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

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Dr Maria Zalm
Editor
BMC Palliative Care

Dear Dr. Zalm:

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.

We look forward to hearing back from you.

Sincerely,

Ayumi Kyota
Department of Nursing
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. Lines 3-11 do not make sense. Rather than saying “palliative care is required in 37.4% of all-cause deaths worldwide”, instead the point the authors should be making is that “in 37.4% of cases, patients who died could have benefited from specialist palliative care”.

Response: Thank you for your gracious advice. In accordance with your comment, we have changed the following text in the Background from:

Page 3, Line 3

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].

To

Page 3, Line 3

In 2011, 37.4% patients who died worldwide could have benefitted from specialist palliative care [1]. Additionally, more than 34% of adults in need of palliative care eventually died due to cancer [1].
2. Clarification is also needed about what is meant by 'palliative care'. This term could be used to refer to a specialist palliative care service, or the end-of-life care provided by any clinician to a dying person. There are significant differences, and it is not clear which is being referred to.

Response: We use palliative care in the sense of a specialist palliative care service. This includes care for terminal stage patients. If only showing the end-of-life care, it is declared "palliative care to terminally ill patients." We have changed the following text in the Background:

Page 3, line 35-40

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.

To

Page 3, line 37-45

Patients who can receive specialist palliative care, such as PCUs and palliative care teams, are limited to specific hospitals and few home hospice clinics. To address this issue, the Japanese government adopted the policy of promoting palliative care and home hospice [6].

3. Line 21, sentences commencing with “There were 357....” does not follow from the previous sentences, and are not clearly or logically presented. Are Palliative Care beds only provided for those with cancer and ‘acquired immune-deficiency syndrome’? What about all other patients with a terminal illness?

Response: We understand that palliative care is not limited to cancer and AIDS patients. However, palliative care units in Japan cover only cancer and AIDS patients. This is also an issue for Japanese society. Terminal patients due to other chronic diseases etc. are spending at general wards and facilities such as nursing homes. We have separated the paragraphs in the Background from:

Page 3, line 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. There were 357 palliative care units (PCUs) and 7,184 beds to serve Japan’s population of 127 million [3].

To

Page 3, line 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.

There were 357 palliative care units (PCUs) and 7,184 beds to serve Japan’s population of 127 million [3].

4. Define ‘professional palliative care.

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

Page 3, line 35-40

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.

To

Page 3, line 37-45

Patients who can receive specialist palliative care, such as PCUs and palliative care teams, are limited to specific hospitals and few home hospice clinics. To address this issue, the Japanese government adopted the policy of promoting palliative care and home hospice [6].

5. a number of statements are not supported by academic references. Some examples include:-

Page 3, Line 38, “To solve this problem...”
Page 3, Line 40, “The number of cancer patients...”

Page 4, line 26, “Healthcare professionals...”

Page 5, line 8-28 are not supported by academic references.

Response: We added the references in the Background from:

Page 3, line 38

To solve this problem, the policy of the Japanese government is promoting palliative care and home hospice.

To

Page 3, line 38

To address this issue, the Japanese government adopted the policy of promoting palliative care and home hospice [6].

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 [7, 8].

To

Page 3, line 45

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 [7, 8]; 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 [7, 8].

Page 4, line 26
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.

To

Page 4, line 30

Healthcare professionals are keenly interested in assisting with the anxiety and spiritual suffering experienced by terminal cancer patients [14, 15]. The trajectories of functional decline at the end of life are substantially different between patients diagnosed with cancer and other advanced organ diseases [16].

Page 5, line 8-28

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 become clear that some patients are harboring sorrow, anxiety, or depression. Symptom assessment scales are used by 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.

To

Page 5, line 28-45

It is necessary for nurses in the outpatient section and wards to assess patients’ mental health and consult with doctors in order to request relevant care, but it is not easy. Symptom assessment scales [22, 23] are often used by nurses to identify the need for special interventions such as by palliative care teams. However, it has also been pointed out that there is a lack of consensus in the cut-offs of symptom assessment tools and timing for outpatient palliative care referral [24]. Therefore, it is necessary to assess the mental state of patients not only on a scale but also based on the patients’ own narration.

