

Mapping gender and sexual minority representation in cancer research: a scoping review protocol

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Abstract

Background: Addressing the risk of people from gender and sexual minority (GSM) groups experiencing inequities throughout the cancer continuum requires a robust evidence base. In this scoping review, we aim to map the literature on cancer outcomes among adults from GSM groups and the factors that influence them along the cancer continuum.

Methods: This mixed-methods scoping review will follow the approach outlined by JBI. We will systematically search electronic databases for literature in collaboration with a health sciences librarian. Two reviewers will screen titles and abstracts to determine eligibility based on inclusion criteria, and then retrieve full text articles for data extraction. Results will be reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews. Quantitative data will be qualified through a narrative interpretation and pooled with qualitative data. We will use meta-aggregation to synthesize findings. This protocol was developed in collaboration with GSM patient and public advisors. We will engage people from GSM groups, community organizations and knowledge users in disseminating results.

Interpretation: This review will direct future research efforts by expanding the wider body of research examining cancer disparities across the cancer continuum that GSM groups experience, identifying literature gaps and limitations, and highlighting relevant social determinants of health that influence cancer outcomes for adults from GSM groups.

People from gender and sexual minority (GSM) groups are at high risk of experiencing inequities throughout the cancer continuum.¹⁻³ Inequities are defined as unfair, unacceptable and avoidable differences in health resulting from unequal distribution of power, prestige and resources across groups.^{4,5} This risk is primarily attributed to the heterocisnormative environment of the health and cancer systems that discriminates against GSM populations and invalidates their experiences. Heterocisnormativity is defined as “the assumption that heterosexuality is the standard for defining normal sexual behavior and that male–female differences and gender roles are the natural and immutable essentials in normal human relations.”⁶ In the cancer system, this manifests in many ways, including a lack of GSM identifiers in cancer registries,⁷⁻⁹ the exclusion of people from GSM groups from organized cancer screening programs,¹⁰ a lack of culturally appropriate care,^{7,11} and individuals from GSM groups with cancer experiencing homophobia and transphobia, and discrimination from cancer care providers.^{7,11,12} The implications of heterocisnormativity are profound and observed in the cancer-related inequities GSM populations experience, such as lower screening rates,¹³⁻¹⁵ higher incidence of viral-related cancers (e.g., HPV),^{1,16} and receipt of culturally inappropriate and unsafe care.^{12,17,18}

Addressing these inequities necessitates a robust synthesis of existing research. Most knowledge syntheses on this topic have been narrative in nature. Few systematic reviews exist, and those that do have focused on specific phases of the cancer continuum (i.e., psychosocial care and survival)^{19,20} or only included studies within a limited time frame.²¹ Systematic data are lacking on cancer outcomes and experiences of people from GSM groups through all phases of the cancer continuum. In this review, we seek to address this gap through systematically mapping the evidence base describing cancer outcomes for adults from GSM groups and exploring the literature describing cancer care experiences for this population. This scoping review will answer the broad question of

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how cancer affects GSM populations through the following objectives: outline the ways people from GSM groups are described in cancer research; describe how cancer outcomes and experiences of people from GSM groups are investigated; map the impact of being an individual from GSM groups on adult cancer screening, stage at diagnosis, treatment and survival relative to those who are not a sexual or gender minority; and describe how intersectionality, oppression and social determinants of health are attributed to cancer outcomes and experiences in people from GSM groups.

Methods

Broadly, GSM is an umbrella term used to refer to groups who identify as gender and sexual minorities. Gender is a multidimensional construct that relates to the roles and characteristics embedded in social and cultural norms.^{22,23} People use many terms to describe their gender, including, but not limited to, woman, feminine, man, masculine and androgynous. Gender encompasses both identity and expression. Gender identity refers to an individual's sense of self and how they see themselves as a woman, a man, transgender, non-binary or something else. Gender expression relates to the way people express their gender, such as their behaviours, clothing and voice.²² We use the term gender minority to denote the wide variety of individuals whose gender identity and/or expression does not align with the sex they were assigned at birth. This includes transgender, nonbinary and agender people. Sexual orientation is a complex identity that encompasses identity, attraction and behaviour.⁶ Sexual minorities are individuals whose sexual orientation is not heterosexual or straight, and include but are not limited to lesbian, gay, bisexual and queer people. We note that GSM is not a term individuals typically use to self-describe their identity.²² We use GSM to describe gender and sexual minority groups, while acknowledging that there are numerous intersecting sexual, romantic and gender identities.

