

BMJ Open Notion of a good death for patients with cancer: a qualitative systematic review protocol

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ABSTRACT

Introduction Promoting the quality of death and achieving a good death is one of the most important goals of palliative care in cancer care. Few studies synthesised views of patients with cancer on the notion of a good death and its associated factors. By eliciting the core elements of a good death, the review aims to identify potential unmet needs of patients with cancer and reveal their common values and care preferences at the end of life. The review also has the potential to inform the development of guidelines for clinical care and shared decision-making in palliative care practice.

Methods and analysis A qualitative systematic review will be conducted and reported according to the Joanna Briggs Institute (JBI) methodology for systematic review and synthesis of qualitative data and the Preferred Reporting Items for Systematic Review and Meta-Analysis. Comprehensive search will be performed in six English and two Chinese databases from inception to 30 April 2022 to retrieve relevant qualitative articles focusing on the notion of a good death from the perspective of patients with cancer. Data will be extracted using the JBI standardised data extraction tool for qualitative research. The quality of the included studies will be critically appraised using the JBI Qualitative Assessment and Review Instrument. Data extraction and quality appraisal will be conducted by two reviewers independently. A meta-aggregative approach and narrative summary will be used to synthesise data.

Ethics and dissemination Ethical approval is not needed. We will disseminate the findings through international conferences related to cancer care or palliative care. The final review will be submitted and published in a peer-reviewed journal.

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INTRODUCTION

The International Agency for Research on Cancer reported 19.3 million new cases of cancer and 10.0 million cancer deaths in 2020 globally.¹ Although the survivorship of a number of cancer types has been substantially prolonged because of the advances in medicine and technology over the recent decades, cancer is still frequently considered being synonymous with the term ‘death’, especially advanced cancer. A cross-sectional study of 402 cancer deaths in Canada reported that only 39% of deaths were rated ‘good’ or

Strengths and limitations of this study

- ⇒ The qualitative systematic review will be conducted according to the Joanna Briggs Institute methodology for systematic review and synthesis of qualitative data to ensure a high level of rigour.
- ⇒ The review is designed to enhance understanding of a good death and facilitate the building of an empirical intervention model that promotes good death.
- ⇒ The synthesised findings on good death for patients with cancer are expected to impact on clinical cancer care, shared decision-making and future research in palliative care.
- ⇒ Some studies can be overlooked because this review will only include studies published in Chinese and English.

‘almost perfect’.² Promoting the quality of death and achieving a good death is one of the most important goals of palliative care.

Previous research has shown that the concept of good death is complex. It means that patients with cancer and stakeholders (ie, families and caregivers) can be free from distress and suffering and patients are dying in accordance with patients’ wishes and clinical, cultural and ethical standards.³ A qualitative study of patients with cancer, 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.⁴ Another study on the bereaved families of patients with cancer reported that physical and psychological suffering, caregivers’ distress and emotions are important factors associated with good death.⁵

However, good death is dependent on the perspectives of dying individuals and proxy views might not be able to reflect patients’ actual thoughts.^{6,7} A 2007 Sweden qualitative study with 66 adult palliative patients with cancer indicated that patients viewed death as



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a process rather than an event.⁸ A good death was deemed a 'successful dying process' when patients are living with the prospect of imminent death, preparing for death and dying comfortably. However, patients in Eastern countries (eg, China) face challenges when preparing for death because of lower frequencies of bad news (eg, diagnosis and prognosis), breaking practices and stronger taboos on death discussions compared with those in Western countries. They are more likely to miss the optimal time to discuss the impending death and make preparations for definite departure.⁹ Hence, understanding how patients from different cultures view a good death can support development of interventions to through an acculturation approach improve quality of death.

