Scoping review protocol: mapping gender and sexual minority representation in cancer research

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Funding: This project was funded by the Canadian Cancer Society Emerging Scholar Award for MEGAN-CAN (Mahar; Grant #707149), and a Canadian Institutes of Health Research Canada Graduate Scholarship Doctoral Award (Stirling, Grant # 175933). The funders had no role in developing the protocol.

Abstract

Background

Gender and sexual minorities (GSM) are at high risk of experiencing inequities throughout the cancer continuum due to heterocissexism in the cancer system. Alongside this risk is a lack of evidence describing these inequities and factors influencing them. This review will address this gap by mapping the literature on cancer outcomes among GSM adults and the factors that influence them along cancer continuum.

Methods

This mixed methods scoping review will follow the approach outlined by the Joanna Briggs Institute. 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, followed by retrieval of full text articles for data extraction. Results will be reported following the PRISMA extension for scoping reviews (PRISMA-ScR). Quantitative data will be qualitized through a narrative interpretation and pooled with qualitative data into themes.

Interpretation

This review will direct future research efforts by expanding the wider body of research examining cancer disparities, identifying literature gaps and limitations and highlight relevant social determinants of health that influence cancer outcomes for GSM adults.

Background

Gender and sexual minorities (GSM) are at high risk of experiencing inequities, defined as unfair, unacceptable and avoidable differences in health resulting from unequal distribution of power, prestige and resources across groups,[1,2] throughout the cancer continuum.[3-5] This risk is primarily attributed to the heterocisnormative environment of the health and cancer systems that discriminates against GSM populations and invalidates their experiences. In the cancer care system, 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] This manifests in a myriad of ways, including lack of GSM identifiers in cancer registries,[7-9] exclusion of GSM from organized cancer screening programs,[10] lack of culturally appropriate care,[7,11] as well as GSM with cancer experiencing homo/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 incidences of viral-related cancers (i.e. HPV)[3,16], and receipt of culturally inappropriate and unsafe care.[12,17,18]

Addressing these inequities necessitates an evidence base to guide this work. Unfortunately, the research in this area is sparse.[3,8,14] Narrative reviews have described low screening rates, insufficient screening recommendations [8,14] and a dearth of demographic information collection on gender identity and sexual orientation and evidence-based cancer-related clinical guidelines.[3,8] Recognizing patients' gender identity and sexual orientation allows providers to develop a holistic view of the patient, their condition, and to inform an appropriate treatment plan.[14] Conversely, patients who experience inappropriate care and discrimination by providers may withdraw from care, leading to worse outcomes.[14] Psychosocial support has been widely cited as integral throughout all phases of the cancer continuum.[3] However, there is a lack of GSM-specific support, and GSM patients routinely report feeling unwelcome in general cancer support groups,[3,11] limiting their access to support services.

The failure to collect demographic information results in a lack of knowledge and understanding about GSM's cancer experiences and outcomes.[3,8,14] The incorporation of more robust demographic collection must be combined with culturally appropriate and informed care by oncology nurses[3] and physicians[3,8] to meaningfully improve the cancer care experience for GSM patients. Although there is some evidence capturing important aspects of the GSM cancer care continuum, there have been no structured literature reviews synthesizing and mapping GSM cancer outcomes and experiences. This proposed review will fill this gap by providing a comprehensive and rigorous description of the range of GSM cancer outcomes and experiences.

Broadly, GSM is an umbrella term used to refer to those individuals who identify as gender and sexual minorities. Gender refers to socially constructed roles, behaviours, and identities of women, men , and gender minority people.[19] Gender minorities are individuals whose gender identity and/or expression does not align with the sex they were assigned at birth. Gender minorities include but are not limited to transgender and non-binary people. Sexual orientation is a complex identity that encompasses identity, attraction, and behaviour.[6] Sexual minorities are individuals whose sexual orientation are not heterosexual or straight, and include but are not

limited to lesbian, gay, bisexual, and queer people. While not all studies refer to GSM explicitly, the use of GSM in this study is a deliberate choice to be inclusive of the various sexual, romantic, and gender identities, and acknowledges the intersections between these identities.

