CANCER'S MARGINS: SEXUAL AND GENDER MARGINALITY AND THE
BIOPOLITICS OF KNOWLEDGE

by

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Abstract

Research in Canada and the United States indicates consistent health inequities among sexual and gender minority populations, including cancer health disparities. The *Cancer's Margins* project ([www.lgbtcancer.ca](http://www.lgbtcancer.ca)) is likely the first nationally-funded project to investigate the complex intersections of sexual and gender marginality and experiences of cancer-related health, treatment, support networks, and decision-making. The *Cancer's Margins* database includes 121 interviews with sexual and/or gender minority breast and/or gynecologic cancer patients and members of their support networks across Canada, including pilot interviews in the San Francisco Bay area. As part of *Cancer's Margins*, this dissertation research examines sexual and/or gender minority breast and/or gynecologic cancer patients’ experiences, access to knowledge, knowledge mobilization, and the organization of cancer care.

Where approaches to “LGBT health”/“SGM health” have subsumed transgender and other gender diverse people into a general LGBT umbrella or less helpfully, as an aspect of minority sexuality, this dissertation—by contrast—examines sexual marginality and gender marginality intersectionally. The analysis takes into account the biopolitical production of identity, knowledge regimes, and sexuality and gender.

The qualitative analysis in this dissertation documents and analyzes how different bodies of knowledge shape complex relationships between marginalization, gender and sexuality, and experiences of cancer health and decision-making. The findings reported here provide evidence that assemblages of cancer care systems are informed by and reinforce heteronormative, cisnormative, homonormative, and repronormative modes of sexuality, gender, and embodiment. Findings also point to the importance of population-specific cancer knowledge for minority
cancer patients and the key role of communitarian and experiential knowledge in treatment decision-making by marginalized patients. Additionally, these findings suggest that understanding illness narratives of sexual and/or gender minority cancer patients requires an analysis that takes into account distinct generational cohorts of knowledge related to sexuality, gender, and the production of identity and marginalization.

To ameliorate population health disparities, cancer care environments need to account for diverse intersectional models of identity and embodiment. By analyzing the systems of biomedical and biographical knowledge informing cancer patients, providers, and regimes, this dissertation contributes new evidence to undergird culturally-specific and culturally-effective cancer care and practice with sexual and/or gender minority cancer patients.
Lay Summary

This research identifies and examines the complex relationships between categories of sexual marginality and gender marginality and investigates how sexual and/or gender minority people experience cancer care, treatment, and decision-making. The analysis in this dissertation investigates how sexual and/or gender minority breast and/or gynecologic cancer patients locate, navigate, and mobilize health knowledge within complex social, cultural, and relational networks.

Gender and gendered embodiment are experienced non-normatively by sexual and/or gender minority people, and cancer care providers and systems. The by-now typical organization of cancer care into “women’s cancers” and “men’s cancers” is deleterious to the care experiences of sexual and/or gender minority patients, is insufficient to support collaborative patient-provider relationships, and leads to cancer health disparities.

By documenting the knowledge that informs how marginalized patients make decisions about cancer treatment and care, this research provides evidence that can inform the design of culturally-specific and culturally-effective cancer care and treatment systems.
Preface

The research in this dissertation was undertaken in accordance with the guidelines of the UBC Behavioural Research Ethics Board (Certificate number: H11-00275). Data is drawn from the Cancer’s Margins project, led by Principal Investigator Dr. Mary Bryson and funded by a Canadian Institutes for Health Research Operating Grant (#275227). I am a Co-Investigator with Cancer’s Margins, and my dissertation research was funded by a Canadian Institutes of Health Research Frederick Banting and Charles Best Canada Graduate Scholarships Doctoral Award (#128158).

The research in this dissertation was conducted as part of the Cancer’s Margins project, which, as a team project, necessarily involved mentorship from the more seasoned researchers. Co-investigators and researchers were involved at all stages of the research project and the project itself is a collaborative effort on behalf of dedicated researchers spanning from Nova Scotia to British Columbia who collectively undertook and sustained a massive amount of coordination and effort in order to conduct a pan-Canadian project across 5 provinces and universities.

The Cancer’s Margins research team collaborated on various aspects of the research project, however, each chapter of this dissertation was written by me, Evan Taylor, with feedback from committee members being incorporated into the final draft.

As a co-investigator with the project, I was responsible for data collection, data analysis, and manuscript development—including the preparation, writing, and revision of the manuscripts in Chapters 3 & 4 that were published in journals as multi-authored articles, as well as Chapter 2 that was prepared for a conference presentation. The contributions of the co-authors to these
chapters were in reviewing and providing feedback on pre-publication drafts of the manuscripts, and providing a critique of the work and suggestions for strategic improvements. I was responsible for the preparation and revisions of the manuscripts, data analysis, and ongoing literature and methodological reviews. Contributions from co-authors to the dissertation were consistent with committee or collegial duties—I undertook the primary authorship for the chapters previously published in journals or as a conference presentation and all writing is my own.

- The initial analysis in Chapter 2 was authored for a conference presentation at the World Professional Association of Transgender Health 24th Biennial Scientific Symposium (2016) in Amsterdam, Netherlands and was subsequently expanded for this chapter.
- A version of Chapter 3 was published in LGBT Health: Taylor, E. T., & Bryson, M. K. (2016). Cancer’s Margins: Trans* and gender nonconforming people’s access to knowledge, experiences of cancer health, and decision-making. LGBT Health, 3(1), 79–89.

This dissertation is a manuscript-based dissertation and, as such, the organization of the dissertation has some non-traditional elements to it. Chapters 3, & 4 have already been published in peer-reviewed academic journals, and Chapter 2 is based on a conference presentation. As a
result, there is some repetition in the dissertation—for instance, each chapter has a methodology section and there is some repetition across chapters of information related to research design, methods, demographics of participants, etc. There may also be differences between chapters in the consistency and use of terms. For instance, acronyms such as LGBT, LGBTQ, LGB/T, LGB etc. are purposefully deployed in relation to the analysis and findings in each chapter and the use of the terms is consistent throughout each analysis. Each data chapter, however, represents a distinct analysis and contribution to the research landscape and the overall arguments of the dissertation.
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List of Abbreviations

AIDS: Acquired Immunodeficiency Syndrome
BA: Bay Area (San Francisco)
BC: British Columbia
BRCA1 or BRCA2: Mutation of BRCA1 or BRCA 2 genes
CA: Canada
DCIS: Ductal Carcinoma in Situ
GNC: Gender Nonconforming
LGBQ: Lesbian, Gay, Bisexual, Queer
LGBQ/T: Lesbian, Gay, Bisexual, Queer, and Transgender
LGBT: Lesbian, Gay, Bisexual, Transgender
MB: Manitoba
NS: Nova Scotia
ON: Ontario
QC: Quebec
QLB: Queer, Lesbian, Gay
SGM: Sexual and Gender Minorities
SOC: Standards of Care
SSM: Social Study of Medicine
UBC: University of British Columbia
US: United States
WHO: World Health Organization
WPATH: World Professional Association for Transgender Health
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Thank you to the participants in Cancer’s Margins who so generously offered their stories to this work, with a special respect for those who took time at the end of their lives to contribute their knowledge and perspectives.

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To my research supervisory committee, Dr. Mary Bryson, Dr. Blye Frank, and Dr. Sally Thorne, I offer my heartfelt appreciation for your time and enthusiasm.

I thank Dr. Blye Frank for his enduring support and great passion for my work. Your confidence in me renewed my commitment to this work when I needed it and you kept me inspired by encouraging me to foster connections to my academic pedigree.

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taught me to enjoy hierarchies and how to trust benevolent authority—this was no simple task. Your surgical precision with words has pushed me to create work that I am proud of and that I couldn't have imagined before I read it myself. And the honesty of your leadership has given me spectacular new perspectives on life and communication that I will carry always.

Finally, I offer my lifelong thanks to my spouse, Kyle Shaughnessy, who inspires me to aspire to become better versions of myself. The names and locations may change, but the love will only multiply. You make things possible with your heart. Thank you for your patience and enthusiasm. Time for the next big thing?
Dedication

To the generations of queer and trans people whose blood, sweat, tears, ideas, resistance, bravery, anger, survival tactics, and subversion made/make space for me and for work like this to be possible.
Chapter 1: Introduction: *Cancer’s Margins* and Sexual and/or Gender Marginality in Cancer Health Research

1.1 Location of Research

The significance of non-normative gender identity and expression relative to knowledge mobility and decision-making practices pertinent to experiences of cancer health and treatment is an underdeveloped area of research (Burkhalter et al., 2016; Polite et al., 2017; Watters, Harsh, & Corbett, 2014). The research conducted for this dissertation was conducted as part of the *Cancer’s Margins* project (www.lgbtcancer.ca) which addresses a number of gaps in the current research landscape in order to inform medically competent and culturally effective cancer health and care for sexual minority and gender minority populations. *Cancer’s Margins* is the only nationally funded research project to-date that specifically investigates and disaggregates the breast and gynaecologic cancer health experiences of both sexual minority and gender minority cancer patients.

*Cancer's Margins* was designed as an arts-based and community-based research project to investigate how sexual and/or gender minority cancer patients locate and share cancer health knowledge and to document sexual and/or gender minority cancer patients’ experiences of cancer health, support, and care. Health is operationalized so as to include a wide variety of mental, emotional, spiritual, sexual, and physical health (WHO Commission on Social Determinants of Health, 2008). And support and care were understood to mean a wide range of cancer support sources: formalized institutional medical support, complementary health care
providers, community-level social support, and any type of informal network of support (Sinding, Grassau, & Barnoff, 2006).

As part of the project, Cancer's Margins has also published the first archive of sexual and/or gender minority patient cancer micro-documentaries (www.lgbtcancer.ca). Participants from the project, along with researchers and mentors, developed digital stories of participants’ experiences of cancer in order to document what was important to them about their experiences of health, treatment, care, and support. These stories are archived online to contribute to the visibility and availability of cancer knowledge developed by and for sexual and/or gender minority patients.

Cancer's Margins is the first nationally-funded, pan-Canadian study to address the significance of both sexuality and gender marginality, and related modes of identity, expression, embodiment, and cancer decision-making. This project specifically advances knowledge concerning experiences of sexual and/or gender minority patients and particular questions relative to cancer and gender marginality, experiences of cancer health and care, and the production and mobility of knowledges relative to sexuality, gender, and cancer.

1.2 “LGBT” Health and Cisgender Assumptions: Issues in the Current Research Context

Much of the foundational work (Boehmer & Case, 2004; Dibble & Roberts, 2002; Sinding, Barnoff, & Grassau, 2004) that has been done on cancer and sexual marginality has been distinctly focused on experiences of lesbian women, and almost exclusively focused on breast cancer. The ground-breaking cancer research work of Ulrike Boehmer has centred on the experiences of breast cancer care and decision-making among sexual minority women. Indeed, Boehmer and colleagues collected very rich data in the late 1990’s about sexual minority women
and breast cancer experiences—including decision-making—and published numerous related articles in the early 2000s. However, Boehmer and her contemporaries at the time used the category of “sexual minority women” (Bowen & Boehmer, 2007) as a catch-all that did not explicitly analyze and distinguish between the heterogeneously differentiated gender identities and expressions of sexual minority “women” in their sample—trans and other gender minority people were subsumed under the category of sexual minority women. Sexual minority was operationalized to include “homosexual, bisexual, transgendered, transsexual, and intersex individuals” (Bowen & Boehmer, 2007, p. 343). As a result, the findings from the collective works of Boehmer and the related Canadian research from the early 2000s (Barnoff, Sinding, & Grassau, 2005; Sinding et al., 2004) are useful for providing a evidence base to begin to understand sexual marginality and cancer, but more research on the particularities and “intersectional” (Crenshaw, 1991) identities of minority patients is needed to understand the interrelated positionalities of both sexuality and gender marginality.

Current approaches to medical care have generally adopted the position that gender and sexuality, are inter-related and inter-dependent, but still separate aspects of health and well-being (Association of American Medical Colleges, 2014; Institute of Medicine, 2011). Research in the area of “LGBT” health has been increasing and there is also an increasing interest in “LGBT cancer care” (Burkhalter et al., 2016; Griggs et al., 2017; Polite et al., 2017).

Specific consideration for differentiations in cancer health between each facet of “LGBT” populations has gone, for the most part, unaddressed in the research literature—with the exception of a small area of research that has tended to focus on “lesbians” and breast cancer (J. P. Brown & Tracy, 2008; Rubin & Tanenbaum, 2011; Sinding et al., 2004)—which has provided evidence of population-based health disparities. However, as with the research by Boehmer with
sexual minority cancer patients, this work has almost exclusively focused on the experiences of lesbians (assumed to be cisgender).

