

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Notion of a good death for patients with cancer: A qualitative systematic review protocol
AUTHORS	Xiao, Jinnan; DING, JINFENG; Huang, Chongmei

VERSION 1 – REVIEW

REVIEWER	Rochmawati, Erna Universitas Muhammadiyah Yogyakarta, Nursing
REVIEW RETURNED	26-Sep-2021

GENERAL COMMENTS	<ul style="list-style-type: none"> - Abstract <ul style="list-style-type: none"> a. The authors need to add explanation whether the protocol was registered in PROSPERO or other registration body. - Introduction <ul style="list-style-type: none"> a. P6. Line 27. Please omit the first sentence “Yet,...?” b. Please follow the citation style consistently. c. The authors need to provide more justification and clarification on focusing the review on patients with cancer as similar systematic review was published in 2020. For example, is this related to cancer trajectory that different from other advanced illness - Method <ul style="list-style-type: none"> a. Will the review include patients with cancer in all cancer trajectory? b. Regarding to the process, will the authors conduct data extraction first followed by quality appraisal or vice versa? Please check the JBI guideline! c. The authors state that will use Covidence, JBI Sumari as tools to facilitate the review. Aren't these two tools have similar function? d. P13 line 12-25. What do the authors refer the instrument to? Please clarify!
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REVIEWER	Lawton, Andrew Dana-Farber Cancer Institute, Psychosocial Oncology & Palliative Care
REVIEW RETURNED	12-Oct-2021

GENERAL COMMENTS	<p>Comments:</p> <p>(1) The authors effectively describe their study protocol which has an important aim: to synthesize qualitative studies to identify the core elements of a “good death,” specifically from the perspective of patients with cancer. The authors anticipate that the notion of a “good death” developed from this review will be used by investigators to study aspects of palliative care practice, including</p>
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	<p>identifying unmet palliative care needs and developing interventions that promote a good death. This review protocol addresses an important concern in oncology care and merits dissemination in the medical and oncology literature.</p> <p>(2) There are many grammatical errors, including multiple regarding single versus plural nouns and confusing syntax. I include several examples below (and in comment #3). Manuscript should be revised for grammar at these spots and throughout.</p> <ul style="list-style-type: none"> - Second sentence of abstract, should be “synthesize their views” - In abstract, Ethics and dissemination: should be “through international conferences” - Second paragraph of introduction: should revise to say “A qualitative study of patients, families, and healthcare providers in Japan showed that freedom from pain or physical and psychological symptoms is the most frequently cited attribute of a good death, followed by having good family relationships, dying in the preferred place, and having good relationships with medical staff.” <p>(3) Considering the last sentence in the first paragraph of the Introduction, I am not sure most oncologists would agree that promoting a good death is one of their most important goals. I think most hope to improve survival and quality of life. This goal re: good death feels more germane to palliative care. You might revise this sentence to say, “...is among the most important goals of palliative care in oncology.”</p> <p>(4) The first few sentences of the third paragraph of the Introduction are confusing. I believe you are saying that the concept of a good death is dependent on the perspectives of both patients and caregivers, and yet those perspectives may differ. Assuming that is correct, I would recommend just saying that... and then proceeding to describe the literature on patients’ perspectives.</p> <p>(5) First sentence of last paragraph of the introduction: I think many would argue that understanding the concept of a good death is relevant and important because we know patients and families face unique and burdensome challenges near end of life, including likely many unmet palliative care needs (as your Introduction suggests elsewhere) – and intervening on those struggles is likely part of good care. However, the first sentence of this paragraph seems to suggest that this subject is important to study “given the growth of palliative care... and the right to die movement”. The need for palliative care and the right to die movement seem more effects here, not causes of the increased focus on death. I recommend cutting this first sentence and just starting the paragraph from “To the best of our knowledge...”</p> <p>(6) Inclusion criteria: As a reader, I’m left wondering why studies involving mixed groups of subjects (patients and non-patients / families / clinicians) were excluded, and if this might cause the authors to miss out on important patient perspectives that are included in these studies. I recognize that the protocol cannot likely be changed at this point, I just offer that as a point of reflection. Are there patient voices we are missing based on this exclusion criterion? Perhaps the authors could add a sentence saying more about why mixed group studies were excluded.</p>
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(7) The search strategy and methods described seem sound.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Dr. Erna Rochmawati, Universitas Muhammadiyah Yogyakarta

Comments to the Author:

Abstract

a. The authors need to add explanation whether the protocol was registered in PROSPERO or other registration body.