Several reviews have been conducted to enhance understanding of the notion of a good death. However, the findings of the reviews cannot be used in promoting a good death in cancer because of their limitations. For example, a recent review of the notion of a good death from patients' perspectives¹⁰ found that control of pain and symptom, clear decision-making, feeling of closure, being seen and perceived as a person, prepared for death and being still able to give something to others were core elements for a good death. However, the review included a heterogeneous patient population, such as patients acquired immune deficiency syndrome, cardiovascular disease, chronic obstructive pulmonary disease and cancer. The sufferings, physical and psychosocial distress the patients experienced during the cancer trajectory differ from other advanced diseases, which might affect their notion on a good death. Hence, the conclusions resulting from a heterogeneous group of patients may not perfectly fit patients with cancer. Other reviews included patients with multiple stakeholders, such as families and healthcare providers, or a combination of patients with cancer and non-malignant disease.^{11 12} The implications on patients with cancer may be limited. A review of notion of death concentrating to patients' perspective would help elicit and meet their needs in the end of life.

To the best of our knowledge, no review has synthesised qualitative studies to reveal the notion of a good death specifically from the perspective of patients with cancer. By eliciting the core elements of a good death, the review aims to identify potential unmet needs of patients with cancer and reveal their common values and care preferences at the end of life. The review also has the potential to inform the development of guidelines for clinical care and shared decision-making in palliative care practice.

AIM

This review aims to identify, appraise and synthesise the existing qualitative evidence exploring the notion of a good death of patients with cancer from the perspective of patients. The review will particularly seek to answer the following questions:

1. What are the characteristics of the existing studies that explored a good death for patients with cancer?

2. What are the core elements of a good death for patients with cancer?
3. What are the main factors associated with a good death?

METHODS

Study design

A protocol was developed according to the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols and the Joanna Briggs Institute (JBI) methodology for systematic review and synthesis of qualitative data.¹³ A meta-aggregative approach will be used to present a comprehensive understanding of patients' perceptions on a 'good death'.¹⁴ The review protocol was registered in the international prospective register of systematic reviews (PROSPERO).

Inclusion/exclusion criteria

Types of participants: this review will consider studies that only included adult patients with cancer. 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 (eg, families, healthcare providers and other stakeholders) will be excluded, because the findings synthesised from a combination group may be unable to reflect the patients' actual thoughts.

Phenomena of interest

This review will consider studies that explore the notion of a good death (eg, the views/perspectives/attitudes/belief about a good death) or main factors (environmental, illness-related or other possible factors) that associated with a good death. Epidemiological studies and studies focusing on certificate of death will be excluded.

Context

This review will include studies conducted in any setting where patients with cancer are cared for, including but not limited to hospitals, hospices, long-term care facilities and private residences of patients.

Types of studies

Eligible studies should employ a qualitative methodology, including but not limited to phenomenology, ethnography and grounded theory. Quantitative studies, mixed-method studies, case studies, reviews, commentaries, letters, opinion papers and conference abstracts will be excluded. Only studies published in either English or Chinese language will be included.

Search methods

This review will consider papers published by academic publishers as well as grey literature. A comprehensive search will first be performed on MEDLINE (via PubMed), EMBASE, PsychINFO, CINAHL, Scopus, Web of Science and two Chinese databases (ie, CNKI and WANGFANG DATA) from inception to October 2021. Grey literature

Table 1 The initial search strategy

'cancer' OR 'neoplasm'
AND
'good death' OR 'quality of death' OR 'quality of dying' OR 'good dying' OR 'dying well'

search will be performed via Google Scholar with the same keywords. The initial search strategy is shown in [table 1](#). Reference lists of studies that meet the inclusion criteria will be screened for additional studies.

The initial search strategies were carried out in PubMed in July 2021, and the following queries were used: ("cancer"[Title/Abstract] OR "neoplasm"[Title/Abstract]) AND ("good death"[Title/Abstract] OR "quality of death"[Title/Abstract] OR "quality of dying"[Title/Abstract] OR "good dying"[Title/Abstract] OR "dying well"[Title/Abstract]). Two-hundred and eighty-nine results were identified. The first author will screen these results first with the purpose of refining and developing specific search strategies for each database. The full-search strategies for all databases are found in online supplemental file 1.