Trans and other gender minority populations continue to be either excluded from the research or included as part of the larger analysis of “LGBT” participants, so the research studies that do include and address any issues regarding trans and gender diverse people and cancer have usually been done under the banner of “LGBT” population health, which artificially and arbitrarily locates populations whose experiences are organized by sexual marginality and populations whose experiences are marked by gender marginality as necessarily part of the same category represented by “LGBT”.

When research is conducted under the rubric of “LGBT” health, the particularities and specificities separately related to sexuality and gender are conflated. Cancer health issues specific to trans and other gender minority people—whose relationship to gender identity and expression differs from cisgender modes of identity and expression (Mayer et al., 2008)—have often been conflated with (LGB) sexuality specific concerns (Mayer et al., 2008; Watters et al., 2014). “Institutional erasure” (Bauer et al., 2009) and the related failure to gain access to culturally competent and/or gender affirming care for trans and gender diverse populations is linked very strongly with suicidal ideation and suicide attempts (Bauer, Scheim, Pyne, Travers, & Hammond, 2015; Clements-Nolle, Marx, & Katz, 2006). This underscores the imperative to take up a broad understanding regarding trans and other gender minority people and population health disparities in terms of access to care as a specific aspect of reducing suicidality (Kuper, 2015), as well as the systemic design of care, patient experiences and perceptions, and the health literacy and health decision-making of gender minority patients. Gender marginality has specific and significant impacts on shaping trans and other gender minority peoples’ overall experiences.
of health and care (Alleyn & Jones, 2010; Ellis, Bailey, & McNeil, 2015; James et al., 2016) and “LGBT” population health approaches are not sufficient for identifying the specificities that pertain to gender identity, expression, and marginality for the various populations purportedly represented by the “LGBT” acronym.

Sexual minority women’s non-normative relationships with femininity and categories of womanhood and gender performance have substantial and meaningful impacts on their experiences and understandings of cancer (Sinding et al., 2006). Narratives of cisgender normativity continue to inform the research and scholarly work related to cancer and sexuality, and thus, fail to recognize and attend to the specificities and differentiations of gendered identity, experience, expression, and embodiment. When research is organized by assumptions of cisgender embodiment and experiences, there are multiple deleterious consequences. Trans and other gender minority people remain excluded from and rendered invisible within models of cancer health and care, and, therein, gender diversity and related knowledge of queer women and trans and gender diverse people is further marginalized.

1.3 Population Health Research: Gender Minorities and Cancer Health Disparities

As a result of an oversimplification and reduction of issues pertaining to gender marginality and its erroneous inclusion in the category of sexual marginality, the specific health needs of trans and gender diverse people as gender minorities have been consistently overlooked in the population-based research not only on health and wellness generally, but specifically, regarding cancer care (Bryson & Stacey, 2013; Stroumsa, 2014; Watters et al., 2014).
In the research knowledge regarding cancer health and care, trans and other gender minority people have been left out of epidemiological data collection (Bowen & Boehmer, 2007; Deutsch et al., 2013). Trans and other gender minority people are underrepresented in health professional curricula generally (Association of American Medical Colleges, 2014; Obedin-Maliver et al., 2011), and in cancer research specifically (Bare, Margolies, & Boehmer, 2014). There are, for example, no population-based epidemiological data that track cancer prevalence or outcomes for trans and other gender minority populations (Agénor, 2015). This problem limits the evidence available to inform interprofessional practice and care coordination that takes into account the multiple health needs that might overlap between trans health and gender affirming care and cancer care—compounding the “informational and institutional erasure” (Bauer et al., 2009) of gender diversity in health.

Watters, Harsh, and Corbett (2014) conducted a comprehensive literature review of cancer research articles published between 1968 and 2012 and found only 23 research articles that addressed gender diverse populations and cancer care. Studies that do specifically address gender diverse populations and cancer care tend to be case study reports (Dhand & Dhaliwal, 2010; Pattison & McLaren, 2013; Turo, Jallad, Prescott, & Cross, 2013), largely focused on cases involving transgender women. Additional literature in this area tends to focus on changes to clinical approaches—such as care guidelines and protocols or clinical training and education (Dutton, Koenig, & Fennie, 2008; A. W. Gibson, Radix, Maingi, & Patel, 2017; Urban, Teng, & Kapp, 2011)—but does not include the experiences and narratives of gender diverse patients in their research, analysis, or suggestions.

There is an ongoing debate and concern within gender diverse and medical communities about the short and long term effects of gender affirming hormone therapies and treatments and
their relationship to possible increases in cancer risk (Braun et al., 2017; Irni, 2017; Moore, Wisniewski, & Dobs, 2003). While there are a number of studies that suggest an increase in cancer risk (Bentz et al., 2010; Moore et al., 2003; Mueller & Gooren, 2008), there is also a small body of research suggesting no deleterious effect of hormone treatments on long term cancer risk and mortality—instead suggesting that hormone therapy may contribute to some protective aspects concerning cancer risk and mortality (Asscheman et al., 2011; Gooren, Giltay, & Bunck, 2008; Gooren, van Trotsenburg, Giltay, & van Diest, 2013). While there is some evidence to suggest that hormone administration may affect the overall cancer risk profile for trans and gender diverse people who take them as part of gender affirming care (Asscheman et al., 2011), there is not yet enough research evidence to provide useful knowledge or any definitive conclusions about cancer risks for gender diverse populations seeking gender affirming hormonal interventions.

There is growing evidence surrounding some cancers, such as colon cancer or lung cancer, that suggests that these cancers may be related to and/or treatable with interventions such as hormone therapy (Katcoff, Wenzlaff, & Schwartz, 2014; Lin & Giovannucci, 2010; Machens et al., 2004). Hormone therapy is already a widely practiced part of cancer treatment (i.e. estrogen blockers to treat and prevent recurrences of estrogen positive breast cancers) as well as a widely practiced aspect of gender affirming medical care for some trans and gender diverse people, and so there is a significant opportunity to contribute new knowledges by adding to the research at the overlap of gender affirming care practices and cancer health issues, particularly when they are relative to gender diverse patients.

Recent findings specific to trans and other gender minority populations and cancer health behaviours report that gender minority patients are more likely to underutilize cancer screening
in comparison with cisgender patients (Bazzi, Whorms, King, & Potter, 2015; Peitzmeier, Khullar, Reisner, & Potter, 2014), and also more likely to delay follow up care, in comparison with cisgender patients (Peitzmeier, Reisner, Harigopal, & Potter, 2014). Additionally, recent research with cancer care providers themselves (Schabath et al., 2019) has found that oncologists significantly overestimate their knowledge relative to working with sexual and/or gender minority patients. Practitioners are often unaware of the specific care needs of trans and other gender minority patients and the importance of sexuality and/or gender identity for patient care and health decision-making.

Where measurements of health report inequalities and health disparities among populations of sexual minority and gender diverse people and communities, it is “challenging, but necessary, to convince policy makers and others that the health of the population is important precisely because it is a measure of whether, in the end, a population is benefiting as a result of a set of social arrangements” (Marmot, 2005, p. 1103).

1.4 Queering Cancer: Signs, Practices, Production

“What does it mean for LGBT people to become subjects and objects of biomedical scrutiny in these new ways and to themselves adopt biomedical modes of understanding their identities and communities? Is the focusing of medical attention on sex/gender subjectivities a good thing in the sense that it attracts people and resources to the study of previously underserved communities? Or is it a dangerous thing in the sense that it encourages us to treat sexual and gender identities as fixed biologic or cultural types and as an illness category?” (Epstein, 2007b, p. 164).
While neoliberal politics of inclusion assume that the recognition of populations automatically decreases the unequal distribution of life chances across varied populations, the complex relationships between categorical recognition and knowledge production and mobilization require a more nuanced attention to the specificities of both the context and origins of experience (Scott, 1991) and the marginalization of recognized population categories (Bryson & Stacey, 2013; Epstein, 2007a). Experiences of health and health decision-making are invariably wrapped up in complex webs of power, knowledge, and disciplinary political, economic, and social mechanisms (Foucault, 1975) that cannot be separated from the production of experience and the narration and biographical interpretation of experience (Scott, 1991).

The process described by Epstein (2007a) as the “reification” of population health disparities is based in the notion of legible categories of populations and the function of linking measurements of risk—for instance, cancer risk profiles—with individual responsibility and the categorization and description of sets of human bodies (Bryson & Stacey, 2013; Clarke, Shim, Mamo, Fosket, & Fishman, 2003).

While identity itself does not constitute a measurement of risk or resiliency to a cancer diagnosis, nonetheless, it is simultaneously true that individual persons who have ascribed themselves or who are ascribed a demographic location or identity are held to the narratives of risk and individual decision-making and surveillance that are associated with the population identity category and the management of risk, health, and wellness (Mason, 2002). Approaches related to “population(s) health”, in this way, fail to recognize and operationalize the diversity of the people, narratives, and experiences within the population(s) that the categorical boundaries claim to stake out.
Access to health knowledge and the ability to mobilize that knowledge and make decisions that are individually culturally informed and competent is a biopolitical issue within institutional structures of health that are ill-prepared for the mobilization of knowledge that is both medically competent and culturally effective. The capacity of marginalized populations to mobilize knowledge within the context of biopolitical structures that are structurally incompetent and the neoliberal imperative for patients to manage their cancer risk in relation to the overall political and cultural environment around them is to be tasked with “an imperative to manage the unmanageable” (Mason, 2001, p. 40).

1.5 Cancer and Knowledge Regimes

The design of the Cancer's Margins project is informed by the Social Study of Medicine (SSM) (Diedrich, 2007; Mol, 2002; Patton, 2007)—a research approach which proceeds by means of the documentation and archiving of the various signs and practices that together, make up medical systems where “conceptions of diagnosis, origin, and social effects of a disease differ” (Patton, 2007). The theoretical frameworks informing the design of the Cancer's Margins project are drawn from the SSM by simultaneously considering the production of the marginalized sexual and/or gender minority body as a categorical location (Epstein, 2007a; Foucault, 1978), as well as the production of normatively and non-normatively gendered bodies—cancer “patients”—through the diagnosis and treatment of cancer (Bryson & Stacey, 2013; Jain, 2013; Stacey & Bryson, 2012). Tracing the genealogical production of knowledge and narratives, and how they are mobilized, allows Cancer's Margins to contribute new evidence about the collection of practices and knowledge mobilities.
These assemblages of cancer knowledge and practices have previously been conceptualized as “regimes” of cancer (Klawiter, 2004), wherein cancer is gendered into separate regimes of “men’s cancers” (such as prostate cancer), and “women’s cancers” (such as breast and gynecologic cancers). When cancer care is organized into binary gendered “regimes” of care (Klawiter, 2004; Taylor & Bryson, 2016), the competing knowledge systems around sexuality and gender lead to the invisibilization of knowledge systems relative to gender diversity; subsuming non-normative narratives of the intersections of sexuality and gender. Collective knowledges that inform understandings and conceptualizations of disease, health and wellness shape the “treatment” of disease in terms of biomedical interventions (Diedrich, 2007), as well as the organization of care systems and the “politicizing of patienthood” (Diedrich, 2007).

In order to understand the production of identity, embodiment, biopolitical categories, and the location of all of these in relation to cancer treatment, this dissertation positions these “regimes” (Klawiter, 2004) and “fields of knowledge” (Foucault, 1980) that come together at the intersection of sexuality, gender identity, and cancer treatment as an assemblage of knowledge practices that can only exist “in the body multiple” (Mol, 2002).

1.6 Fields of Knowledge and Experience

“Missing is a description of living with cancer which simultaneously accounts for the individual’s experience of illness as well as the organization of a patient’s social world and its location in a medical system” (Mathieson & Stam, 1995, p. 286).

The fields of knowledge that come together at the intersection of cancer and sexual and/or gender marginality such as biomedical knowledge and biographical knowledge are
positioned in cancer health treatment systems as siloed realms of knowledge, each with little influence on each other—the prevalent ideas being that “cancer doesn’t discriminate” (Weir-Hughes, 2005) and “cancer affects everyone the same” (Lisy, Peters, Schofield, & Jefford, 2018; Tamargo, Quinn, Sanchez, & Schabath, 2017). Although, as the rhetoric goes, while cancer doesn’t discriminate, health care providers do (Weir-Hughes, 2005)—and so the interaction between biomedical knowledge and biographical knowledge begins at the very basic level of patient-provider interaction. This point of interrogation becomes increasingly more salient and productive when considered in terms of reconciling individual patient-provider narratives of care with the larger institutional and systemic production of those narratives.