Response: Yes, the protocol was registered in PROSPERO, the register number is CRD42021266629.

- Introduction

a. P6. Line 27. Please omit the first sentence "Yet,...?"

Response: The sentence was deleted accordingly.

b. Please follow the citation style consistently.

Response: We have carefully checked the citation style.

c. The authors need to provide more justification and clarification on focusing the review on patients with cancer as similar systematic review was published in 2020. For example, is this related to cancer trajectory that different from other advanced illness

Response: We further provide justification and clarification as follow: The sufferings, physical and psychological distress the patients experienced during the cancer trajectory differ from other advanced disease, which might affect their notion on a 'good death'. Hence, the conclusions of a heterogeneous group may not perfectly fit patients with cancer.

- Method

a. Will the review include patients with cancer in all cancer trajectory?

Response: Yes, we plan to include patients with cancer, regardless the cancer stages because we want to know whether patients at different stages of cancer have different views of a good death.

b. Regarding to the process, will the authors conduct data extraction first followed by quality appraisal or vice versa? Please check the JBI guideline!

Response: According to the JBI guideline, we should conduct critical appraisal before data extraction. We have revised it accordingly and will follow the guideline to complete the review.

c. The authors state that will use Covidence, JBI Sumari as tools to facilitate the review. Aren't these two tools have similar function?

Response: During our study screening, we found that JBI SUMARI can also do the screening so that in our review process, we only used JBI SUMARI. The sentences related the description of Covidence were deleted in the revised manuscript.

d. P13 line 12-25. What do the authors refer the instrument to? Please clarify!

Response: The clarification for referring the instrument has been added as suggested: The ConQual approach is similar to the GRADE approach applied in quantitative systematic reviews to rate the quality and confidence of the findings. Dependability and credibility are two elements considered to influence the confidence of qualitative synthesized findings. A set of critical appraisal questions are proposed to establish dependability, whilst credibility can be ranked according to the goodness of fit between the authors' interpretation and the original data. By following the ConQual, an overall ranking can be assigned to rate the confidence of synthesized qualitative findings.

Reviewer: 2

Dr. Andrew Lawton, Dana-Farber Cancer Institute

Comments to the Author:

Comments:

(1) The authors effectively describe their study protocol which has an important aim: to synthesize qualitative studies to identify the core elements of a “good death,” specifically from the perspective of patients with cancer. The authors anticipate that the notion of a “good death” developed from this review will be used by investigators to study aspects of palliative care practice, including identifying unmet palliative care needs and developing interventions that promote a good death. This review protocol addresses an important concern in oncology care and merits dissemination in the medical and oncology literature.

Response: Thank you for your encouragement.

(2) There are many grammatical errors, including multiple regarding single versus plural nouns and confusing syntax. I include several examples below (and in comment #3). Manuscript should be revised for grammar at these spots and throughout.

- Second sentence of abstract, should be “synthesize their views”
- In abstract, Ethics and dissemination: should be “through international conferences”
- Second paragraph of introduction: should revise to say “A qualitative study of patients, families, and healthcare providers in Japan showed that freedom from pain or physical and psychological symptoms is the most frequently cited attribute of a good death, followed by having good family relationships, dying in the preferred place, and having good relationships with medical staff.”

Response: We have carefully checked and revised the grammatical errors.

(3) Considering the last sentence in the first paragraph of the Introduction, I am not sure most oncologists would agree that promoting a good death is one of their most important goals. I think most hope to improve survival and quality of life. This goal re: good death feels more germane to palliative care. You might revise this sentence to say, “...is among the most important goals of palliative care in oncology.”