6. Page 3, line 52, the authors refer to “end of life care.” but it is unclear if this is different to palliative care, referred to earlier.
Response: We used palliative care as a reference for the definition of WHO. In the preceding paragraph, if it is described as palliative care, it includes not only end of life care but also symptom management at the beginning of treatment etc. In this paragraph, it was targeted the end of life, we used the word “palliative care to terminally ill patients.” We have changed the word so that our intention is easy to communicate.

Page 3, line 52

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

To

Page 3, line 55

Professionals providing palliative care for terminally ill patients have focused on what patients feel, think, and desire regarding their impending death [9].

7. Page 4, line 35, please clarify why is nurses (sole) responsibility to understand the suffering and impact it has on patients' lives' - surely all clinicians should have the same responsibility, particularly given the global trend to multidisciplinary teams. Furthermore, patients dying from diagnoses other than cancer can have similar experiences, so it is not clear why they are not acknowledged here.

Response: Thank you for bringing this to our notice. Since our study focused on nurses, we only highlighted their responsibility; however, you rightly pointed out that other healthcare professionals must also take responsibility, and therefore we have revised the text. As you pointed out, patients dying from diseases other than cancer have similar experiences. However, trajectories of functional decline at the end of life are substantially different between patients with cancer and other advanced organ diseases, and therefore we focused on cancer patients. We have changed the following text in the Background:

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]. 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.

To

Page 4, line 30

Healthcare professionals are keenly interested in assisting with the anxiety and spiritual suffering experienced by terminal cancer patients [14, 15]. The trajectories of functional decline at the end of life are substantially different between patients diagnosed with cancer and other advanced organ diseases [16]. Cancer patients who have reached a terminal stage despite treatment attempts suffer in various ways; physical pain, loss of meaning, loss of autonomy, feeling of being a burden, fear of future suffering, and worry occur frequently among patients with terminal cancer [17]. Healthcare professionals, including nurses, have a responsibility to understand this suffering and its impact on their patients’ lives. Nurses have the important task of screening patients for specialized mental healthcare that may be necessary. Therefore, some patients are referred to mental healthcare professionals, such as grief and bereavement counsellors, social workers, psychologists, and psychiatrists.

8. Page 4, line 48, the authors state data to support the relationship between anxiety and depression and a cancer diagnosis, but fail to explain how these symptoms can also be viewed as normal human responses to a cancer diagnosis and/or terminal illness. It needs to be explained that perhaps it is the impact of these feelings, or the degree to which they impact patient coping that is what is important. Essentially, I would expect any person with a cancer diagnosis, or with a terminal illness of any sort, to have some degree of sorrow, anxiety and or depression at some point.

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

Page 4, line 48

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.

To

Page 5, line 1

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 [18]. This value is higher than the healthy people population [19]. The desire for death in terminally cancer patients is associated with depression and anxiety; however, patients with no mental disorders may also desire death [20]. Patients who do not receive professional mental healthcare must manage various emotions such as sorrow, anxiety, and depression, with the help of their daily care nurses.

9. One of the biggest flaws with this manuscript is the statement commencing on page 4, line 57 in which the authors state 'However, no studies.....'. I do not agree with this statement. If this is the justification for this study, then it is flawed.

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

Page 5, line 57

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.

To

Page 5, line 15

Several transdiagnostic psychological treatments for anxiety and depressive disorders have been reported [21]. However, there are not well established methods for nursing support to manage the feelings of anxiety and depression associated with terminal cancer patients who have not clearly expressed a depressed mood or intense grief.

10. Page 5, line 8, please define 'general nurse' - who, where, quals etc.
Response: In this case, “a general nurse” means nurses at the outpatient section and the ward, and they often use some tools such as the Edmonton Symptom Assessment System (ESAS) or distress thermometer (DT). We have changed the following text in the Background from:

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.

To

Page 5, line 29

It is necessary for nurses in the outpatient section and wards to assess patients’ mental health and consult with doctors in order to request relevant care, but it is not easy. Symptom assessment scales [22, 23] are often used by nurses to identify the need for special interventions such as by palliative care teams. However, it has also been pointed out that there is a lack of consensus in the cut-offs of symptom assessment tools and timing for outpatient palliative care referral [24]. Therefore, it is necessary to assess the mental state of patients not only on a scale but also based on the patients’ own narration.

11. As a qualitative researcher, I am not familiar with a 'psychophenomenological approach, which is a descriptive phenomenological approach originating from Husserl's approach'. It is customary to provide enough detail, backed up by academic sources, to enable the reader to understand. This has not been provided.