Biomedical fields of knowledge position the patient as the receiver of health care and realms of social and relational positions of oppression/marginality are often seen as unrelated to the provision of care (Bryson & Stacey, 2013; Clarke et al., 2003; Epstein, 2007b). Marginalized research participants notoriously underplay the impact and occurrence of stigma—often reporting in the beginning of the Cancer's Margins interviews that they did not experience poor care, and then going on to detail instances of discrimination in great detail. Previous research with sexual minority cancer patients has identified “a legacy of heterosexism (that) appears to prompt strategic efforts to avoid homophobia and also appears to foster gratitude for equitable care” (Sinding et al., 2004, p. 171).

While the experience of the individual is key to understanding the positionality of the narrative, it is not a singular source of knowledge that provides a robust analysis (Scott, 1991). Challenging experience “as the origin of knowledge” (Scott, 1991, p. 777) is imperative to understanding cancer as having political and cultural implications. It is simultaneously necessary to consider both the lived experiences of participants as well as the relationship and production
of their experiences within complex biopolitical regimes of knowledge and power. “We are not simply oppressed but produced through these discourses, a production that is historically complex, contingent, and occurs through formations that do not honor analytically distinct identity categories” (W. Brown, 1997, p. 87).

The methodology of *Cancer’s Margins*, and relatedly, throughout this dissertation, simultaneously considers both phenomenological experiences of health and treatment, as well as the genealogical systems of knowledge related to illness and conceptualizations of disease and “treatments” (Diedrich, 2007) as productive of categorizations and locations. This approach to understanding health and disease takes into account both the productive role of structures of genealogic knowledge, where the body is acted upon and produced by multiple disciplinary processes, as well as a more phenomenological perspective on embodied experiences that accounts for bodily ways of knowing and doing (Bryson et al., 2018; Bryson & Stacey, 2013; Mason, 2002; Mol, 2002).

This research is designed in order to “analyze cancer in terms of fields of knowledge—systems of knowledge that are shaped and organized within specific generational and institutional frames of reference” (Stacey & Bryson, 2012, p. 199), in order to (a) document and examine the institutionalized practices, authoritative discourses, and social relations that produce the categories of “sexual minorities”, “gender minorities” and “cancer patients” and, (b) to identify and question the mechanisms through which cancer treatment overall simultaneously produces cancer patients and disciplines their bodies in relation to normative discourses of sexuality and gender.
1.7 Gendered Cancer Regimes: The Organization of Cancer Care and Treatment and Opportunities for Research

Through the lens of an “elegiac politics” (Jain, 2007b, p. 77), Lochlann Jain’s article “Cancer Butch” (Jain, 2007a) offers a first-hand, experience-based ethnographic interrogation of cancer and “the relentless hyper- and heterosexualization of the disease (that) results in something of a recursive process through which gender is produced and policed” (Jain, 2007a, p. 506). The conceptualization of cancer as being divided into “regimes” of “women’s cancers” and “men’s cancers” (Klawiter, 2004) creates an opportunity to examine the structure of those regimes and the socio-cultural-political mechanisms that produce gendered normativities through studying cancer, as an ethnographic object (Jain, 2007a).

The cisnormative rubric of “men’s cancers” and “women’s cancers” has been identified in the findings from Cancer’s Margins as being insufficient for understanding trans and other gender minority patient experiences of breast and gynaecologic cancer (Taylor & Bryson, 2016). Previous work in the area of gender and other cancers has recognized that this essentializing rubric is also insufficient for understanding patient experiences of cancer health, care, and treatment for other cancers, such as lung cancer (Katcoff et al., 2014) or colon cancer (Emslie et al., 2009). However, cancers such as lung cancer or colon cancer, despite the role of gender in shaping various aspects of patients’ experiences of cancer health and overall risk factors (Payne, 2001), are not understood to be inherently related to a specific gender in the same way that prostate cancer is considered to be a “men’s cancer” and breast and/or gynaecologic cancer are considered to be “women’s cancers”. For this reason, this research in this dissertation investigates breast and gynecologic cancer as cancers that are widely understood as “women’s cancers” in order to develop a robust understanding of how sexuality and gender marginality
each function separately and interdependently to shape marginalized patients’ access to and experiences of cancer health and treatment, support, and knowledge mobility and decision-making.

1.8 Generational and Cohort Demographics and Genealogical Context of Categories, Recognition, and Identity

This dissertation is based on research by the Cancer’s Margins project team that was conducted and published between 2012–2019. The period of work that this research was conducted in has included the moment of time labelled in Western North American contemporary society as the “transgender tipping point” (Deshane, 2017; Steinmetz, 2014). In the last few years, there has been a considerable surge of legislative and institutional policy changes related to gender diversity that have quickly spread among public institutions of law, education, and health and social service sectors (Picard, 2018). Notably, Bill C-16 was passed in the Canadian House of Commons and was given Royal Assent in June 2017, amending the Canadian Human Rights Act to specifically address both “gender identity” and “gender expression” as prohibited grounds of discrimination (The Government of Canada, 2017).

The focus of this dissertation on gender marginality and trans/gender discourses is due, in part, to a large cultural shift over the last 10 years that has brought increased attention and visibility to gender diversity and transgender people, communities, and related social, political, and cultural issues. In particular, the increased ubiquity of online social and cultural engagement has changed how sexual and/or gender marginalized populations find knowledge, identity, and community (Bryson, 2004; Cavalcante, 2016; Rawson, 2014).
The timing of this study is highly significant, because the data set (Table 1.1) includes 2 major cohorts of participants that are uniquely located in relation to a) socio-political knowledge mobilities, and b) queer and trans generational knowledge relative to both sexuality and gender (Bryson et al., 2018).

<table>
<thead>
<tr>
<th>Age Group</th>
<th>33–46</th>
<th>47–56</th>
<th>57–66</th>
<th>67–75</th>
</tr>
</thead>
<tbody>
<tr>
<td>Count</td>
<td>19</td>
<td>34</td>
<td>21</td>
<td>7</td>
</tr>
</tbody>
</table>

Table 1.1 Participant age range table

A significant portion of Cancer's Margins study participants—those who were 55–75 years old—grew up in a time in North America when homosexuality was illegal and ideas of transgender embodiment and identity were far from mainstream consciousness and relegated to fringe discussions. Indeed, this cohort of research participants who came of age during the late 1970s–mid-1980s, grew up and lived through and past a time where being gay, lesbian, or bisexual was still classified as a disease of mental illness. Some of the participants from this generation steadfastly refused any connection between gender marginality and sexual marginality—for instance, a number of these participants refused to even answer the question about gender identity in the interview protocol (Appendix 1), stating that it wasn’t relevant because they were “just a woman”. This cohort of participants between 55–75 represents an important generation of participants to identify in this research as they are the only generation of sexual and/or gender minorities to have experienced the advent of 2 significant cultural shifts that have shaped sexual and gender marginalization: the decriminalizing of homosexuality, and the explosion of the internet.
Similarly, but on the other end of the age range, participants younger than 55 came of age in the late 1980s–1990s and lived through a highly active period of activism and change for sexual and gender minority rights. Coming of age in an era just after the devastation of the AIDS crisis in gay communities in the 1980s was a very different time for sexual and/or gender minority people—it was the first era and generation of gay, lesbian, bisexual, and queer people who had an understanding of themselves as a specifically identifiable and locatable group in relation to population health efforts and culturally-specific care (Numer & Gahagan, 2009). This cohort also has particular significance, generationally speaking, about sexual marginality and gender marginality, as they are the first generation to recognize themselves as having population-based health needs and also a recognition of these as correlates of appropriate and competent health care delivery by both individual providers, and larger systems of health and disease prevention and treatment. Additionally, this cohort is the first generation of patients who has also been exposed to and able to engage with narratives of transgender identity and embodiment. Not only have they been present for the introduction of trans identities into common discourses, but they have also seen the “biomedicalization” (Clarke et al., 2003) of health and associated advances related to gender affirming care.

It must be acknowledged that the categories of representation used in this dissertation are constantly evolving, wildly unstable, and will likely be out of date and relevance in the near future. We are living through a currently rapid time of change in the social, political, and cultural inclusion and participation of sexual and/or gender minority people and communities (Pearce, Steinberg, & Moon, 2019; Ventriglio, Kalra, & Bhugra, 2018). Additionally, we are also living in a time of unsurpassed speed in communication and a proliferation of discourses around sexuality as well as gender identity and expression (Cover, 2018; Deshotels & Forsyth, 2019).
As such, this dissertation seeks not to prescribe a particular course of action or clinical protocols related to cancer health and wellness for minoritized patients, but to contribute new knowledge to inform engagement with the constantly-evolving discourses that are simultaneously both shaped by and also continue to reify sexual marginality and gender marginality (Epstein, 2016).

1.9 Researcher Positioning

“For those of us in the applied health realm, the truly exciting questions are always complex and inherently messy... In the world of health, they typically have to attend simultaneously to bodies, to minds, to social contexts past and present” (Thorne, 2011, p. 450).

As a trained and Registered Social Worker in British Columbia, one of my key practice ethics is the imperative to simultaneously consider both the wellbeing of the individual alongside and in balance with the pursuit of social justice and “collective interests in the service of humanity” (Canadian Association of Social Workers, 2005).

My purposeful engagement with the robust qualitative methods in the Social Study of Medicine allows the overall methodology for my dissertation research to be designed in a way that investigates the individual and lived experiences of real people, honoring the “inherent dignity and worth of each person”, while simultaneously working to understand the systemic production of marginalized subjects and the contexts within which they are located—with the goal of producing new knowledge and understanding that will “promote a more just society” (Canadian Association of Social Workers, 2005). The creating of alternative knowledges of
cancer is a contribution to a new biopolitical approach to cancer and queer health, and to queer cancer health.

By deliberately engaging social work ethics in how I frame my methodology and analysis, this dissertation research contributes evidence about the intersection of cancer and sexual and/or gender marginality that is not only credible, but that is also grounded in a disciplinary framework that has wide reaching influences from/for interdisciplinary institutions of health, education, law, and social and cultural community practices. By “layering complexity, foregrounding problems, thinking outside easy intelligibility and transparent understanding, the goal is to move educational research in many different directions in the hope that more interesting and useful ways of knowing will emerge” (Lather, 2006, p. 53).

1.10 Reflexivity

Since this research explores the intersections of cancer regimes and the production of gender discourses and sexual and gender marginalities, there are three main areas to which I need to locate myself and the analyses that I bring forward in this dissertation: as a trans person who is familiar with gendered discourses and disrupting them, as a person who has lived in various queered sexualities, and as a person who has not been diagnosed with cancer.

While notions of reflexivity are not able to resolve the problematics of representation—relative to the social locations of being “queer” or “trans and/or gender nonconforming” or as a “cancer patient”—a “reflexivity of discomfort” (Pillow, 2003, p. 192) assists me in navigating the messy work of these politics of representation and the power relations that are unavoidable in the research process (Karnieli-Miller, Strier, & Pessach, 2009). Using reflexivity as a methodological tool positioned “not as clarity, honesty, or humility, but as practices of
confounding disruptions” (Pillow, 2003, p. 192), I am not seeking to clarify these points of reference into a tidy coherence. Instead, I seek to explore and deepen the complexity of the social positionings that I occupy and re-inscribe in the process of conducting this research.

As the author and investigator for this research, I have an intimate investment and knowledge of trans and gender diverse communities that comes from having understood myself to be, in some way, gender nonconforming for my entire life. Relatedly, because of my non-normative relationship to gender, my identity and location in relation to sexuality has been consistently non-normative. Living and working in and with sexual minority and trans and gender diverse populations and communities supports me in my efforts as a researcher to develop research knowledge about sexual and gender marginality and health knowledge; I have an understanding of languages and discourses used in these communities. I am perceived as an “insider” and can quickly create trusting relationships with participants based on their perceptions of our shared understandings and my ability to navigate the invariably complex terrains of sexuality and gender identity and expression.

As a person who identifies as both trans and gender nonconforming and who has undergone both hormonal treatments as well as surgery, I have some understanding of the processes by which self knowledge and embodied knowledge are developed in relation to biomedical discourses and disease regimes and the ways in which patients navigate the complex politics of representation and subjectivity within health care systems.

As a scholar and researcher who has also been a clinical and community health provider, my background as a social worker has afforded me various avenues of experience in navigating and coordinating individual patient care and experiences in relation to larger systemic processes. In conducting and reporting on the research in this dissertation, my professional background
allowed me to have a significant level of skill and comfort in navigating, interpreting, and
documenting the interactions between fields of knowledge—in this case, embodied knowledges
relative to gender identity and expression, and knowledges relative to cancer “disease regimes”
(Klawiter, 2004).