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

This review seeks to address the absence of equity and provide an overview of the literature on cancer outcomes among gender and sexual minority adults and the factors that influence them over the cancer continuum, from risk and prevention to end-of-life/survivorship. The primary objectives of this scoping review are to systematically map and examine the evidence base comparing cancer outcomes for GSM adults to others, and to explore the literature describing cancer care experiences for this population. It will focus primarily on cancer risk, screening, stage at diagnosis, treatment, and survival, centering on patient perspectives as opposed to clinicians. Our goals are to direct future research efforts by identifying literature gaps and limitations and highlight relevant social determinants of health influence cancer outcomes for GSM adults.

Methods & Analysis

About the team

Central to this study's goal of mapping and describing GSM's cancer-related experiences and outcomes is an analysis of their relationship to power and oppression. It 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.[20]

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.

The primary objective of this mixed methods scoping review is to describe the evidence base related to outcomes and experiences of GSM with cancer. [21] A mixed methods approach is useful for providing a comprehensive and holistic understanding of an issue by integrating qualitative and quantitative results.[22] It differs from single method reviews, or reviews that present quantitative and qualitative data separately, as its emphasis is on integrating results'.[22] Given the breadth of this study's focus and its overall purpose, a scoping review is an appropriate method. The scoping review will follow a framework that has been adapted from Arksey and

O'Malley, Levac et al., Colquhoun et al. and Peters et al.[23-26] 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 Joanna Briggs Institute guide for Mixed Methods Systematic Reviews and Meta-Analyses. This protocol was developed following recent guidance from Peters et al.,[27] and adheres to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews checklist and explanation.[28]

Review Question and Objectives

In describing this evidence base, this scoping review will respond to a broad question of how cancer affects GSM populations. To do so, this review will accomplish the following objectives:

1) Outline the ways GSM are described in cancer research.
2) Describe how GSM cancer outcomes and experiences are investigated.
3) Map the impact of being a GSM on adult cancer risk, screening, stage at diagnosis, treatment, and survival relative to those who are not a sexual and/or gender minority.
4) Describe how intersectionality, oppression and social determinants of health are attributed to GSM minorities cancer outcomes and experiences.

Search Strategy & information sources

The primary search strategy was developed for Medline by the research team in collaboration with a librarian. An example is provided in the Supplementary material. We will execute a similar search in Embase, Cochrane, CINAHL, Scopus and PsychInfo. In addition to these electronic databases, we will search for grey literature in the OpenGrey database as well as review reference list of included studies to identify additional relevant publications. Search terms will use MeSH headings for cancer and GSM. We will use Boolean operator OR within a category and using 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

Following the search, all identified citations will be uploaded into Covidence and duplicates removed. Two reviewers will screen titles and abstracts 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 to determine eligibility. Disagreements will be resolved through discussion or with a third reviewer. We will report the study selection process using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram. Table 1 outlines inclusion and exclusion criteria following the population, concept, context categories for scoping reviews.[26] Studies published in 2010 and later will be included. This date was selected as there is clear increase in GSM health studies published during this time period.[29]

Table 1: Inclusion and Exclusion Criteria

	Inclusion Criteria	Exclusion Criteria
Population	Sexual and/or gender minority adults (age ≥ 18) Family members Chosen family Caregivers	Studies where the outcomes of sexual and/or gender minority people cannot be distinguished from other samples (i.e. non-sexual/gender minority persons; study describes the prevalence of sexual and/or gender minorities in the study population but does not stratify results) Studies where primary sample is comprised of health care providers.
Concept	Studies describing outcomes or experiences along cancer continuum: risk, screening, diagnosis, treatment, survivorship Studies investigating impact of HRT on cancer risk	Studies where cancer isn't primary disease or cancer outcomes are not separately reported Studies exploring relationship between pathology and/or etiology of cancer with sexual orientation or gender identity Non-human lab studies
Context	Grey literature Original research articles (quantitative, qualitative, mixed methods) Papers published after 2010 Case reports All settings considered	Opinion/Commentary papers Editorials Conference abstracts Systematic reviews, meta-analyses, network meta-analyses, narrative reviews, critical reviews, qualitative reviews Summary report Pre-prints Archival studies

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 publications details, study populations (e.g. age, sex and gender, socioeconomic status, sexual orientation), phase of cancer continuum explored in the study, sources of information and data collections methods (e.g. hospital records, cancer registry, survey, interview), study design and methods, sample size, outcome measures, and results. We will also record whether GSM populations were included/consulted during the study. The data charts will be piloted by two

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.

