



BMJ Open Assessing research methodologies used to evaluate inequalities in end-of-life cancer care research: a scoping review protocol

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To cite: Davis LE, Webber C, Datta GD, *et al.* Assessing research methodologies used to evaluate inequalities in end-of-life cancer care research: a scoping review protocol. *BMJ Open* 2022;**12**:e064743. doi:10.1136/bmjopen-2022-064743

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-064743>).

LED and CW are joint first authors.

Received 13 May 2022
Accepted 23 June 2022



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ABSTRACT

Introduction To provide equitable cancer care at the end of life, it is essential to first understand the evidence underpinning the existence of unequal cancer outcomes. Study design, measurement and analytical decisions made by researchers are a function of their social systems, academic training, values and biases, which influence both the findings and interpretation of whether inequalities or inequities exist. Methodological choices can lead to results with different implications for research and policy priorities, including where supplementary programmes and services are offered and for whom. The objective of this scoping review is to provide an overview of the methods, including study design, measures and statistical approaches, used in quantitative and qualitative observational studies of health equity in end-of-life cancer care, and to consider how these methods align with recommended approaches for studying health equity questions.

Methods and analysis This scoping review follows Arksey and O'Malley's expanded framework for scoping reviews. We will systematically search Medline, Embase, CINAHL and PsycINFO electronic databases for quantitative and qualitative studies that examined equity stratifiers in relation to end-of-life cancer care and/or outcomes published in English or French between 2010 and 2021. Two authors will independently review all titles, abstracts and full texts to determine which studies meet the inclusion criteria. Data from included full-text articles will be extracted into a data form that will be developed and piloted by the research team. Extracted information will be summarised quantitatively and qualitatively.

Ethics and dissemination No ethics approval is required for this scoping review. Results will be disseminated to researchers examining questions of health equity in cancer care through scientific publication and presentation at relevant conferences.

INTRODUCTION

End-of-life cancer care aims to prevent and alleviate suffering, enhance quality of life and support patients' care preferences. However, a growing body of literature indicates that there are substantial variations in end-of-life

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This scoping review will follow the expanded framework for scoping reviews developed by Arksey and O'Malley and refined by Levac *et al.*
- ⇒ Relevant studies will be identified through a rigorous search strategy, developed in conjunction with a health sciences librarian, applied to four electronic databases to capture studies published over a 12-year period.
- ⇒ While our search strategy includes an extensive list of equity stratifiers as search terms, we may not capture studies that examine equity stratifiers but do not use these terms in ways that would be captured by the search.
- ⇒ This review will not include a search of the grey literature as the intention is to provide a synthesis of methods applied in peer-reviewed scientific literature.
- ⇒ The focus of this review is on healthcare inequalities in end-of-life cancer care; as such, we will not be able to draw conclusions about how equity research is conducted in cancer care more generally.

cancer care across social, demographic and economic characteristics, such as income, education, sex and ethnicity and race.¹² These variations in care represent health inequalities, defined as measured differences in the health or healthcare of individuals or groups.³⁻⁵ These variations in care may also represent health inequities, defined as differences that are deemed to be unfair, unacceptable and avoidable, and which result from the unequal distribution of power, prestige and resources across groups.³⁻⁵ Stigma, bias and structural racism can all contribute to health inequities. Importantly, while health inequalities can result in health inequities, not all inequalities are inequitable.

Research plays an important role in understanding and addressing end-of-life cancer

care inequalities.^{6 7} High-quality health equity research requires the use of appropriate methods for investigating equity stratifiers, defined as characteristics that identify population subgroups who may experience differences in health and healthcare that may be considered unfair or unjust. Examples include race, ethnicity, gender, sex, religion and socioeconomic status. Decisions made through the research process regarding the measurement and analysis of equity stratifiers, and the context in which decisions are made (eg, social systems, histories, values and biases) are particularly important. Different measurement choices and methodological decisions can result in different findings, affecting conclusions as to whether inequalities are present, and in turn, leading to different priorities for health research and policy.^{6 8 9} Appropriate methods include the use of causal frameworks to inform the research question, theory-driven selection and measurement of equity stratifiers and covariates, and consideration of intersectionality among equity stratifiers. Further, appropriate analytical approaches should be applied, including principled approaches to covariate adjustment, considering appropriate reference groups and reporting both additive and relative effects.^{6 8 10} Further, research findings should be interpreted in the context of broader system influences and intersectionality.^{1 6 8 11} Applying rigorous methods to questions of end-of-life cancer care inequalities can improve the identification of subgroups of the population who are at risk of inequitable end-of-life care, a necessary first step in the process of addressing and eliminating health inequality and inequity. By making reasoned methodological decisions a priori, providing rationale for these decisions and explaining them clearly we can foster a greater understanding of research results for health policy-makers who can act on those findings.¹¹

While many national and international organisations and guidelines are currently calling for the reduction of inequalities in end-of-life cancer care, a detailed and thorough literature review is needed to understand the current state of methods used in observational studies aimed at addressing these inequalities.¹²⁻¹⁴ The aim of this scoping review is to provide a synthesis of the methods used in the scientific literature to evaluate inequalities in end-of-life cancer care, with the goal of identifying gaps in methodological approaches and areas for improvement in future research. We will survey the literature examining inequity and inequality in end-of-life cancer care published across a 12-year period (2010–2021). By providing a broad overview of the methods in end-of-life cancer equity literature, we hope future research will be of higher quality and provide more actionable information for policy makers and healthcare practitioners to reduce inequalities in end-of-life cancer care.