Additionally, it is important to note my position as a person who has not been diagnosed
with cancer. My health status relative to my cancer health is markedly different than that of the
participants who provided their stories for this research, who—unlike myself—were all
diagnosed with cancer at some point. Accordingly, there are ways that participants have come to
understand themselves and their experiences relative to cancer that are not part of my embodied
knowledge; I have not personally experienced cancer care, diagnosis, and treatment, and
therefore, have not experienced the same bodily invasions of chemotherapy or radiation, and/or
the profound sense of mortality that can accompany a cancer diagnosis and treatment. In relation
to the function of support, I have had the experience, on multiple occasions at different points in
my lifetime between (and inclusive of) both childhood and adulthood, to witness and support
friends, family members, and colleagues who have been diagnosed with and treated for cancer.

1.11 Dissertation Objectives

In order to begin to answer questions about the gaps in understanding of both experiences
of cancer, and intersectional locations of sexuality and gender marginality, this dissertation
contributes 3 research papers that address the knowledge access, decision-making, and cancer
care and support experiences of sexual and/or gender minority breast and/or gynecologic cancer
patients. The overall aim of this research project is to contribute new evidence on the mobility of
non-normative knowledges relative to both cancer and categories of gender and sexuality.
The specific objectives of this dissertation are to:

1. Identify and examine the complex intersectional relationships between categories of sexual marginality and gender marginality and how these positionalities shape care and treatment experiences of sexual and/or gender minority breast and gynecologic cancer patients throughout the “trajectory” (Lebel, Rosberger, Edgar, & Devins, 2007) of cancer treatment.

2. Document what knowledges inform the treatment decision-making of sexual and/or gender minority breast and gynecologic cancer patients.

3. Analyze how sexual and/or gender minority breast and/or gynecologic cancer patients navigate the complex social, cultural, and relational networks of health knowledge access and mobilization.

1.12 Advancement of Knowledge

The design of this research is intended to contribute new knowledge about marginalized patient experiences of cancer treatment and support. By disaggregating and identifying the specificities of how sexuality and gender shape cancer health and care for sexual and/or gender minority patients, this research project aims to create a more robust understanding of intersectional modes of not only care experiences, but also the institutional organization and implementation of cancer health and care protocols and systems of care.

This research and dissertation is intended to advance knowledge regarding sexuality and gender minority status as salient intersectional issues of competent practice and health decision-
making in cancer care, and has been designed in order to contribute new evidence and knowledge that can underwrite new approaches to cancer care and support systems and inform the design of more effective and patient-centred care delivery, protocols, and ongoing clinical and structural research. Ultimately, the knowledge advanced by the *Cancer's Margins* project overall, and this dissertation research specifically, is intended to contribute new perspectives on addressing cultural and structural competencies related to sexuality and gender marginality in cancer care provision.

### 1.13 Organization of Dissertation

This dissertation consists of five chapters, including this first introductory chapter. This dissertation follows a manuscript-based format, and therefore, Chapters 2, 3, and 4 are all sets of analysis that have been produced for various knowledge translation activities and publications, as detailed below. All data for these body chapters are drawn from the *Cancer’s Margins* project. Chapter 5, the final chapter, provides a summative review of the contributions of our findings to the fields of sexual and/or gender minority population health and knowledge mobility and suggests implications of the dissertation research findings for public policy and health systems organization and the design and provision of ethical and effective cancer health and support services for sexual and/or gender minority patients. The final chapter also provides a theoretical summary of the contributions and challenges that this dissertation brings to the fields of knowledge and competencies that organize health care generally, and cancer care specifically.

Chapter 2 draws on the entire patient dataset from *Cancer’s Margins* that includes both sexual minority and gender minority breast and gynecological cancer patients. The purpose of
this particular data analysis is to identify how sexual marginality and gender marginality function intersectionally to shape the cancer care and treatment experiences of sexual and/or gender minority cancer patients. This analysis also examines how sexual and/or gender marginality are related to knowledge access, knowledge mobility, and access to support for marginalized cancer patients. This chapter provides a disaggregated analysis of sexuality and gender within populations that have previously been subsumed under the homogenous and cisnormative categories of “lesbian” or “sexual minority women”. The results from this chapter can be used to inform the design and provision of care and treatment for sexual and/or gender minority cancer patients that takes into account the culturally-specific knowledge that sexual and/or gender minority cancer patients use to inform their decision-making throughout the trajectory of cancer treatment.

In Chapter 3, I identify the specific experiences of breast and gynecological cancer health and treatment for trans and gender nonconforming populations. This analysis includes the subset of Cancer’s Margins participants (n=10/81) who identified themselves as trans and/or gender nonconforming. This analysis provides the first comprehensive look at the particular narratives and experiences of breast and/or gynecological cancer for gender minority cancer patients (Taylor & Bryson, 2016). The analysis in this chapter contributes understandings about the systemic and structural design of cancer care and access to knowledge that informs patient decision-making. In Chapter 3, I identify and explore the regimes of knowledge relative to both cancer and gender that shape the experiences of trans and gender nonconforming cancer patients. This chapter also documents the specifics of gender marginality in shaping cancer health and treatment experiences as well as treatment decision-making among gender minority patients. The
implications of these findings include: approaches to identifying and addressing gender
marginality within cancer care systems; designing and implementing treatment protocols and
environments that consider the needs and experiences of gender minority patients; and
addressing complex systems of representation and marginality in measurements of competency.

Chapter 4 builds on the results from the previous chapters and applies the
conceptualization of those findings more specifically to identify and document the online
ecologies of knowledge access, mobilization, and the navigation of fields of knowledge for
sexual and/or gender minority cancer patients. Making use of the entire breast and/or
gynecological cancer patient dataset from Cancer’s Margins, in this chapter, I build on and
examine the knowledge and support seeking of minoritized cancer patients in various knowledge
ecologies, both face-to-face and online.

Since current research approaches that take up rubrics of “LGBT cancer” or “SGM
cancer” fail to apply a disaggregated view of how sexuality and gender marginality function in
relation to cancer care, treatment, and support, the aim of this chapter is to examine the online
support and knowledge access of marginalized patients using intersectional approaches to sexual
marginality and gender marginality.

The results of this analysis point to cisnormative and heteronormative knowledge as
overlapping, but distinct influences in online cancer knowledge and narratives and also identifies
specific aspects of the organization of online support and information that are prioritized by
sexual and/or gender minority patients, such as narratives of lived experience and interpersonal
community connections. These narratives are discussed in relation to their particular relevance to
media and knowledge access, knowledge mobility, and patient-provider relationships and
communication. The findings are presented in the context of understanding online health information access and potential opportunities to increase access to population-specific cancer knowledge ecologies that provide relevant knowledge, information, and support for sexual and/or gender minority cancer patients.

Chapter 5: This final chapter synthesizes the findings presented in the data analysis from Chapters 2–4 and locates the contributions of the dissertation within fields of knowledge relative to gender, sexuality, social determinants of health, and the context of designing and delivering culturally effective cancer care and treatment.

The results from the previous chapters are discussed in the context of current approaches to medical practice, ongoing developments in research on cancer and genomics, and the ethics of patient-centred care design and provision. Recommendations for future research and cancer treatment and support delivery designs are proposed that specifically address intersections of medical competency and culturally effective care.

Chapter 5 explores the practical, theoretical, and institutional contexts and opportunities for change and improved care and treatment outcomes for sexual and/or gender minority breast and gynecological cancer patients, along with the larger structural, genealogical, academic, and research-related contexts that this dissertation implicates in its overall analysis. The findings from the dissertation research are situated in relation to current research, education, and practice contexts and are simultaneously examined in relation to advancing the design of intersectional health approaches and the mobilization of diverse forms of knowledge.
Chapter 2: Knowing, Knowledges, and Normativities: Care and Treatment

Experiences of Sexual and/or Gender Minority Breast and Gynecologic Cancer Patients from the Cancer's Margins Project

2.1 Introduction

“Mastectomy necessarily cites gender, mastectomy necessarily queers a woman in a homophobic world... The battle over the recognition of breast cancer is a semiotic, economic, and gender battle. Shit, I am a woman—I am the person whose wheel of fortune pointed to the illness not only of cancer but of femininity.” (Jain, 2007a, p. 526)

There have been recent and multiplying calls for research evidence addressing sexual and gender minority cancer health and care (Burkhalter et al., 2016; Griggs et al., 2017). While previous research on “LGBT” cancer health has suggested significant cancer health disparities for sexual and/or gender minority populations, such studies have focused almost exclusively on “sexual minority women”. A previous Canadian project, the Lesbians and Breast Cancer project (Sinding et al., 2004, 2006), was conducted with sexual minority women and opened up an area of research dealing with sexual marginality and cancer decision-making and care experiences that problematizes the uninterrogated category of “lesbian” and addresses the biopolitical production of identity (Stacey & Bryson, 2012). Lesbians and Breast Cancer (Sinding et al.,

1 This analysis was initially conducted and presented by me at the World Professional Association of Transgender Health’s 24th Biennial Scientific Symposium (2016) in Amsterdam, Netherlands

2004) reported on the context and impacts of homophobia and heterosexism in shaping the cancer health care and treatment experiences of sexual minority women and creating challenges in their relationships with their care providers. The foundational work of Ulrike Boehmer on sexual minority women and breast cancer has also provided excellent insights into the cancer care and support experiences of sexual minority women, including care and treatment decision-making (Boehmer & Case, 2004; Boehmer, Glickman, Winter, & Clark, 2013; Boehmer, Linde, & Freund, 2007). However, the research that has been previously conducted on sexual minority women and cancer has not explicitly recruited trans or gender diverse participants, and so the field of work on sexual marginality and cancer has positioned gender nonconforming women (such as butch women, or androgynous women), or other gender nonconforming people (such as genderqueer or genderfluid people), as well as trans and gender nonconforming people, all under the rubric of sexual minority women. Such conflation obscures the vast heterogeneity of gender identity and expression among sexual and/or gender minority populations.

To build on previous research in this area, the Cancer's Margins project design specifically includes trans and other gender minority participants in order to provide a more intersectional analysis of marginal locations relative to both sexuality and gender. This research aims to disaggregate sexuality and gender and explore how sexuality and gender diversity shape cancer experiences for sexual and/or gender minority populations, as well as giving specific attention to the intersections of sexuality and gender between and within these populations.

The Cancer’s Margins research reported here takes up intersectional (Crenshaw, 1991) and relational approaches (McCall, 2005) to conceptualizing and understanding cancer, sexuality, and gender as objects of study. The aim of the research is to improve existing evidence by tracing and analyzing complex within-group locational and generational patterns of
diverse experiences of health, illness, and embodiment, and of access and contributions to cancer knowledge and its mobilization.

This research approach provides unique evidence of the intersectional relationships between sexuality and gender diversity among sexual and/or gender minority cancer patients and how it shapes their experiences of breast and gynecologic cancer care and treatment decision-making. The data and findings presented here bring a specific contribution to the knowledge regarding marginality and cancer by adding an analysis that is not concerned with an isolated view of sexual marginality, but that is also related to gender identity, expression, and experiences of gender marginality that inform cancer patient experiences.

The findings presented in this analysis describe the ways in which sexuality and gender are intersectionally linked and relevant to how sexual and/or gender minority patients access knowledge, make treatment decisions, and access support around breast and gynecologic cancer health and treatment. Canadian cancer care can be improved by a better intersectional understanding of health equity and an increased evidence base regarding the health care navigation, negotiation, and decision-making by marginalized populations (Ashing, Chávez, & George, 2017).

2.2 Methodology

Documentation of the health experiences of marginalized populations is typically intended to advance knowledge by contributing analytic perspectives on the role of patients and providers in health care systems (Grabinski, Myckatyn, Lee, Philpott-Streiff, & Politi, 2018; Shetty et al., 2016), alongside the productive role of knowledge systems and practices in institutional health settings (Diedrich, 2007; Epstein, 2007b). Knowledge objects, knowledge
practices and relational networks can be usefully documented and analyzed by undertaking specific qualitative analytic methods (Bonevski et al., 2014; Karnieli-Miller et al., 2009; Pope, Ziebland, & Mays, 2000). Qualitative methods support an analysis of health experiences that can advance knowledge (Robinson & Ross, 2013) of the relational, social, and institutional roles of key members of the cancer treatment and care system, including: the patient, treatment providers, support systems and networks, as they relate to the context of knowledge “fields”, access to knowledge, and the mobilization of both biomedical and biographical knowledge (Bryson & Stacey, 2013).

The analytic framework undertaken here is primarily informed and guided by 3 specific research questions:

1. How do sexual marginality and gender marginality intersectionally shape the cancer care and treatment experiences of sexual and/or gender minority breast and gynecologic cancer patients throughout the “trajectory” (Lebel et al., 2007) of cancer treatment?

2. What knowledges inform the treatment decision-making of sexual and/or gender minority breast and gynecologic cancer patients?

3. How do sexual and/or gender minority breast and gynecologic cancer patients access health knowledge—specifically cancer health knowledge—and how do they mobilize this knowledge?