Response: Thank you for providing these insights. We have changed the following text in the Methods from:
Page 5, line 50

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.

To

Page 6, line 6

The present study was based on a psychophenomenological approach, which is a descriptive phenomenological approach originating from Husserl’s philosophy. The descriptive phenomenology is used to illuminate poorly understood aspects of experiences; it aims to identify and describe the meanings behind people’s experiences [25, 26]. Phenomenology is a highly appropriate and suitable methodology for mental health research, since it includes people's experiences and enables silent voices to be heard [27]. The psychophenomenological 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 [28]. This research design was adopted because it aims to explore how terminal cancer patients who have not clearly expressed a depressed mood or intense grief manage their feelings associated with anxiety and depression.

12. The aim statement provided on page 5, line 30 is different from that provided on page 6, line 4.

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

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.

To
The purpose of this study is to explore how terminal cancer patients who have not clearly expressed a depressed mood or intense grief manage their feelings associated with anxiety and depression.

13. Given the focus of the study, it seems odd that patients who 'exhibited a depressed mood or intense grief' were not included in the study. This has not been explained or justified.

Response: Please note that ethical consideration was very important for this study because it involves multiple interviews of patients with terminal cancer. In addition, the approach to patients who clearly express a depressed mood or intense grief is also evident in previous studies. However, it is a motivation for research that it is difficult to grasp the psychology of patients who have not clearly expressed a depressed mood or intense grief. For that reason, we excluded patients who were judged by a doctor or a nurse as exhibiting a depressed mood or intense grief; such patients were not suited for participation in this research. We have changed the following text in the Methods:

Page 6, line 30

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.

To

Page 6, line 57

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 because of ethical considerations.

14. There is also no explanation of who conducted the interviews, their quals etc. This is important so that the reader can make an assessment of their suitability/appropriateness.
Response: We have added the following text in the Methods:

Page 8, line 35

The interviewer was an oncology nurse with a bachelor’s degree, trained to be sensitive to patients' emotional reactions.

15. Please clarify, if the research was explained to 21 people but only 16 signed the consent, does this mean 5 people chose not to proceed? I am also concerned that participants were interviewed multiple times, yet there is little detail to explain if an iterative or incremental approach was used to interviewing to justify multiple interviews. From an ethical standpoint, this needs to be clearly explained. Furthermore, the statement at top of page 7 that 'interview sessions were limited to approximately one week' needs revision. As it is currently written, it means that interviews lasted one week!

Response: When data collection, analysis, and analysis results are inspected in a spiral pattern, the content already analyzed affects the next data collection and analysis. In this research method, this leads to inhibition of free speech of the subject and the prejudice of researchers that "it will be this way." Therefore, in this study, we did not adopt an iterative or incremental approach. Multiple interviews were conducted with the aim of forming a rapport with the patients and ensuring free and deep conversations. We are listed as “once a week,” not “one week.” We have added and changed the following text in the Methods:

Page 6, line 45

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. Each participant was interviewed multiple times to ensure collection of detailed narratives. Given the physical and mental burden on participants, interview sessions were limited to approximately once a week.

To

Page 7, line 14
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 [29]. Sample size was set to five to six for each group in home care and PCUs. Among the 21 candidates who got internal consent, those who remarkably changed the medical condition were excluded; detailed research explanation was given to 19 candidates. Of these, three candidates thought that multiple interviews were difficult, and 16 candidates submitted formal written consent form. Each participant was interviewed multiple times to ensure collection of detailed narratives. Given the physical and mental burden on participants, interview sessions were limited to approximately once a week.

Page 9, line 30

The interviews were recorded and transcribed verbatim, and the resultant data were analysed using the psychophenomenological approach [28], according to the following five-step procedure. In order to avoid inhibition of participants’ free speech and the researchers’ prejudice that “it will be done this way,” analysis was done after data collection was completed.

16. I will not comment further. There are too may flaws in the paper to this point, to warrant publication. I would strongly encourage the authors to seek an additional co-author with English as their first language, and with significant experience in writing for publication, to assist in amending this manuscript.

Response: Thank you for your suggestion. We have received English proofreading on English native speaker.

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

We wish to express our strong appreciation for your insightful comments on our study. Thank you so much.