Understanding the complexity of terminology and identities of people from GSM groups is critical to addressing the cancer-related inequities they experience. Within the GSM community, there is a wide variety of intersecting identities that results in an equally wide array of cancer-related experiences. The research highlights that closing the equity gap will require improving data collection methods, developing inclusive screening and treatment protocols, and increasing access to culturally competent and safe clinical and psychosocial care.

Design

The scoping review will follow a framework that was initially developed by Arksey and O'Malley,²⁴ and expanded upon by Colquhoun and colleagues,²⁵ Levac and colleagues,²⁶ and Peters and colleagues.²⁷ This established approach includes the following steps: identifying the research question; identifying relevant studies; selecting studies; charting the data; collating, summarizing and reporting results; consulting with relevant stakeholders; analyzing evidence; presenting results; and noting implications within findings. As we anticipate a variety

of qualitative and quantitative study designs to be included in the review, we will use a mixed-methods scoping review approach that is adapted from the JBI guide for mixed methods systematic reviews and meta-analyses. This protocol was developed following recent guidance from Peters and colleagues,²⁸ and adheres to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for scoping reviews checklist and explanation.²⁹

Mixed-methods scoping review rationale

This mixed-methods scoping review will describe the evidence base related to outcomes and experiences of individuals from GSM groups with cancer.³⁰ A mixed-methods approach is useful for providing a comprehensive and holistic understanding of an issue by integrating qualitative and quantitative results.³⁰ It differs from single-method reviews, or reviews that present quantitative and qualitative data separately, as its emphasis is on integrating results.³⁰ Given the breadth of this study's focus and its overall purpose, a scoping review is an appropriate method.

Search strategy and information sources

The primary search strategy was developed for Medline by the research team in collaboration with a health sciences librarian. An example is provided in Appendices 1 and 2, available at www.cmajopen.ca/content/11/5/E942/suppl/DC1. We will execute a similar search in Embase, Cochrane, CINAHL, LGBQ+ Source Scopus and PsycINFO. In addition to these electronic databases, we will search for grey literature in the OpenGrey database and review reference lists of included studies to identify additional relevant publications. Search terms will use Medical Subject Headings for cancer and GSM. We will use Boolean operator OR within a category and use Boolean operator AND between cancer and sexual and gender minorities:

- Cancer: [exp neoplasms/]
- Sexual and Gender Minorities: [exp "sexual and gender minority"/]; [exp named groups by sexuality/]

Evidence screening and selection

After the search, all identified citations will be uploaded into Covidence and duplicates removed. Two reviewers will screen titles and abstracts, in duplicate, to determine eligibility based on inclusion criteria. Studies that potentially meet inclusion criteria will be retrieved in full. Two reviewers will assess the full text in detail, in duplicate, to determine eligibility. Disagreements will be resolved through discussion or with a third reviewer. We will report the study selection process using the PRISMA flow diagram. Table 1 outlines inclusion and exclusion criteria, following the population, concept and context categories for scoping reviews.²⁷ Studies published in 2010 and later will be included. This year was selected as it represents the beginnings of a period when there was an increase in affirming and inclusive policies and legislation addressing the rights of people from GSM groups (e.g., the United Nations Human Rights Council's first resolution, the repeal of "Don't Ask, Don't Tell" in the US military, and inclusion of gender

Table 1: Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria
Population	<ul style="list-style-type: none"> Sexual and/or gender minority adults (age ≥ 18 yr) who are cancer patients or caregivers Noncancer patients who provide support to GSM adult cancer patients, including family members, chosen family and caregivers 	<ul style="list-style-type: none"> Studies in which the outcomes of sexual and/or gender minority people cannot be distinguished from other samples (i.e., non-sexual/gender minority people; study describes the prevalence of sexual and/or gender minorities in the study population but does not stratify results) Studies in which the primary sample is composed of health care providers
Concept	<ul style="list-style-type: none"> Studies describing outcomes or experiences along the cancer continuum: risk, screening, diagnosis, treatment and survivorship 	<ul style="list-style-type: none"> Studies in which cancer is not the primary disease or cancer outcomes are not separately reported Studies exploring relation between pathology and/or etiology of cancer with sexual orientation or gender identity Nonhuman laboratory studies
Context	<ul style="list-style-type: none"> Grey literature Original research articles (quantitative, qualitative and mixed methods) Articles published after 2010 All settings considered English language 	<ul style="list-style-type: none"> Opinion or commentary articles Editorials Conference abstracts Systematic reviews, meta-analyses, network meta-analyses, narrative reviews, critical reviews and qualitative reviews Summary report Preprints Case reports or series Archival studies Non-English language