The analytic framework deployed in this analysis uses research methods informed by the field of work commonly understood as the Social Study of Medicine (SSM) (Diedrich, 2007; Mol, 2002; Patton, 2007) to combine elements of divergent methodological approaches. Cancer's
*Margins* combines a focus on phenomenological patient experiences, along with a post-structural approach (Epstein, 2007a) to understanding the social and institutional contexts that shape sexuality and gender as knowledge systems that are located and organized by/within particular institutional frameworks.

This analysis of interview transcripts identifies the systems of knowledge, knowledge practices, and the organization and mobilization of knowledge in sexual and/or gender minority breast and/or gynecologic cancer patients’ varied social, community, and institutional contexts of cancer care and cancer decision-making.

By simultaneously attending to “fields of knowledge” (Foucault, 1975) and the experiential knowledge produced within institutional systems (Clarke et al., 2003; Scott, 1991), the analysis presented here brings together both a feminist focus on lived experience, along with a genealogical view of power, knowledge, and the social and institutional contexts that produce that experience and shape its narration (Smith, 2005). Furthermore, by engaging with methodological processes that complexly situate and understand the production of experience, the findings in this research elevate the narratives of participants from a status of the anecdotal, into “experiential evidence” (Ziebland & Herxheimer, 2008) that can be used to increase the quality and relevance of biomedical research evidence (Bryson & Stacey, 2013; Caron-Flinterman, Broerse, & Bunders, 2005).

### 2.2.1 Logic of Participant Inclusion

*Cancer’s Margins* recruitment efforts were aimed at recruiting a diverse sample of sexual and/or gender minority people diagnosed and treated for breast and/or gynecologic cancer (Canadian Cancer Statistics Advisory Committee, 2018). Participants were recruited from
various geographical locations across Canada in rural, suburban, and urban locations in British Columbia (BC), Manitoba (MB), Ontario (ON), Quebec (QC) and Nova Scotia (NS). The sample (Table 2.1) used for data analysis in this dissertation also includes pilot interviews conducted in the Bay Area of San Francisco (BA) (n = 15). All interview participants had been assigned female at birth and all had been diagnosed and treated (currently or previously) with breast and/or gynecologic cancer.

Consistent with optimal sampling methods for hard-to-reach populations (Faugier & Sargeant, 1997), purposive and non-random sampling methods, such as snowball sampling, were utilized in order to create a diverse sample of participants in relation to age, race and/or ethnicity, socio-economic status, dis/ability, gender identity, gender expression, and sexual orientation and identity. Research studies on sexual and/or gender minority population health are often under-representative of racial and ethnic diversity and other intersectional locations (Meyer & Wilson, 2009). Proactive efforts were made in participant recruitment in order to engage marginalized populations in this research study. As a result of this proactive recruitment, interviews were conducted with participants from a variety of urban, suburban, and rural locations. The overall sample of participants in the Cancer’s Margins project generally mirrors the demographic make up of the overall Canadian population in terms of race and ethnicity (Statistics Canada, 2017).

The recruitment for this research took up specifically proven and recommended methodological approaches from successful Canadian health research with sexual and/or gender minority groups. Greta Bauer (2012) has published numerous methodological recommendations from extensive research with sexual and/or gender minority populations and the recruitment processes in this project were developed with the consideration of Bauer’s recommendations. For instance, while discourses and identity groups vary widely, recruitment materials and documents
used the phrase “QLB women and Transgender people” with the intention of deploying terminology for sexual and gender self-identification that, while far from coherently representing a heterogenous group of people, is language that is both widely circulating and commonly understood (Institute of Medicine, 2011). Recruitment materials also made clear that “transgender” was being employed as an over-arching term that represented a wide range of non-cisgender identities such as genderqueer, trans, transsexual, etc.

<table>
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<tr>
<th>Geographic Location</th>
<th>Age</th>
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<tr>
<td>BC: CA</td>
<td>33-46 47-56 57-66 67-75</td>
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<td>MB: CA</td>
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<tr>
<th>Gender: Do you identify as Transgender?</th>
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<tr>
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<td>Yes: GNC</td>
<td>No: Genderqueer</td>
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<tr>
<td>No: Cisgender</td>
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<td>Yes: Trans</td>
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<tr>
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<tbody>
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Table 2.1 Participant demographic table
Participants (n=81) ranged in age from 33–75, and used a wide array of identity locations and descriptions to describe their identifications related to categories of race and ethnicity, socio-economic status, dis/ability, and, in particular, to gender identity, gender expression, and sexual orientation and identity. Participants identified themselves as one or more of: queer, lesbian, bisexual, and/or as transgender, gender nonconforming, or Two-Spirit, in addition to an assortment of specific and nuanced identities in relation to sexuality and gender.

Where previous studies with sexual minority women did not specifically recruit and include trans and other gender minority people, the group of Cancer's Margins participants recruited included and documented significantly more gender diversity than has previously been reported. All participants were asked specific questions about their gender identity and expression and given the opportunity to self-identify as trans and/or gender nonconforming. While only 10 participants answered ‘yes’ to the transgender self-identity question, a slight majority of the 72 participants who did not identify as trans and/or gender nonconforming also did not identify as simply cisgender, with 38 of these participants going on to use complex and nuanced words and identities to describe their gender identity, expression, and locations.

2.2.2 Data Collection

Cancer's Margins was given ethics approval by the Behavioural Research Ethics Boards of the University of British Columbia, Dalhousie University, and Concordia University. Semi-structured interviews were conducted in either French or English. Participants were informed about the rationale for the study, time involved, and their right to refuse to answer questions or withdraw from the study without consequences. Each participant provided written informed consent for the interviews, which were around 2 hours in length and were conducted in private,
quiet spaces such as homes, offices, or private meeting rooms at community centres. The interviews were carried out by research team members with significant experience in understanding the complex role that sexuality and gender play in cancer and health. The interview protocol (Appendix 1) followed a “trajectory” (Lebel et al., 2007) of cancer care events that most commonly occur in succession as: screening, diagnosis, surgery, treatment(s) (chemo, radiation, hormones), follow up/surveillance, and/or metastatic care. The interview protocol included demographic questions, followed by open-ended questions that allowed participants to contextualize their experiences of cancer, treatment, and knowledge-seeking practices as they related to their primary intersectional locations and self-identifications, including how they articulate their gender identity, gender expression, and sexual orientation.

2.2.3 Data Analysis

This data analysis undertakes an operational definition of “knowledge mobilization” and “access to knowledge” (Kapczynski, 2008) for sexual and/or gender minority cancer patients as: the capacity to access, communicate about, assess, distribute, modify, and make use of culturally informed knowledge relative to cancer health decision-making (Bryson & Stacey, 2013).

Consistent with established principles of qualitative research methodologies (Cussins, 1998; Mason, 2002; Saldaña, 2013), data analysis started with a set of codes informed by a theoretical framework that focused specifically on: a) multiple, distinct systems of knowledge that constituted participants’ explanatory systems, and b) practices relevant to the mobilization of knowledge in decision-making. The initial coding system included the identifying of the various functions of knowledge in decision-making, and treatment and support design by coding for: biomedical knowledge, biographical knowledge, knowledge mobility in decision-making, and
support networks in participants’ narratives. Experimentation with these exploratory codes was performed on a sample of 24 transcript interviews using MAXQDA qualitative analysis software.

In order to identify key themes to undergird the modification and elaboration of the coding scheme, the next stage involved an in-depth analysis of the subset of transcripts to develop a more expansive coding system for schematizing systems of knowledge and knowledge mobilization practices. A robust coding scheme (see Appendix 2) was developed by the Cancer's Margins research team that utilized over 70 codes (63 subcodes across 8 major codes). Major categories in the coding system included: identity and expression, the cancer trajectory, care contexts and encounters, feeling cancer, knowledge access/types/mobilization, locations/spaces, support, and treatment providers. Coding analysis made extensive use of cross-coding (Saldaña, 2013) to identify specific patterns and themes within and across coding categories.

The entire dataset was coded and analyzed in MAXQDA by various members of the research team. Following guidelines for establishing intercoder reliability, coders were trained together and follow-up sessions were conducted to ensure that the coding system was applied reliably across coders. Finally, using the intercoder reliability functions of MAXQDA to track agreement, the reliability rate was brought up to over 80% across 30% of the interviews, according to satisfactory rates established in previous methodological literature for reliability in qualitative studies (MacPhail, Khoza, Abler, & Ranganathan, 2015; Saldaña, 2013). Data analysis made use of all interview transcripts and codes in order to conduct a thorough analysis of the relevant areas and mobilizations of knowledge.

The analysis presented here focuses on cancer as an “ethnographic object” (Jain, 2007a) and seeks to describe how it is that sexuality and gender marginality function as disaggregated,
yet specific intersectional locations within which sexual and/or gender minority patients seek out and make use of health knowledge and self knowledge—and the contexts in which they describe decision-making and accounts of care experiences. The decision-making and “doing” (Schilt & Westbrook, 2009) at these sites of knowledge are framed as narratives in order to map out the narration of cancer, alongside a disaggregated, but intersectional view of sexuality and gender to understand “what illness narratives do” (Diedrich, 2007, p. xvii) and how it is that a queered narration of cancer articulates new intersectional knowledges.

2.3 Findings

2.3.1 Disclosure and Negotiation of Intersectional Identities

*Cancer's Margins* research has pointed to an “awkward choreography” (Bryson et al., 2018) that sexual and/or gender minority cancer patients navigate in relation to the disclosure of sexuality and/or gender identity and the potential impacts on patient-provider relationships and quality of cancer care (Bryson et al., 2018). The navigation of disclosure is significant to understanding sexual and/or gender minority patient experiences as there is evidence to support associations between the disclosure of sexual orientation and gender identity in cancer care and treatment settings and the health outcomes of sexual and/or gender minority cancer patients (Kamen, Smith-Stoner, Heckler, Flannery, & Margolies, 2015).

Previous research with sexual minority cancer patients has identified that sexual and/or gender minority patients make decisions about disclosing their sexual identity in cancer care settings after evaluating and considering their perceptions of safety (Boehmer & Case, 2004). Our findings add to the existing knowledge around disclosure for sexual minority patients by identifying that, in addition to sexual orientation, both sexual minority and gender minority
patients also navigate disclosure of gender identity and expression. Disclosure of sexuality or gender identity is considered by minoritized patients in the context of measuring cultural safety and the potential for discrimination by providers.

“I was really worried about how I'd be treated as a dyke and how my partner would be treated. There was only one care provider, which was a nurse, when I was in the recovery room. That nurse was obviously really not okay with me being a lesbian, or trans, or whatever. She was not okay.” Jolene (ON, 59, Caucasian, genderfluid, queer, breast cancer)

*Cancer's Margins* participants were constantly vigilant of their vulnerability to stigma and bias in cancer care environments, alongside the potential for stigma and bias to compromise the quality of cancer care and treatment offered and available to them. They typically made decisions about disclosure of sexuality or gender identity after evaluating safety and the possible impact of disclosure on quality of cancer care. As such, patients were constantly tasked with bridging the gap between their self-knowledge and the knowledge that informed systems of care.

“I had all these moments in treatment where I was like, ‘Do I say something? Do I say, “By the way I’m bisexual”?... Medicalization can be erasing of so many aspects of your identity. I felt completely invisible. It was awful.” Serena (BC, 39, Caucasian punk femme bisexual, breast cancer)

The perceptions that participants had of their experiences of cancer care and treatment were influenced intersectionally by sexuality and gender, but also by other social and generational locations such as race, ethnicity, class, dis/ability, religion, and so forth. Participants
who identified as racialized and/or Indigenous related ways that their personal knowledge and experiences of sexuality and gender were additionally interconnected and intertwined with embodied knowledge and lived experiences of racism, ethnocentrism, and “minority stress” (Meyer & Frost, 2012)—compounding the complexity of their vulnerability to stigma and discrimination and related “institutional oppression” (Epstein, 2007b).

“When I was first coming out, my girlfriend was white... As ludicrous as this sounds, I thought I was the only one... I was living in a very small Ontario town... A lot of my experiences weren’t positive. Of racism... People yelling at me from cars... People following me around stores. Of some facility not giving me the benefit of the doubt in things.” Florence (ON, 41, Black Caribbean, lesbian woman, breast cancer)

Social locations related to class and socio-economic status were also relayed by participants as having specific intersections with sexuality and gender that participants connected to their choices around disclosure and the potential for disruptions in patient-provider relationships or contributing to issues with quality of care provision related to stigma. Terry (BA, 40, Caucasian, femme, queer, breast cancer, BRCA2) wasn’t offered fertility treatments—which she attributed to the intersection of her identity as queer, as well as being a sex worker and how stigma shaped her care.