Response: We agree with the reviewer and revised the sentence as follow: Promoting the quality of death and achieving a ‘good death’ is one of the most important goal of palliative care in oncology.

(4) The first few sentences of the third paragraph of the Introduction are confusing. I believe you are saying that the concept of a good death is dependent on the perspectives of both patients and caregivers, and yet those perspectives may differ. Assuming that is correct, I would recommend just saying that... and then proceeding to describe the literature on patients’ perspectives.

Response: Sorry for the confusion, we have revised the sentence as follows: However, good death is dependent on the perspectives of dying individuals and proxy views might not be able to reflect patients’ real thoughts

(5) First sentence of last paragraph of the introduction: I think many would argue that understanding the concept of a good death is relevant and important because we know patients and families face unique and burdensome challenges near end of life, including likely many unmet palliative care needs (as your Introduction suggests elsewhere) – and intervening on those struggles is likely part of good care. However, the first sentence of this paragraph seems to suggest that this subject is important to study “given the growth of palliative care... and the right to die movement”. The need for palliative care and the right to die movement seem more effects here, not causes of the increased focus on death. I recommend cutting this first sentence and just starting the paragraph from “To the best of our knowledge...”

Response: We agree with the reviewer and delete the sentence as suggested.

(6) Inclusion criteria: As a reader, I’m left wondering why studies involving mixed groups of subjects (patients and non-patients / families / clinicians) were excluded, and if this might cause the authors to miss out on important patient perspectives that are included in these studies. I recognize that the protocol cannot likely be changed at this point, I just offer that as a point of reflection. Are there patient voices we are missing based on this exclusion criterion? Perhaps the authors could add a sentence saying more about why mixed group studies were excluded.

Response: We agree that we may miss some important patients’ perspectives when excluding the studies involving mixed groups of subjects (patients and non-patients/ families/ clinicians). But in this

review, we particularly focused on the experiences of the patients from qualitative research and to identify unmet satisfaction of the patients. In the studies with a mixed group, its findings were usually synthesized by integrating the patients and other participants' opinions, which might be unable to reflect the patients' real thoughts and have a good understanding of their opinion. We give the reason for excluding these studies on page 7 line 138: Studies involving patients with non-cancer diseases, families, healthcare providers, experts or social workers or a mixed group of patients with cancer and other stakeholders (e.g. families, healthcare providers and other stakeholders) will be excluded, because the findings synthesized from a combination group may be unable to reflect the patients' real thought.

(7) The search strategy and methods described seem sound.

Response: Thank you, we attached full search strategies for all databases in the supplementary file.

VERSION 2 – REVIEW

REVIEWER	Chan, Carmen Wing Han The Chinese University of Hong Kong
REVIEW RETURNED	21-Jan-2022

GENERAL COMMENTS	The author has addressed comments adequately.
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REVIEWER	Jeong, Sarah University of Newcastle, School of Nursing & Midwifery
REVIEW RETURNED	30-Jan-2022

GENERAL COMMENTS	<p>Thank you for the opportunity to review this interesting manuscript. I personally have a great interest and involvement in the topic. I believe that this topic will be of an interest of international readers, which also meets the scope and aim of BMJ Open. I have the following queries and suggestions to improve the quality and scientific value of the manuscript. Thank you for your consideration.</p> <p>Introduction: Given that patients with cancer at early stage may not contemplate what a good death for him/her will be like, will it be necessary to draw a scope or boundary of what stage of cancer that this review is interested in. Or is the scope left open to find out what's out there, and then will the authors synthesise depending on what they find? A statement about this in Introduction will clarify.</p> <p>P8, line 162-165: Have the authors considered 'dying well'?</p> <p>P9, line 182: Will any studies be excluded based on quality appraisal?</p>
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REVIEWER	Thetford, Clare University of Central Lancashire, School of Nursing
REVIEW RETURNED	01-Feb-2022

