why were 16 patients as a number chosen originally and were there any limitations with having just 11 respondents? Particularly as it is stated that saturation could not be reached with the research method used which seems unusual as the method appears to be qualitative.

Response: We decided that sample size was set to 5 to 6 for each group in home care and PCUs. However, because there were participants in the interview cancellation due to exacerbation of their physical conditions etc., we continued recruitment of participants till at least 5 people. As a result, we explained to 21 candidates and got consent from 16 people. We have changed the following text in the Participants and Setting from:

Participants and Setting

The study purpose was presented in a detailed document, wherein 16 respondents who provided formal written consent were selected as participants.

Analysis

Because it is important that people with experience provide numerous narratives in phenomenology, the sample size was intentionally reduced to include approximately one to six participants [19].

To
Participants and Setting

Because it is important that people with experience provide numerous narratives in phenomenology, the sample size was intentionally reduced to include approximately one to six participants [16]. Sample size was set to 5 to 6 for each group in home care and PCUs. Researchers used detailed documents to explain the research content to 21 candidates, and 16 participants submitted formal written consent form.

5. Also could some more information be provided as to who decided and if there was a measure to decide which "Patients exhibited depressed mood or intense grief (i.e., because they had been unable to reach mental stability)" - how was this judgment made as their views in relation to spiritual pain would be particularly important and certainly would need a lot of support had they been included. In relation to the ethical committee approval was support offered to patients who were interviewed that did experience distress?

Response: The candidate for this research was selected by the nurse manager. Physicians, nurse manager, nurse in charge judged “Patients not exhibited depressed mood or intense grief.” Also, this decision was made on the day of each interview. The assessment scale of the spiritual pain was not used this time. Because physicians and nurse manager at PCU and home hospice had sufficient clinical experience for assessment of spiritual pain. There was no participant who required physicians and nurses follow-up as the physical and psychological burden increased after the interview. We have added the following text in the Participants and Setting and Ethical Considerations:

Page 6, line 35

Participants and Setting

[…]The candidates for this research were selected by the nurse manager. The nurse manager explained to them the outline of the research and asked whether the researcher could visit to give a more detailed explanation. If consent was obtained, the researcher visited the candidate and explained the research.

Page 8, line 45

Ethical Considerations
There was no participant who required physicians and nurses extra support as the physical and psychological burden increased after the interview.

6. From the discussion as detailed above can the authors make comparison with other countries based on the statement; “Their feelings swing between acceptance of death (i.e., "I have to accept it") and the desire to live, and this is part of the preparation for death in Japan.” (It is addressed about the numbers who wish to die at home in other countries and the figures of those who actually die at home.) Should it be added to the title at the end; ‘In Japan’? this may overcome the need to refer to what happens in other countries in relation to the 5 themes that have been identified.

Response: Thank you for providing these insights. We targeted the Japanese people, but our focus is not “to characterize the Japanese people” but “to deeply read the feeling, emotions, and ideas of terminal cancer patients.” The result, which is derived as “I have to accept it” and “it can not be helped,” is a character of “the end period where death can not escape” more than the characteristics of the Japanese. Therefore, we think that there is universality that applies not only to Japanese patients but also to patients all over the world. For these reasons, we did not add “In Japan” to the title at the end. To make our intention easier to convey, we have reduced the description of the characteristics of the Japanese from the Discussion and added the universality in multicultural. Research on patients who are in front of death is extremely valuable and we believe that the results of this study will be widely applied in the international community. We have added the following text in the Discussion:

Discussion
Page 17, line 47- Page 18, line 24

This study demonstrated that patients told themselves that “I have to accept it” to manage their feelings when facing death. Thus, they felt thankful for being alive and around people, and they were finding positive meaning even in such a serious situation. […]

It is not only Japanese patients who tell themselves “I have to accept it” in a difficult situation that cannot be controlled. This is one of the cognitive reinterpretation and adaptive coping skills, which involves “reinterpreting adverse experiences to find meaning and benefit” [26]. Thereby, the patient maintains self-efficacy for coping with cancer [27]. The results of this research have universality and thus are applicable to patients with terminal cancer globally regardless of culture or race.
Facing cancer and their own deaths, which they had been trying to avoid

This is consistent with spiritual suffering resulting from a sense of unfairness and wondering, “Why was it me who developed such a disease?” [28]. Cancer is a major cause of death in many countries including Japan [29].

The unsatisfactory body and circumstances

[…] Close attention has recently been paid to cognitive behavioral therapy [30] and Mean-Centered Psychotherapy-Palliative Care [31] to help patients deal with spiritual suffering (e.g., despair and the loss of meaning in their lives). By accepting themselves with reduced independence, patients notice that “It is important to maintain self-determination ability if they cannot engage in self-care.”

In addition, a good death in Japan is characterized by an emphasis on interpersonal relationships with family members and loved ones [32]. A similar trend has been observed in Korea (a country in a cultural zone that is close to that of Japan) [33], and others [34, 35], where terminal cancer patients rate “not being a burden to the family” as very important. By believing that “I have to accept it” to receive care from others, patients reconsider themselves from the perspectives of others. Thus, they realize that there are still things they can do for their family and the others and find meaning in life.

Consciousness of the transcendental existence of destiny

Some participants stated that the “higher power” was Buddha, but for many, it was an inconclusive, vague concept that included “nature.” Numerous people from around the world including the Japanese have scientism-based worldviews. The rate of atheist, agnostic, and nonbeliever exceeds 80% in some countries, with the highest in the order of Sweden, Vietnam, Denmark, Norway, and Japan [40]. This perspective does not appear to be specific to Japanese people and is observed frequently in patients with terminal cancer from other cultural and racial backgrounds.

[…] In this way, these patients attempted to achieve mental well-being under difficult and severe circumstances. Thus, patients reinterpret the circumstances and life experiences. They experience
gratitude towards their life, self-determined, and families, and can thereby find meaning in their life.

7. Need to check English eg page 5;

Response: We have changed English. We have changed the following text in the Background and Methods:

Page 3, line 40

[…] The number of cancer patients who will spend their final days at home or in PCUs is expected to increase, particularly in high-income countries; this shift is due to advancements in high-quality palliative care provided as a result of the trends of increasing patient needs and demand for reductions in healthcare expenditures [6, 7].

Page 5, line 50- Page 6, line 35

Methods

Study design

The present study was based on a psychophenomenological approach, which is a descriptive phenomenological approach originating from Husserl’s philosophy. This approach is designed to gain a deep understanding regarding the lived experiences. This research design can reflect the essence of feeling, thinking, and ideas which are conscious or unconscious in participants, through the analysis of intensive and extensive interviews [15]. This research design was adopted because it aims to clarify the dynamics of psychological functioning in participants who do not communicate about their depressed mood or intense grief.

Participants and Setting

Japanese patients receiving palliative care at home or in PCUs were the participants. Purposive sampling was used to select the research participants. For recruiting patients who were aware of their terminal conditions, the clinics that operated according to the principle of hospice care were selected. Additionally, patients admitted to hospital PCUs after deciding to not take active treatments such as chemotherapy were selected. The study involved cancer patients who had (a)
been advised that active treatment that aimed to provide a cure was judged ineffective, (b) been predicted to have a survival period of no more than six months, (c) no serious complications other than cancer, and (d) been judged by physicians or nurses as capable of engaging in interviews. Patients who exhibited a depressed mood or intense grief and were judged as unsuitable for participation by physicians or nurses were excluded from the study.