“Maybe if I had come in with a husband or something... But, also, it was about class... (Other cancer patients) around me were like, “I got egg retrieval’. None of that was brought up with me. I think that I was not seen as valuable to reproduce because I am open about being a sex worker.” Terry (BA, 40, Caucasian, femme, queer, breast cancer, BRCA2)
Finding themselves suddenly thrust into the medicalized environment of cancer care systems and the immediate onslaught of medical provider appointments and interactions, sexual and/or gender minority cancer patients made decisions about the disclosure of their sexual orientation and/or gender identity that were based on their perceptions of how best to mitigate their vulnerability by reading care environments for signs of safety. Perceptions of safety, and potential for stigma and bias were related to knowledges gleaned from myriad intersectional social locations—including sexuality and gender.

2.3.2 Generational Differences in “Lesbian” Health Knowledge

Participants of different generations were differently informed by sexuality and gender politics that were specific and relevant to their generational locations. There were 2 distinct cohorts of participants that had lived through different eras and therefore had specific narratives around sexuality and gender that were particular to their generational cohort. Participants aged 56 or older, juxtapositioned with participants aged 55 years or younger, expressed distinct generational perspectives and narratives around health knowledge mobilities. Perspectives on sexuality, gender, health decision-making, and patient-provider relationships proved to be highly influenced by generational cultures of queer knowledge (Bryson & Stacey, 2013).

Participants under 55 were informed by a generational value, in a post-crisis era of HIV/AIDS sexual health, that positions sexuality and gender as vitally important information relative to health decision-making (Numer & Gahagan, 2009; Robinson & Ross, 2013). Participants under 55 were more likely to expect their care providers to be prepared for and sensitive to their specific needs as a population marginalized relative to sexuality and gender.
“I do not want to be explaining my identity to cancer providers everywhere I go. I'm there for treatment, so why am I educating them? Like, I'm not here to educate you right now. You know?” John (ON, 33, Chinese-Canadian, trans man, queer, breast cancer)

While participants who were under 55 often sought health information from their medical care providers or formalized support systems, participants who were over 55 reported more “medical mistrust” (Brenick, Romano, Kegler, & Eaton, 2017) in their relationships with providers and medical systems. Participants over 55 were more likely to conceptualize health knowledge and their access to health knowledge as being connected with community relationships and experiential knowledge. They related to cultural ideologies that position “women’s health” as being a feminist political issue and used their community relationships to access health knowledge. This generation of participants came of age and into sexual and gender identities in a time without the widespread availability of online information and social media. These participants prioritized communitarian knowledge - culturally-specific narrative information about the personal experiences of others in their community when they were making decisions about their cancer care.

“I called up every woman I knew who'd had a hysterectomy. We didn't get a second opinion, we got dozens!” Cheryl (BC, 65, Caucasian, woman, dyke/lesbian, uterine cancer).

Participants who were under 55 came of age in a generation with different political agendas around sexuality and gender. They reported a more fluid approach to the intersections of
sexuality and gender and were less likely to identify as, for instance, lesbians. These participants were more likely to forego the presupposition that is made in the categorization of “lesbian” that marks both the person in reference to the identity and their sexual partner(s) as “lesbian women”. Participants under 55 (and trans and/or gender nonconforming participants) were more likely to identify themselves using the language of a “queer” politics and health, as well as being informed by a “trans” narrative to make sense of gender diversity and embodiment.

Dario (BA, 50, Latinx, genderqueer, queer, breast cancer) lived and developed self-knowledge through a time of shifting and opening consciousness about trans and other gender minority people, lives, and communities, and related medical intervention. As such, Dario felt that their mastectomy surgery held a multi-faceted meaning. While Dario understood the surgery as a cancer treatment, it also held meaning to them as a trans person with a genderqueer identity by creating a non-normative gendered embodiment through cancer treatment.

“That's how I identify. Over time, I have added the gender queer to the queer.

That's been a long time coming, but definitely with the cancer diagnosis, with the bilateral mastectomies, and that just fuels. With the more trans-affirmative kind of community that I belong to now, it feels like that really opened up a comfortable space for me, and my body.” Dario (BA, 50, Latinx, genderqueer, queer, breast cancer)

Participants from distinct generations were informed by different narratives of sexuality and gender in understanding their diagnosis and the impacts of their cancer treatments. Understanding the cohorts of queer and trans “generations” gives a more robust picture of the types of knowledge and experiences that informed how patients sought out and mobilized
knowledge, as well as how they made treatment decisions, and what was important to them in making those decisions.

2.3.3 Repronormativity, Heteronormativity, Homonormativity, and Cisnormativity in Cancer and Fertility Decision-Making

Cisnormative and heteronormative relationships to procreation and reproduction, as well as to family structures and constructions of relational categories have been identified as a function of “repronormativity” (Weissman, 2016). The systems of knowledge that informed participants’ decision-making around cancer treatment were different from the knowledge that their treatment providers assumed and used themselves. Repronormativity was thus tied to the heteronormative and cisnormative assumptions that shaped patient-provider interactions. Fertility was a specific aspect of cancer treatment that was navigated very differently by sexual and/or gender minority cancer patients than by their providers.

“My cancer diagnosis resulted from my attempts to get pregnant... By the time I knew, it was a race to see how quickly I could get a hysterectomy—in my mind. They didn't think it was such a race.... With somebody of my age—especially who was trying to get pregnant—they didn't like to do that (hysterectomy). That seemed really drastic and so they wanted to let me know that there were some other options... But it took me about thirty seconds to realize that 'No, I didn't want to do that.'” Diane (NS, 39, Caucasian, femme, lesbian, uterine/endometrial cancer)
Diane’s decision-making didn’t follow with the normative expectations of her providers—cisnormative, heteronormative, homonormative, repronormative—that a young cisgender lesbian would prioritize fertility in the context of cancer treatment decision-making.

Conversely, John had to convince his providers to delay chemotherapy treatments because he wanted to pursue fertility options. His providers had not considered that John would want to pursue egg preservation options, despite his young age and despite widespread standards of cancer care for young persons that include the offering of fertility treatment options before chemotherapy treatments.

“At this meeting, I said ‘OK, when is a good time to ask you about fertility?’ And jaws fell to the floor and they were crestfallen. They said, ‘No, you should have been exploring this six months ago, three months ago. We’re going to start chemo, like, now.’ I said, ‘No, we are not. Nobody has offered me this option. Nobody has spoken to me. I have asked for resources.’ Why do people assume that I did not want to do this? As a young reproductively viable person?” John (ON, 33, Chinese-Canadian, trans man, queer, breast cancer)

John speculated that his providers assumed that because he was trans, he wouldn’t want to pursue fertility treatments. The normative narratives informing the provision of care harmfully position trans people as if they do not procreate, are unconcerned with being sterile, or as if they do not wish to pursue fertility options and/or do not want to parent. John’s fertility concerns were pushed off to the side and not considered, marginalizing not only his reproductive health, but also his emotional and mental wellbeing in a time that was already extremely challenging for
him and his partner, and his narrative of his embodied gender and health. John’s location as a trans person is shored up in the marginalization of his fertility concerns as he is construed into a normative trans narrative that dismisses reproductive options in favour of coherently binary-gendered embodiments, expressions, narratives, and decision-making.

The preservation of fertility was prioritized in the organization of cancer treatment protocols for cisgender women, but treatment practices did not prioritize or even include fertility protocols for trans and other gender minority patients. This analysis provides evidence that cancer care systems are informed and shaped by reppronormative, homonormative, heteronormative, and cisnormative systems of knowledge that presume fertility as a priority in decision-making for cisgender women and simultaneously assumes a lack of procreative or parenting goals for trans and other gender minority people.

2.3.4 Sexual and Gender Marginality and Embodied Knowledge Related to Cancer Treatment

There is documented research evidence to support the health benefits of providing treatment for trans and other gender minority people who wish to access medical interventions such as hormones and surgery in order to alter their embodiment to be more compatible with their self-knowledge and gender identity (Bauer et al., 2015; James et al., 2016). Many of the same medical interventions are also performed as part of the treatment process for breast and/or gynecologic cancer (i.e.: mastectomy, hysterectomy, hormone therapy), however there is little evidence to describe how it is that these interventions might impact patient self-knowledge and gender identity post-treatment. Medical providers largely understand and make sense of the
surgical process as a purely biomedical process, but sexual and/or gender minority cancer
patients understand surgery as an intervention that has the potential to be part of cancer treatment
and simultaneously hold meaning as gender affirming care (Taylor & Bryson, 2016).

Participants who identified as sexual minorities, but who didn’t identify themselves as
being transgender, still reported that they took up information from the systems of knowledge
that they were familiar with from gender minority people to make treatment decisions.
Participants named that they coped with the trauma of cancer surgery through their
understanding and use of an alternative narrative for their embodiment—one that they were
exposed to and familiar with based on their relative association and proximity to trans and
gender diverse people and communities. While they still “felt like women”, some sexual
minority breast and/or gynecologic cancer patients aligned themselves with having an
alternative, non-normative experience of their gendered embodiment post-surgery. The “top
surgery” narrative of gender affirming care made available through the proximal knowledge of
gender affirming surgeries provided an alternate narrative to the standard narrative of
mastectomy and breast cancer that is centred around normative femininity (Jain, 2007a) and
processes of loss and reconstruction (Nielsen, 2018).

Holly (BA, 44, Jewish, Femme, Queer bisexual, breast cancer, BRCA1) described how
her bilateral mastectomy impacted her gender identity following surgery. For Holly, her
prioritized knowledge system was less about gender expression in terms of projecting a
normative femininity, and more about her awareness of the possibility that this change in
embodiment would impact her relationship to gender and the complex ways that her gender
identity is intertwined with her embodiment.
“Having breast cancer, I have had almost all of my biological female parts removed. I’m just at the beginning of thinking about what that means in terms of my identification as female.... I'm so lucky to be living in an area where some people choose not to have breasts and celebrate that. I can learn from them, right? I don't know what that will do to my identity in the long run.” Holly (BA, 44, Jewish, Femme, Queer bisexual, breast cancer, BRCA1)

Holly lives in an area where there is a large enough population to create a notable presence of trans and gender diverse people. She is also part of a generation of queers that is aware of and involved in issues and politics related to trans and gender diverse populations. Holly was able to conceptualize her post-treatment body as still recognizable in relationship to sexuality, desire, and gendered embodiment. While she took up a medical narrative to make sense of the surgical process of mastectomy, Holly was also informed by her knowledge of gender diverse people in her community and took up a non-normative narrative to interpret her post-surgical body.

2.3.5 Decision-Making, Incommensurable Knowledge Systems, and Care Experiences

Research suggests that the negative care experiences of sexual and/or gender minority patients are connected to fraught communication and relationships with their care providers (Boehmer et al., 2013; James et al., 2016; Russell, Galvin, Harper, & Clayman, 2016).

Cancer's Margins participants reported that their providers struggled to understand and accept their decision-making when it contravened normatively gendered expectations of embodiment. For example, participants reported that, when they arrived to the surgeon’s office
with a decision about mastectomy, their care providers struggled to accept their decisions and repeatedly questioned them—particularly in situations when patients desired prophylactic mastectomies or when they declined post-mastectomy breast reconstruction. The organization of cancer into gendered regimes shapes systems of care that limit the uptake of patient decision-making.

For Dario, the decision to have a bilateral mastectomy came easily to them because of a familiarity with diverse narratives related to gender and embodiment. Dario had a context for the surgery that they could use to undertake their decision-making options that was less traumatic than the cancer context.

“I had already decided I wanted a bilateral mastectomy. It was really immediate and strong for me. So I said that. And (my surgeon) he’s like, “Why would you do that?” And I’m like, “There’s a lot of women in my community who are transitioning. You know—having top surgery. I don’t see this as a bad option.” The way (my partner) blogged about it was, ‘You could just see his little mind peddling as fast as it could to try to keep up with what we were talking about, ‘cause he had no frigging idea.’ And I think we really unnerved him,” Dario (BA, 50, Latinx, genderqueer, queer, breast cancer)

Liwayway (BA, 50, Filipino/Aboriginal, genderqueer, trans, butch, Two-Spirit, ovarian cancer) also met with significant resistance when they considered a path of cancer treatment decision-making that didn’t neatly align with cisnormative structures of practice. Liwayway explored the possibility of prophylactic mastectomy, but found themselves engaged in an uncomfortable conversation with a care provider who not only failed to understand Liwayway’s cancer health decision-making around their embodiment, but who also completely
misunderstood the medical and hormonal aspect of their cancer treatment in terms of the relationship, or perhaps lack thereof, to gender affirming medical care.

“I talked to my doctor. “If it's spread to my breasts, take them off. Mastectomy.” I talked to the trans men, to see which doctor they go to to have their breasts removed... I'm a drag king. I play a lot of roles being a man. So I decided to be flat chested.” The doctor was accusing me of trying to get a free surgery to get my breasts removed.”