GENERAL COMMENTS	<p>Thank you for submitting a revised version of this article. I feel there remain some issues with English expression but these can be remedied easily. In the attached document I make some suggestions.</p> <p>I would also like to see further clarity around the scope and aims - 'cancer' is very broad, as is the care context. This could be refined further to be more clear. You state the review will have global</p>
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	<p>implications but will only review articles in the English or Chinese languages - you should address the limitations this imposes.</p> <p>Some further suggestions and minor queries are made in the marked up document using reviewer comments.</p> <p>In terms of what the review might offer, informing the development of future research appears to have been neglected.</p>
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VERSION 2 – AUTHOR RESPONSE

Reviewer: 4

1. Given that patients with cancer at early stage may not contemplate what a good death for him/her will be like, will it be necessary to draw a scope or boundary of what stage of cancer that this review is interested in. Or is the scope left open to find out what's out there, and then will the authors synthesise depending on what they find? A statement about this in Introduction will clarify.

Response: Yes, the scope is left open to find out what's out there and then we will synthesis depending on what we find. We now have clarified this in the revised manuscript.

2. line 162-165: Have the authors considered 'dying well'?

Response: Thank you for your suggestions. We will add this term in the search strategies and update our search.

3. Will any studies be excluded based on quality appraisal?

Response: Studies will not be excluded based on quality appraisal.

Reviewer: 5

1. I would also like to see further clarity around the scope and aims - 'cancer' is very broad, as is the care context. Given there are many different forms of cancer, will it be possible to create an understanding which is appropriate for all cancer? This could be refined further to be more clear.

Response: Thank you for your comments. Patients with cancer usually suffer similar physical and psychosocial distress due to the similar cancer trajectory and treatments such as chemotherapy, radiotherapy, and surgical, thus it is possible to summarise the general characteristics of good death them. To expand the generalisability of the findings to all cancers, we will include the studies recruiting different types of cancer. At the meantime, we will try to identify whether the type of cancer will affect patients' views on good death.

2. You state the review will have global implications but will only review articles in the English or Chinese languages - you should address the limitations this imposes.

Response: We have deleted the global implications. We also reported that some studies can be overlooked because only studies published in Chinese and English would be included.

3. In terms of what the review might offer, informing the development of future research appears to have been neglected.

Response: Thank you for your suggestions. We have added the implications on informing the development of future research in the revised manuscript.

4. Given the type of cultural differences highlighted, as well as variation in how death may come about inc timing etc, will it be possible to create a definition/understanding of a good death that is universally acceptable?

Response: Thank you for your comment. In this review, we are not going to create a universally acceptable definition of a good death, but understand how patients from different cultures view a good death, including the same attributions and different attitudes relevant to specific cultures.

5. Does this then create a need for condition-specific descriptions of a good death? Could there be a 'core' understanding, and some variable components dependent upon the specific condition?

Response: Thank you for your comment. The sufferings, physical and psychosocial distress the patients experienced during the cancer trajectory differ from other advanced disease, thus the review

included a heterogeneous patient population may affect the understanding of the notion of good death for patients with cancer. By understanding the cancer-specific description of a good death, the review will inform the implications on the development of an empirical model in promoting a good death.

6. Both patient and family views/experiences of death are important – palliative care incorporates care of loved ones.

Response: We agree that both patients and family views of death are important. However, good death is dependent on the perspective of dying individuals and proxy views might not be able to reflect patients' actual thoughts. Hence, the current review focus on understanding the experiences of good death from the perspective of patients with cancer.

7. This is very broad – will you be able to identify and deal with different issues raised in different care contexts?

Response: Thank you for your comment. For the inclusion criteria related to the context, the review will include studies conducted in any setting where patients with cancer are care for, including but not limited to hospitals, hospice, long-term care facilitators and private residences of patients. This will help us to obtain a comprehensive literature on good death. It also helps us to compare whether the care context will affect patients' views on good death.

8. Small number, As this is a protocol, shouldn't the protocol be agreed before this?

Response: Thank you for your comment. A agreed protocol of search strategies in each database are attached in the supplementary file.

9. The issues with English expression were revised accordingly in the revised manuscript.