METHODS AND ANALYSIS

This scoping review protocol is reported in accordance with reporting recommendations from the Johanna

Briggs Institute.¹⁵ This scoping review will follow the framework for scoping reviews originally developed by Arksey and O'Malley¹⁶ and later expanded by Levac *et al.*¹⁷ Reporting will follow the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension (PRISMA) or Scoping Reviews.¹⁸ To ensure an equity lens is taken throughout the review, we will also follow the relevant methodology from the PRISMA reporting guidelines for equity focused systematic reviews.¹⁹ Amendments to this protocol will be documented and published with the results of the scoping review.

Step 1: identifying the research question

This scoping review aims to answer the questions: What measures and statistical methods have been used in the contemporary scientific literature to evaluate end-of-life cancer care inequalities? Our goal is to describe the study design, measures, and statistical and analytical methods used in quantitative and qualitative primary research studies of end-of-life cancer care inequalities and to consider how these methods align with recommended approaches for studying health inequalities, such as the use of a conceptual framework, consideration of intersectionality and appropriate analytical techniques. Through our review and synthesis of the literature, we will identify gaps in methodology and areas for improvement in future studies that can help advance our understanding of cancer care inequalities. As noted above, the terms inequity and inequality have different meanings, with inequality related to measured differences while inequity related to differences interpreted relative to social structure, power, patient preferences and injustice. For this scoping review, we are focusing on research studying end-of-life cancer care inequalities, regardless of whether they are interpreted as inequities or not.

Step 2: identifying relevant studies

We will identify relevant research studies by searching electronic databases of published literature including MEDLINE, EMBASE, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PsycINFO. The search will be limited to studies published between 1 January 2010 and 31 December 2021. The search strategy, which was developed in consultation with a health sciences librarian at McGill University, is provided in online supplemental appendix.

To identify end-of-life cancer care and outcomes, three broad categories of search terms will be used. These will include terms related to cancer, terms related to end-of-life care and terms related to health inequalities. These three categories of search terms will be combined with the AND Boolean operator to identify studies that included terms from all three categories. To capture studies examining health inequalities, we will use the subject filter for health disparities and minority health developed by the National Library of Medicine (NLM) ('healthdisparities' (Filter)).^{20 21} Subject filters are specialised search strategies that are developed in consultation with librarians and

subject specialists at the NLM.^{22 23} The subject filter for health disparities captures key terms related to inequality, disparity and inequity in combination with specific equity stratifiers, such as race, sexual orientation, geography etc, in order to capture a broad range of literature. The filter will be combined with the Medical Subject Heading (MeSH) terms for 'human rights' and 'health equity' using 'OR' to capture concepts of equity not already covered under the subject filter. The search strategy was developed in MEDLINE and translated to the other databases with the help of a health sciences librarian using established criteria.²⁴ A preliminary search identified 999 potential citations in Medline, 3844 in Embase, 156 in PsycINFO and 533 in CINAHL (without removing duplicates).

Step 3: study selection

Following the search, all citations will be uploaded to Covidence²⁵ and duplicates removed. The study selection process will include two screening steps: a title and abstract screening, followed by a full-text screening. For each screening step, two reviewers will independently screen the studies against a set of inclusion criteria, described below. These criteria will be tested on a sample of 5% of the title and abstracts prior to beginning the study selection process and revised as deemed appropriate by the study team. For each screening step, both reviewers must independently identify that a study has met the inclusion criteria for it to move forward to the next screening step and/or data extraction. Any disagreements will be noted and resolved by consensus between the two reviewers, with a third author consulted to make a final decision if consensus cannot be achieved.

Studies will be included if they meet the following inclusion criteria:

Study outcome

Studies examining end-of-life care and outcomes for patients with cancer will be included. For instance, studies examining the receipt of palliative care, symptom burden prior to death or place of death.

Exposure

Studies examining any health equity stratifier will be included. Equity stratifiers may be studied as the main exposure or included as risk factors for the outcome. Studies will be included that measure equity stratifiers at the area or individual level. Our identification of equity stratifiers will be informed by the PROGRESS-Plus framework, which defines the following characteristics as equity stratifiers: place of residence, race or ethnicity, language, occupation, gender or sex, religion, education, socio-economic status, social capital, as well as other personal characteristics associated with discrimination, such as age or disability.²⁶ This framework is used by the Cochrane and Campbell Collaborations to inform equity-focused research, and it has been incorporated into PRISMA reporting guidelines for equity-focused reviews.¹⁹

Study population

Studies focusing on adult populations (age 18+) will be included. All types of cancers will be included. No limits will be placed on the geographic region of the study population.