**Liwayway** (BA, 50, Filipino/Aboriginal, genderqueer, trans, butch, Two-Spirit, ovarian cancer)

*Cancer’s Margins* participants reported that their cancer care providers regularly underestimated the importance of gender for patients in terms of their relationships to the changes in embodiment that occurred over the course of cancer treatment.

John felt he had to make significant and specific effort to communicate with his cancer surgeon about his preferences for cancer surgery in order to work around his recent mastectomy and reconstruction related to his gender affirming care. He had to be “tactful” and try to give his input into how his body would look in a way that wouldn’t offend his providers or impact his quality of care. John was willing to undergo a different treatment protocol in order to coordinate his cancer care with his gender affirming care—specifically in order to retain his nipples that would give him a male appearing chest.

“By the time the lumpectomy came, I was really worried that they were going to mess up my (chest). I paid a lot of money, you know? (laugh) I went to a very expensive cosmetic surgeon... They wanted to take my nipples, and I said no. I'm like, “Yeah, sure I'll have extra radiation as long as I can keep my nipples.” I paid too much money for
you to just chop it off! Like, no. It was a bit of vanity, but also, because as a trans person, I'm so self aware of how I'm perceived and body image stuff... Keeping my nipples was important to me to maintain a chest that I would be able to go shirtless with.” John (ON, 33, Chinese-Canadian, trans man, queer, breast cancer)

Sexual and/or gender minority breast and/or gynecologic cancer patients consider cancer treatment and the potential to impact gendered embodiment using different systems of knowledge than their care providers. The assumed gender of the patient that breast and gynecologic cancer treatment systems are designed around is deployed as a one-size-fits-all model of gender (Klawiter, 2004), which has significant impact on patient-provider relationships and, relatedly, on patient experiences of care (Baker & Beagan, 2014; Grabinski et al., 2018).

This analysis adds specific evidence about the impact of cisnormative and heteronormative knowledge systems on patient-provider communication, and therefore the care and treatment experiences of sexual and/or gender minority patients.

2.3.6 Gender Marginalization: Denial of Care and Barriers to Support

Consistent with previous research (Sinding et al., 2004), while cisgender sexual minority women in this study reported that they didn’t experience widespread overt discrimination from care providers, they narrated their experiences with care as being negative or unsatisfactory. While none of the cisgender participants in this project reported being refused care by providers, trans and/or gender nonconforming participants often related that they experienced various forms of service refusal and that they were denied care or support. Some trans patients experienced outright denial of care when accessing cancer treatment.
“I showed up for my appointment and I was immediately told, ‘You are in the wrong place, sir.’” James (BC, 58, Caucasian, trans man, queer, cervical cancer)

The Canadian Lesbians and Breast Cancer project found that relationships between care providers and sexual minority patients related to homophobia and heterosexism contributed to the social “isolation and disconnection” (Sinding et al., 2006, p. 65) of sexual minority cancer patients. Consistent with previous literature on sexual minority women and support networks (Boehmer, 2015), Cancer's Margins’ cisgender LGBQ participants were notably more reliant on their partners and friends for support during treatment than family, when compared to heterosexual women with cancer. Cisgender LGBQ participants in this study relied primarily on partners for support during treatment, followed by friends, and then family members.

Trans and/or gender nonconforming patients have even less family/friend support than cisgender sexual minority breast and/or gynecologic cancer patients. Cancer's Margins findings reveal that trans and/or gender nonconforming cancer patients have an added challenge in cancer treatment in terms of accessing support from friends and family members (Taylor & Bryson, 2016). All of the trans and/or gender nonconforming participants who reported support noted that their support providers were current or former partners. In fact, some trans and/or gender nonconforming participants directly discussed and named instances where their family members were actually a source of additional stress during treatment.

“(With) my family, it was really hard. So, part of the decision to do the chemo was also like, it would have taken a lot more strength to refuse chemo than to do chemo. But I don’t really know whether it was the right decision in my case.” Dario (BA, 50, Latinx, genderqueer, queer, breast cancer)
Trans and other gender minority cancer patients experience inadequate cancer care that is both culturally unsafe and medically incompetent. Additionally, this analysis provides evidence of the negative impacts of cisnormative knowledge systems and how they create particular barriers and vulnerabilities for gender diverse cancer patients.

### 2.4 Conclusions

Where previous research has identified the relationship of heterocentrism to sexual minority women and their experiences of cancer care (Boehmer & Case, 2004; Fish, 2010; Sinding et al., 2004), this data analysis additionally contributes evidence that points to the elements of cisnormativity that are experienced by both sexual and gender minority cancer patients. This project brings a specific contribution to our understanding of sexual marginality and cancer decision-making by adding an analysis of gender identity, expression, and experiences of gender marginality. The findings presented here provide evidence that both sexual and gender minority cancer patients navigate health decision-making related to gender identity and rely on non-normative gender narratives.

Cancer, and its accompanying treatment, has profound effects on how patients feel about their bodies (Ellingson & Borofka, 2018; Parton, Ussher, & Perz, 2016), and sexual minority and gender minority populations already have an intersectionally complex relationship to sex, gender, sexuality, and expression and embodiment that compounds these effects (Braun et al., 2017; Rubin & Tanenbaum, 2011). Providers tend to assume normative relationships to gender and sexuality and aren’t prepared for the diversity of ways that sexual and/or gender minority people identify, express, and manage embodiment.
Access to culturally contextualized information and experience-based evidence and narratives is an important part of the decision-making process for patients making health decisions (Ziebland & Herxheimer, 2008). “Health literacy” (Hoffman-Goetz, Donelle, & Ahmed, 2014) and access to health knowledge (Mancuso, 2008; Ziebland & Herxheimer, 2008) are key aspects of patients’ ability to make informed decisions about health care generally, and cancer health specifically. Participants in this research consistently noted a need for culturally-specific knowledge and support for sexual and/or gender minority cancer patients to address the invisibility of non-normative narratives of sexuality and gender pervasive in the practices, protocols, and the institutional organization of cancer care.

Generational differences are evident in the narratives of sexuality and gender that are informing patient meaning-making and perspectives. Sexuality and gender need to be considered in cancer care as interdependent, but distinct social locations that shape how patients experience and narrate cancer care, treatment, and support.

The findings in this analysis challenge previously held notions of a “one size fits all” approach to cancer care and suggest that targeted and population-specific cancer care protocols, treatment, support, and information are indispensible to providing ethical and effective cancer care and support for sexual and/or gender minority patients.
Chapter 3: Trans and Gender Nonconforming People’s Access to Knowledge, Experiences of Cancer Health, and Decision-Making

3.1 Introduction

3.1.1 LGB/T Populations and Health Disparities

Marginal cultural locations, specifically in relation to sexuality and gender, have been associated with numerous general health disparities (Association of American Medical Colleges, 2014; J. P. Brown & Tracy, 2008; Case et al., 2004; Hatzenbuehler et al., 2014; Institute of Medicine, 2011; Lim, Brown, & Justin Kim, 2014; Mayer et al., 2008; Steele, Ross, Dobinson, Veldhuizen, & Tinmouth, 2009; Tjepkema, 2008). In particular, research regarding transgender (trans) and gender nonconforming people has identified that gender marginality is associated with health care avoidance overall (Bauer, Schein, Deutsch, & Massarella, 2014; Clark, Bonacore, Wright, Armstrong, & Rakowski, 2003; Harrison, Grant, & Herman, 2012). In research on cancer health and care, sexual and gender minority populations are locations for multiple “overlooked health disparities” (J. P. Brown & Tracy, 2008); diverse groups which have been left out of the most basic epidemiological cancer surveillance and other broad-based data collection carried out by national and international health agencies (Bowen & Boehmer, 2007; Cahill & Makadon, 2014; Deutsch et al., 2013; Reisner et al., 2015). Sexual and gender minority populations are underrepresented in health professional curricula (Association of American Medical Colleges, 2014; Obedin-Maliver et al., 2011), leaving care providers without sufficient

education and knowledge to provide relevant and appropriate care. Recent findings show that sexual minority cancer patients are 60% less likely than heterosexual cancer patients to rate their health as “good” (Jabson, Farmer, & Bowen, 2015), whereas sexual and gender minority cancer patients who are able to access cancer care in supportive environments are more likely to rate themselves higher in regard to their health (Kamen et al., 2015).

3.1.2 Cisgender Assumptions: Breast and Gynecologic Cancers as “Women’s Cancers”

Despite the by-now widely accepted assertion that gender and sexuality, while inter-related and inter-dependent, are separate aspects of health and well-being (Association of American Medical Colleges, 2014; Institute of Medicine, 2011), issues specific to gender minorities (Mayer et al., 2008; Reisner et al., 2015) have often been conflated with concerns specific to sexual marginality (Association of American Medical Colleges, 2014; Bauer et al., 2009; Reisner et al., 2015). As a result of this erroneous reduction of issues pertaining to gender marginality to those pertaining to sexual marginality, the specific health needs of trans and gender nonconforming people as “gender minorities” have been largely unaddressed in public health research—regarding both health and wellness generally, and cancer specifically (Mayer et al., 2008; Stroumsa, 2014; Watters et al., 2014).

The relatively small body of research in North America that addresses the experiences of sexual minority women and cancer health (Bowen, Boehmer, & Russo, 2007; J. P. Brown & Tracy, 2008; Rubin & Tanenbaum, 2011; Sinding et al., 2006) has provided evidence about cancer related health disparities (J. P. Brown & Tracy, 2008; Sinding et al., 2004, 2006). Sexual minority women are more likely to express dissatisfaction with cancer care provision (Fobair et al., 2001) and underutilize cancer screening (Matthews et al., 2013; Matthews, Brandenburg,
Johnson, & Hughes, 2004; McElroy, Wintemberg, & Williams, 2015). Research on sexual minority women and decision-making about cancer treatment and care has found significant effects of sexual marginality on these women’s experiences of cancer and how they make decisions about cancer treatment and surgery (Boehmer et al., 2007; Dhami, 2011; Rubin & Tanenbaum, 2011). Sexual minority women’s breast cancer decision-making has been found to be undergirded by body image and value matters that are directly influenced by their marginalized sexual identity (Boehmer et al., 2007; Rubin & Tanenbaum, 2011). Research on sexual minority women and cancer to-date has focused almost exclusively on the experiences of cisgender lesbians.

Non-normative relationships with femininity and categories of womanhood and gender performance have been reported to significantly affect how sexual minority women experience and make sense of cancer (Boehmer et al., 2007; Sinding et al., 2006) but work in the area of cancer and sexuality and gender tends to assume cisgender embodiment, identity, and expression. There are no studies available to-date that specifically address trans and gender nonconforming people’s experiences of cancer health generally, and treatment specifically (Lombardi, 2001; Watters et al., 2014). The significance of non-normative gender identity and expression relative to knowledge and practices pertinent to experiences of cancer health and treatment is an underdeveloped area of research.

3.1.3 Trans Cancer and the Cancer Research Landscape

Gender marginality has significant impacts on overall experiences of health and care (Alleyn & Jones, 2010; Bauer et al., 2009; Ellis et al., 2015; Grant et al., 2011; Harrison et al., 2012). However, trans and gender nonconforming people have been overlooked consistently in
the research on cancer health and care (Bare et al., 2014; Watters et al., 2014). To address this gap, the *Cancer’s Margins* project ([www.lgbtcancer.ca](http://www.lgbtcancer.ca)) critically examines binary constructions of sex and gender that are reified in the biomedical classification of certain cancers—breast cervical, ovarian, uterine, vaginal, and vulvar—as “women’s cancers” (King, 2006; Sulik, 2011). This research seeks to add a perspective informed by models of intersectional, gender-based health disparities and report herein on trans and gender nonconforming patients’ cancer care and treatment experiences.

As yet, there are no population-based epidemiological data that chart cancer prevalence or outcomes for trans and gender nonconforming populations (Agénor, 2015). A recent research review (Watters et al., 2014) reports a count of 23 research articles dealing with trans people and cancer care published between 1968 and 2012. Typically, these are reports of case studies that attempt to extrapolate suggestions about practices and protocols regarding cancer health for trans populations (Watters et al., 2014)—often recommending guidelines for screening protocols and/or increased attention to cultural competency (Bauer et al., 2015; G. R. Brown, 2015; Dhand & Dhaliwal, 2010; Dutton et al., 2008; Lombardi & Banik, 2015; Pattison & McLaren, 2013; Peitzmeier, Khullar, et al., 2014; Urban et al., 2011).