identity and expression in the *Canadian Human Rights Act*.^{31–33} This policy shift is also reflected in health research ecosystem, as there is a clear increase in GSM health studies published during this period.³⁴ We will include quantitative studies (e.g., randomized controlled trials, observational studies and cross-sectional studies), qualitative studies (e.g., descriptive, phenomenological and grounded theory), and mixed methods (e.g., convergent, sequential and complex). We are interested in all outcomes and experiences along the cancer continuum from screening to survivorship and end-of-life care.

Quality assessment

Quality assessment is not typically performed as part of a scoping review, as risk of bias will not influence data synthesis.^{28,35} However, we will be following JBI’s meta-aggregation approach for synthesizing qualitative data, which highly recommends critical appraisal of included studies.³⁶ In this review, we will use the Mixed Methods Appraisal Tool (MMAT), which was designed for mixed-studies reviews.³⁷ Although we will not exclude studies on the basis of their methodological quality, we will describe included studies’ methodological quality, following MMAT’s criteria. Two reviewers will assess the quality of included studies, in duplicate, using MMAT. Disagreement will be resolved through discussion or a third reviewer.

Data extraction

A data chart for both quantitative and qualitative studies will be developed through consultation with the research team. There will be overlap in type of data extracted from quantitative studies, qualitative studies and mixed-methods studies. Quantitative results of mixed-methods studies will

be extracted alongside quantitative studies. Qualitative results of mixed-methods studies will be extracted alongside qualitative studies. Data extracted will include descriptions of publication details, study populations including determinants of health, which will be informed by those listed by the World Health Organization³⁸ and by Mikkonen and Raphael³⁹ and Raphael and colleagues^{40,41} (e.g., age, sex and gender, socioeconomic status and sexual orientation), phase of cancer continuum explored in the study, sources of information and data collections methods (e.g., hospital records, cancer registry, survey and interview), study design and methods, sample size, outcome measures and results. We will also record whether GSM populations were included or consulted during the study. The data charts will be piloted by 2 reviewers. Differences will be resolved through discussion or a third reviewer. Results from the pilot will be shared with the research team to determine whether the charts capture information in a way that satisfactorily responds to the research questions. Revisions will be incorporated as necessary.

About the team

Central to this study’s goal of mapping and describing the cancer-related experiences and outcomes of GSM populations is an analysis of the GSM relationship to power and oppression. Our study’s objective also requires an acknowledgement that members of this research team, through their own experiences and relationship to oppression and privilege, may influence the research process. This reflexivity about our own positionality increases this study’s transparency and credibility.⁴²

We are a diverse group of researchers with different backgrounds and experiences. Among this team are epidemiologists, clinician–scientists, health services researchers, critical

scholars, nurses and trainees. Some members of the team identify as part of the GSM population, and some identify as allies. As a team and as individuals, we are committed to doing research that can facilitate systemic change to address inequities GSM and other underserved populations experience in the cancer system.