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.[22] 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 which requires developing a narrative interpretation of the quantitative data. This approach is recommended rather than quantitizing qualitative data as it less error-prone than attributing numerical values to qualitative data.[22] Once qualitizing is complete, data will then be pooled with qualitative data through iterative and detailed examination to identify categories based on similarities. Categories will then be aggregated to produce integrated findings. Through integrating data, a mixed methods scoping review allows for investigating whether qualitative and quantitative data in complementary or divergent, identify gaps, and to describe contradictory findings.[22]

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.[30] 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 GSM, community organizations, and knowledge users. This will enable us to ensure the scoping review aligns with research priorities of this community as well as identify suitable approaches for disseminating results and additional knowledge translation activities. This work will be guided by recommendations from JBI's Scoping Review Methodology Group.[31]

Patient and public involvement

The research team includes patient and public advisors. They have been involved in the protocol's development and will be involved throughout the review.

Interpretation

This protocol outlines a rigorous method to map literature on cancer outcomes and experiences for gender and sexual minorities. By applying a novel mixed methods approach to literature synthesis, we will comprehensively explore this topic in a systematic way. The results will map how gender and sexual minorities are represented in cancer research as well as how differing definitions may contribute to heterogeneity in research findings or gaps in the evidence-base.

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-centered approach. Finally, while 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 providing safe and inclusive cancer care for the GSM community.

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Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions

1 exp Transgender Persons/
2 exp Transsexualism/
3 exp Sex Reassignment Procedures/
4 transgender*.tw.
5 transsexual*.tw.
6 ("trans m#n" or "trans wom#n" or "trans person*" or transpeople or "trans male*"or "trans female*").tw.
7 ((gender adj3 (non-binary or agender or fluid* or trans* or non-conform* or nonconform*)) or gender-nonconform*).tw.
8 gender dysphori*.tw.
9 (sex reassignment* or gender reassignment* or gender affirm*).tw.
10 (transfeminine or transmasculine).tw.
11 (AFAB or AMAB).tw.
12 (gender adj (expression* or transition*)).tw.
13 (transvestite* or transvestism).tw.
14 ("gender* identit*" or "gender* inclusi*" or "gender* nonconform*" or "gender non-conform*" or "gender* divers*" or "gender* express*" or "gender* neutral*" or "gender* norm*" or "gender* fluid*" or "gender* dyphoria" or agender* or bigender* or genderqueer* or cisnormativ* or misgender*).mp.
15 exp "Sexual and Gender Minorities"/
16 bisexuality/ or exp homosexuality/ or transsexualism/
17 gay.ab,ti,kw.
18 homosexual*.ab,ti,kw.
19 lesbian*.ab,ti,kw.
20 bisexual*.ab,ti,kw.
21 "men who have sex with men".mp.
22 transgender*.ab,ti,kw.
23 queer*.ab,ti,kw.
24 "gender identit*".mp.
25 "sexual minorit*".mp.
26 "sexual identit*".mp.
27 LGBT*.mp.
28 transexual*.mp.
29 transsexual*.mp.
30 trans-sexual*.mp.
31 LGB.ab,ti,kw.
32 "same sex marriage*".mp.
33 "gender dysphoria*".mp.
34 "same sex couple*".mp.
35 (non-heterosexual* ornonheterosexual*).mp.
6 "same sex relationship*".mp.
37 (trans adj2 (people or person* or female or woman or women or male or man or men)).mp.
38 "same sex parent*".mp.
39 "gender reassignment*".mp.
40 ((nonbinary or non-binary) adj2 (gender or person* or people or patient*)).mp.
41 "gender transition*".mp.
42 ("gender queer" or genderqueer).mp.

43 GLBT.mp.
44 "same sex attract*".mp.
45 "women who havesexwith women".mp.
46 "gender transformation*".mp.
47 homophile*.mp.
48 "gender and sexual diversit*".mp.
49 sex transformation*.mp.
50 sexual dissident*.mp.
51 "same gender loving".mp.
52 GLBQ.mp.
53 heteroflexible.mp.
54 lesbigay.mp.
55 "women loving women".mp.
56 bicurious.mp.
57 exp Neoplasms/
58 (neoplasm* or cancer* or leukemia or leukaemia or malignan* or carcinoma or tumor* or tumour*).ab,ti,kw.
59 or/1-56
60 or/57-58
61 59 and 60