Study design

Included studies will be limited to primary research studies using the following designs: quantitative observational studies, including cohort, cross-sectional or case-control studies, randomised controlled trials, quasi-experimental designs, other non-randomised trials and qualitative studies. Opinion papers, conference abstracts, case reports, systematic reviews, meta-analysis, narrative reviews and theses or dissertations will also be excluded as they do not represent peer-reviewed original research studies.

Study details

Studies published in English or French between 1 January 2010 and 31 December 2021 will be included. We selected 1 January 2010 as the earliest publication date to focus this scoping review on contemporaneous health equity research. This field of study and has evolved over time, and much of the guidance on appropriate methodological approaches was published in the last 10–15 years. We think it is reasonable to evaluate the methodological quality of research published in 2010 onwards against these recommendations.

Step 4: data extraction

A detailed data charting table will be developed to obtain information from each full text article. We will follow established frameworks on methodology in health equity research to inform our data abstraction and interpretation.^{9 12 27 28} The data chart will be developed by the research team and piloted prior to data extraction on 2–3 studies to ensure that it is capturing all relevant information. Key areas abstracted in the chart will include the healthcare system and region where the study was conducted, study design, description of data sources, study timeframe, sample size, inclusion and exclusion criteria, cancer site, use of a conceptual framework, description of the equity stratifier and how it was measured (individual or neighbourhood level, reference group, continuous or categorical, summary measures), and a description of the study outcome and how it was measured. For quantitative studies, we will extract information on the statistical methods used to identify the relationship between the equity stratifier and outcome, effect measures used (relative or absolute), confounders controlled for and results describing relationships between equity stratifiers and end-of-life outcomes. For qualitative studies, we will document themes related to relationships between equity stratifiers and end-of-life outcomes. We will also examine if studies included a discussion of system-related factors, contextualisation of results for stakeholders, implicit

bias and intersectionality as impacting the magnitude of inequality along the cancer care continuum.

Two authors will independently review 10% of the full-text articles in duplicate and their data compared with assess agreement. Any disagreements will be resolved by consensus between the two authors, with a third author consulted to make a final decision if consensus cannot be achieved. If there are disagreements, both authors will independently extract data from the next 10% of full-text articles and compare for agreement. This process will continue until no disagreements are noted, at which time one author will extract data from the remaining full text articles.

Step 5: collating, summarising and reporting results

Results will be synthesised quantitatively and qualitatively to describe the data. Frequencies and central measures of tendency will be used to report the number of studies examining different equity stratifiers, study outcomes and measurement approaches. Descriptive statistics will be presented in tables and a narrative synthesis of the findings will be reported.

Patient and public involvement

The public and patients were not involved in the development of this scoping review protocol. We will engage with cancer patients and family caregivers to inform evidence synthesis and interpretation of the findings of this scoping review.

ETHICS AND DISSEMINATION

Ethics approval is not required for this scoping review. Results will be disseminated to researchers who are studying health equity in cancer care through scientific publication and presentation at relevant conferences.

DISCUSSION

This scoping review will provide an overview of study design, measurement and methods used in current quantitative and qualitative studies examining health inequalities in end-of-life cancer care and outcomes. We will conduct a rigorous search across multiple databases and years to ensure we capture relevant studies. A major strength of this scoping review is the robust research team with expertise in epidemiology, sociology, oncology and palliative care. Collectively, we have a strong understanding of quantitative and qualitative research methodology and of measurement and methodologies appropriate to studies of healthcare inequalities. We have also involved a health sciences librarian to consult on the search strategy and ensure the breadth of the search terms and translation across search databases are appropriate. Finally, the broad approach using a scoping review design is appropriate for an exploratory study to understand the current landscape of methodology in the end-of-life cancer inequality literature. This study is a starting

point for future studies to further summarise and understand how to improve methods in equity research and thus better inform health policy.

There are several limitations to this scoping review. First, we are focusing the search only on studies identified as examining health inequities, inequalities or disparities in cancer end-of-life and palliative care. It is possible that we will not capture studies that examine equity stratifiers but do not use these terms in ways that would be captured by the search. For example, studies examining general differences in end-of-life care or outcomes, including considerations of differences according to equity stratifiers, may not be captured by the health disparities filter. This might result in a pool of studies that are more explicitly equity focused. Second, by focusing solely on end-of-life care, we will not be able to draw conclusions about how equity research is conducted in cancer care more generally. Third, this scoping review will not include a grey literature search, as our focus is on the quality of methodology of peer-reviewed scientific research. While some grey literature may report research findings, we expect that such literature would also be reported in scientific articles indexed in one of the included databases for search in this review. Finally, the scoping review research question is broad, and it may not be feasible to combine results across equity stratifiers or study outcomes if the methodologies are too heterogeneous. In that case, we will report the findings separately for each equity stratifier and/or study outcome.

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Funding This research is funded in part by a Canadian Cancer Society Emerging Scholar Award (Manitoba) (grant #707149), and an unrestricted Research Start-Up Funds grant from the Office of the Vice President (Research & International) at the University of Manitoba (Mahar, Award Number N/A).

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

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