Study selection

References identified in the aforementioned databases will be imported into EndNote 20. In the first step, duplicates will be removed with EndNote's deduplicating capabilities, followed by manual screening. JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI) will be used. JBI SUMARI is a software that supports the entire systematic review process (eg, screening, quality appraisal, data extraction and data synthesis) for different types of systematic reviews. Second, study screening will be performed, and full texts will be checked according to the inclusion criteria by two reviewers independently. All reasons for exclusion will be recorded, and the results of the screening will be cross checked between the two reviewers. Disagreements will be resolved through discussion with the third reviewer. In the third step, all the reference lists in the included studies will be checked for additional studies.

Quality appraisal

Included studies will be critically appraised independently using the JBI Critical Appraisal Checklist for Qualitative Research.¹⁵ The instrument consists of 10 items: five items appraising the congruities between research methodology and stated philosophical perspective, research question, data collection methods and data analysis; two items appraising the researchers' roles and cultures; one item appraising the representation of participants and their voices; one item for ethical approval; and one item for the interpretation of the data.¹³ Two reviewers will be blinded to each other's assessment. The results of the appraisal will only be cross-checked between the two reviewers after the completion of the initial appraisal of an article. In case of any disagreements, a third reviewer

will assist with the appraisal, discussion of the study quality and consensus.

Data extraction

Data extraction will be conducted using the JBI standardised data extraction tool for qualitative research from JBI SUMARI by two reviewers independently. The data to be extracted will include authors and year of publication, journals in which the studies were published, methodologies, methods, phenomena of interest, settings and contexts, characteristics of the participants (age, gender, type of cancer and illness-related information), data analysis, primary findings, authors' conclusions and comments.¹⁶ Any disagreements between the two reviewers will be resolved by the third reviewer.

Data synthesis

A meta-aggregative approach will be adopted for the synthesis of the findings. This approach is aligned with the philosophy of pragmatism and suitably answers a specific question and summarises views on good death.¹⁶ First, the findings of the qualitative research will be identified and assembled. Then, the findings will be categorised into groups with different codes according to similarity in meaning. Finally, the categories will be aggregated for the generation of a set of synthesis findings, which can be used as a basis for evidence-based practice.¹⁷ If the textual pooling is not possible, the findings will be presented in a narrative form.

Confidence in the synthesised findings of the review

This review used the ConQual to rate the confidence of synthesised qualitative findings. In ConQual, dependability and credibility will be determined.¹⁸ The dependability of findings is evaluated using five questions assessing the congruities in the JBI Critical Appraisal Checklist for Qualitative Research. The credibility is established by assessing the congruency between the authors' interpretation and the supporting data. The ConQual will then rank and assign the confidence of the qualitatively synthesised findings into four levels (ie, high, moderate, low or very low) through comprehensively considering the dependability and credibility assessment. A ConQual summary will be presented along with the type of study, dependency score, credibility score and overall ConQual score.

Ethics and dissemination

Ethical approval is not required for this protocol nor the systematic review of qualitative studies. After the completion of the review, the findings will be shared through presentation at international conferences and in an international peer-reviewed journal.

Patient and public involvement

No patient or public involvement.

DISCUSSION

To our knowledge, this will be the first systematic review of qualitative studies that synthesises the findings relating to notion of a good death specifically from the perspective of patients with cancer. The qualitative systematic review will be conducted according to the JBI methodology for systematic review and synthesis of qualitative data to ensure a high level of rigour. The review is designed to enhance understanding of a good death and has the potential to support the development of an empirical model in promoting a 'good death'. Patients' views on a good death and factors associated with their experiences will be summarised. The new knowledge to be contributed by the review would inform the clinical care and shared decision-making and future research in palliative care.

Contributors JX designed the study and drafted the manuscript. CH supervised the study design and critically revised the manuscript. JD contributed to the methods and critically revised the manuscript.

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