Data analysis

Data synthesis and integration

A key feature of a mixed-methods scoping review is integrating qualitative and quantitative results to provide a comprehensive overview of the phenomenon being investigated.³⁰ This review will follow a convergent integrated approach to synthesis and integration, which is suitable when investigating questions that can be answered qualitatively and quantitatively. This approach involves synthesizing qualitative and quantitative data simultaneously. Following this approach requires transforming data so they are in a mutually compatible format. For this review we will qualitize quantitative data. This will involve extracting results from quantitative studies and transforming the results into a textual description so that they may be integrated with qualitative results.³⁰ This approach is recommended rather than quantizing qualitative data as it is less error prone than attributing numerical values to qualitative data.³⁰ Once qualitzing is complete, data will then be pooled with qualitative data and synthesized through iterative and detailed examination to identify categories based on similarities. We will follow the meta-aggregation approach suggested by JBI⁴³ that combines findings across studies in a systematic way. This approach involves a detailed examination of extracted findings of included studies and creating categories based on their similarity in meaning. Similarity in meaning will be operationalized as either conceptual (i.e., where a theme is observed across studies) or descriptive (i.e., where studies use similar terminology to describe concepts or themes).³⁶ Each category must have, at minimum, 2 findings each. Initial categories are then grouped together and further synthesized into findings of at least 2 categories.⁴⁴ This synthesis and aggregation is what enables producing integrated findings. Through integrating data, a mixed-methods scoping review allows for investigating whether qualitative and quantitative data are complementary or divergent, identifying gaps and describing contradictory findings.³⁰

Presentation of results

Descriptive statistics and counts will be used to report study characteristics, such as type of study, point(s) along the continuum investigated, outcomes and experiences investigated, measures of sex and gender used, and factors contributing to outcomes and experiences. We will present on different definitions of GSM across studies and highlight gaps in types of research completed. Intersectionality of characteristics and identities influencing outcomes and experiences will be presented within a nested ecological framework.⁴⁵ The characteristics and identities reported will be informed by the World Health Organization's list of social determinants of health as

well those outlined by Mikkonen and Raphael³⁹ and Raphael and colleagues.^{40,41} Results will be synthesized point by point along the cancer continuum to create an understanding of the depth and scope of the research on this topic. Integrated results will be presented visually in a table and in narrative form.

Consultation

Consultation will be an integral element of this review and, similar to the process of completing a scoping review, will be iterative in nature. Throughout the various steps described earlier, we will engage people from GSM groups, community organizations and knowledge users. This will enable us to ensure that the scoping review aligns with research priorities of this community and identify suitable approaches for disseminating results and additional knowledge translation activities. This work will be guided by recommendations from the JBI Scoping Review Methodology Group.⁴⁶

Patient and public involvement

We have convened an advisory committee composed of individuals with cancer experiences who identify as part of the GSM community. This committee has informed the development of this protocol. This committee will remain involved in the full scoping review by providing guidance and feedback on which data will be abstracted, how to present the results and identifying priorities for disseminating the review's findings, and coauthoring the final publication and any related materials.

Interpretation

This protocol outlines a plan to map literature on cancer outcomes and experiences for people from GSM groups. The results will map how GSM groups are represented in cancer research as well as how differing definitions may contribute to heterogeneity in research findings or gaps in the evidence base.

This scoping review will build on previous research and knowledge syntheses by reporting cancer outcomes and experiences along the entire cancer continuum. It will fill a knowledge gap in mapping social determinants associated with outcomes and experiences. This scoping review will also systematically investigate how definitions of gender are operationalized within cancer studies.

Results from this scoping review will be used to support a program of research focused on GSM and cancer-related health equity.

Limitations

The scoping review research questions are broad and address the entire cancer continuum from risk to end-of-life care. As such, it may not be feasible to combine results across study outcomes if the methodologies are too heterogeneous. In that case, we will report the findings separately for each point along the cancer continuum. Cancer care experiences within the GSM population are diverse as a result of individual and intersecting identities, and therefore, it may not be possible to draw conclusions on the entire community. Careful attention

will be paid to ensuring that results are reported within an intersectional context and a person-centred approach. Finally, although we aim to identify all relevant papers, the ever-evolving language within and surrounding the GSM community may mean it is not possible to adequately capture the most contemporary evidence base. For example, not all terminology used in the GSM community is attached to search terms in academic databases.

Conclusion

This scoping review has the potential to highlight gaps and limitations in the existing body of literature and, in doing so, provide direction for future cancer-control priorities and for providing safe and inclusive cancer care for the GSM community.

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Data sharing: As the authors are conducting a scoping review and extracting data from existing studies, they will not have any data. Included studies will be presented in a tabular form. Results will be made available in an open access journal.

Supplemental information: For reviewer comments and the original submission of this manuscript, please see www.cmajopen.ca/content/11/5/E942/suppl/DC1.