Some case studies suggest there may be a possibility that hormones provided as part of gender affirming care increase cancer risks (Alhabshi, Ismail, & Arasaratnam, 2011; Asscheman et al., 2011; Bentz et al., 2010; Dizon, Tejada-Berges, Koelliker, Steinhoff, & Granai, 2006; Hage, Dekker, Karim, Verheijen, & Bloemena, 2000; Moore et al., 2003; Mueller & Gooren, 2008; Pattison & McLaren, 2013; Shao, Grossbard, & Klein, 2011; Yoshitomo et al., 2015). In contrast, larger cohort, long-term follow up studies suggest that administration of hormone treatments does not significantly affect overall cancer mortality (G. R. Brown & Jones, 2015;
Wierckx et al., 2012), and that some hormonal regimens may in fact have protective factors in relation to cancer risk (Asscheman et al., 2011; Gooren et al., 2008, 2013). Recent studies of trans and gender nonconforming populations and cancer health report underutilization of cancer screening (Peitzmeier, Khullar, et al., 2014) and delays in accessing follow up care (Peitzmeier, Khullar, et al., 2014; Peitzmeier, Reisner, et al., 2014). However, none of the available research articles on trans and gender nonconforming cancer care address gender marginality and patients’ experiences of cancer health and treatment. This research directly addresses this gap in knowledge by means of the documentation and analysis of experiential accounts of trans and gender nonconforming people treated for cancer.

3.1.4 Trans Cancer?: Biographical Compliance and Narration, Knowing, and Knowledge

Approaches to scholarship regarding trans and gender nonconforming populations tend to treat gender identity and expression as individualized aspects of selfhood (Heyes, 2003). The theoretical model for Cancer’s Margins (Bryson & Stacey, 2013; Heyes, 2003) is informed by qualitative, ethnomethodological accounts of the production and management of categories of selfhood and of populations; accounts that, genealogically, track and describe biopolitical discourses concerning minority identities and groups and relatedly, of health disparities within and across populations (Foucault, 1975, 1978). In these accounts, both “cancer” and “trans” are constituted by means of knowledge and practices wherein people and places and practices produce narratives relative to a set of biographical norms that shape gendered modes of knowing and of embodiment (Bryson & Stacey, 2013).
Studies of trans and gender nonconforming health and “cultural competency” typically produce inventories of individual harms, thereby obscuring socially located cultures and ideologies that shape experience (Kumas-Tan, Beagan, Loppie, MacLeod, & Frank, 2007). In this mode of analysis, then, it is perhaps unavoidable that the very terms by which participants are discursively constituted as trans and/or gender nonconforming, are the same terms by which the limitations of gender may be reinscribed as a social construction that constitutes the recognition and pathologization of gender nonconformity. This research proceeds with the goals not only of furthering equality and rights for trans and gender nonconforming people by means of the documentation of modes of systemic or institutional harms, but deploys, in addition, political practices of “feminism under a banner of freedom” (Zerilli, 2004) that seek to inscribe new understandings and knowledge relative to gendered practices of self knowledge, embodiment and expression (Zerilli, 2004).

3.2 Methodology

3.2.1 Doing and Knowing: The Social Study of Medicine (SSM) and Experience

*Cancer’s Margins* is informed by the Social Study of Medicine (SSM)—a research approach which proceeds by means of the documentation and archiving of the various signs and practices that together, make up medical systems where “conceptions of diagnosis, origin, and social effects of a disease differ” (Patton, 2007, p. 341). Tracing the genealogical movements of knowledge—how it is accessed, used, mobilized—can help to create a public archive that documents and analyzes how it is that cancer is “done”. This analysis of cancer as “performative” focuses on cancer as a collection of knowledge practices by trans and gender nonconforming people and seeks to describe how it is that gender marginality functions as a very
specific (albeit intersectional) location within which people encounter, resist, and author cancer health and treatment experiences and knowledge practices.

Feminists have repeatedly emphasized that where experience has been used as an authentic source of knowledge, it fails to account for the historical and cultural roots of that experience (Rice, Chandler, Harrison, Liddiard, & Ferrari, 2015; Scott, 1991). One must look “behind and beyond” (Mason, 2002) accounts of experience to understand the way in which the body in that specific space is being constructed, and how the phenomena has come to be known to be related to that body, discursively (Scott, 1991). The SSM can assist in the design of a methodology that can simultaneously take into account the production of the marginalized trans and gender nonconforming body, as well as the disease of cancer (Epstein, 2007a; Foucault, 1975; Mol, 2002), and the production of gendered bodies through the diagnosis and treatment of breast and gynecologic cancers.

A SSM informed approach to methodology takes up participants’ narratives as discursive artifacts that are positional—as partial and situated narratives located within fields of cancer knowledge characterized by Klawiter as “disease regimes” (Klawiter, 2004). Fields of cancer knowledge construed as “disease regimes” can be examined so as, (a) to document and examine the institutionalized practices, authoritative discourses, and social relations that produce the categories of “gender minorities” and “cancer patients” and, (b) to identify and question the mechanisms through which cancer treatment simultaneously produces cancer patients and disciplines their bodies in relation to gender discourses.
3.2.2 Logic of Participant Inclusion

Sampling for Cancer’s Margins was informed by previous Canadian research with gender minority patients (Bauer, 2012) and also, the World Professional Association for Transgender Health’s (WPATH) Standards of Care (SOC), which provide comprehensive guidelines for maximizing the health and wellbeing of trans and gender nonconforming people (Coleman et al., 2012). The SOC recognize that “the distress of gender dysphoria” is not a defining characteristic of this population, but rather “the extent to which a person’s gender identity, role, or expression differs from the cultural norms prescribed for people of a particular sex” (Coleman et al., 2012, p. 168).

Participants in the Cancer’s Margins project who had been treated for breast and/or gynecologic cancer (n=68) were interviewed in 5 Canadian provinces (British Columbia, Manitoba, Ontario, Quebec, Nova Scotia)—in addition to pilot interviews (n=15), which were conducted with patients in San Francisco Bay area. Canadian interviews were conducted in both French and English. Sampling was designed to articulate a diverse sample of participants in relation to age, race and ethnicity, socio-economic status, dis/ability, gender identity and expression, and sexual identity. This study purposively used non-random methods of sampling, such as snowball sampling, to recruit a diverse group of participants from “hard-to-reach” populations (Faugier & Sargeant, 1997).

This article reports findings from the Cancer’s Margins patient interviews with trans and gender nonconforming interview participants diagnosed with breast and/or gynecologic cancer (n=10). Participants self-identified as trans or gender nonconforming in response to questions in the interview protocol designed to elicit information relative to their felt sense of gender identity, role, and/or expression (defined in WPATH SOC) (Coleman et al., 2012). This sample includes a
diverse group of participants whose gender self-identifications include: transgender, trans, genderqueer, Two-Spirit, transsexual, and many other descriptors. Participants had a wide variety of words and descriptions that they used to convey information about their sexual and gender identities and expressions (Table 3.1). Participants whose interviews are reported here, were all assigned female at birth and were all treated for breast and/or gynecologic cancer. This sampling of trans and gender nonconforming participants ranged in age from 33–64.
<table>
<thead>
<tr>
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<th>Dana</th>
<th>Liwayway</th>
<th>Dario</th>
<th>James</th>
<th>Jake</th>
<th>Blake</th>
<th>John</th>
<th>Jolene</th>
<th>Logan</th>
<th>Max</th>
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<td>Cervical cancer</td>
<td>Ovarian cancer</td>
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<td>Caucasian</td>
<td>Caucasian</td>
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<td>Caucasian</td>
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<td>French Canadian</td>
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<td>Genderqueer, trans, Two-Spirit, butch</td>
<td>Genderqueer</td>
<td>Trans man, trans male</td>
<td>Butch, gender non-conforming</td>
<td>Female-to-Male</td>
<td>Female-to-Male</td>
<td>Gender fluid, transgender</td>
<td>Trans man</td>
<td>Trans man</td>
</tr>
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<td>Queer</td>
<td>Queer</td>
<td>Attracted to gay men</td>
<td>Butch dyke</td>
<td>Married to cis-lesbian</td>
<td>Queer</td>
<td>Queer, dyke</td>
<td>Queer</td>
<td>Attracted to women</td>
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<td>X</td>
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<td></td>
<td>Chemo therapy</td>
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<td></td>
<td>Hormone therapy</td>
<td>X</td>
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<td>Bilateral</td>
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<td>Bilateral</td>
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<td>Lumpectomy</td>
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<td></td>
<td>Hysterectomy</td>
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<td>X</td>
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<tr>
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<td></td>
<td></td>
<td>X</td>
<td>Testosterone</td>
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<td>X</td>
<td>X</td>
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<td>Genital surgery or reconstruction</td>
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<td>X</td>
<td>Hysterectomy</td>
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Table 3.1 Participant demographic table
3.2.3 **Data Collection**

Approval for the study protocol was obtained from the University of British Columbia Behavioural Research Ethics Board. Eligible participants were interviewed according to an approved interview protocol and each were informed about the project and provided their written informed consent to participate. *Cancer’s Margins* interview protocol focuses on participants’ felt sense of self, experiences of treatment for breast and/or gynecologic cancer, cancer health decision-making and access to support networks, as well as access to knowledge regarding cancer care and gender affirming care. The interview protocol includes demographic questions and open-ended questions designed to elicit detailed information that follows a trajectory of cancer health and care, from diagnosis, to treatment, and follow up care. Interviews were conducted in a place convenient to the participant, often in their homes, and were digitally recorded and transcribed. All identifying information has been anonymized and pseudonyms have been used to respect participant privacy.

3.2.4 **Data Analysis**

This qualitative data analysis focuses on articulations of knowledge and knowledge practices narrativized by trans and gender nonconforming people concerning gender affirming care and experiences of cancer health and treatment. The interview transcript data were thematically coded and analyzed with a specific focus on identifying instances and sites of: (i) knowledge-seeking, (ii) knowledge acquisition, (iii) knowledge mobility, (iv) information used to inform cancer health and treatment decision-making, (v) access to peer networks and other modes of support. This thematic analysis prioritizes the production of an account of what trans
and gender nonconforming cancer patients actually “did”—the “doing cancer” (Mol, 2002) and “doing gender” (Schilt & Westbrook, 2009) reported by Cancer’s Margins participants.

3.3 Findings

3.3.1 Cancer Surgeries Experienced as Practices of Gender Affirming Care

While not all trans and gender nonconforming people undergo surgery as part of gender affirming healthcare, all interviewees diagnosed with breast or gynecologic cancer underwent some type of surgical treatment as part of cancer care. Breast and/or gynecologic cancer treatment surgeries such as total or subtotal hysterectomy and/or bilateral mastectomy, are often the very same procedures undertaken by some trans and gender nonconforming people as part of gender affirming care. It is notable that these surgeries are typically performed in two completely different contexts of care—as part of cancer treatment and in a very different context, as part of gender affirming care. Yet, interviewees described a very high level of awareness that, in the very particular context constituted by being a trans or gender nonconforming cancer patient, the overlap for these interviewees of the embodied experience of these forms of surgical intervention was both palpable as well as appreciated as highly significant. This overlap constitutes an aspect of cancer treatment decision-making that appears to be completely unknown to cancer healthcare treatment providers.

A bilateral mastectomy carried out as part of a treatment plan for breast cancer was likely to be experienced by trans and gender nonconforming participants in this study, as also constitutive of “top surgery”—which is to say, as constitutive of a doubled meaning for these participants for whom cancer surgery also embodies and becomes surgery carried out as a practice of gender affirming care.
Blake was well aware of the intersection of cancer treatment and gender affirming care and interpreted his cancer surgery as an opportunity to avail himself of this treatment reconfigured as gender affirming surgery. Blake interpreted the surgical intervention of hysterectomy as an action that was relative to ‘doing gender’ as opposed to ‘doing cancer’ and found the overlap in treatment surgeries to be a welcome occurrence. The differences in gendered embodiment and sense of self that Blake could envision as effects of his cancer treatment were, then, related by him as welcome changes; as changes in embodiment that appeared to be more important to Blake than the probability that this surgery would reveal a diagnosis of ovarian cancer.

“To me, it was all positive. So, in that sense, although I was told, 'There's a possibility of cancer here'—that's not what I heard. What I heard was, I get a free hysterectomy.” Blake (BC, 57, Caucasian, trans man, ovarian cancer)

There are significant differences in how the process of decision-making for surgery is carried out relative to the context of cancer care versus the context of gender affirming surgery. When Jolene’s bilateral mastectomy was performed in the context of cancer treatment, options for the specific technical aspects of the surgery, such as the options for chest contouring, or the reconstruction of a chest with nipples, were not discussed or offered to Jolene—options that, in Jolene’s retrospect, may have been appropriate options for reconstruction; options more consistent with their gender identity.

Participants’ narratives emphasized how consistently cancer surgery directly impacted their felt sense of gender identity, to the extent that they commonly saw their post-mastectomy body as constitutive of a radically altered embodiment of gender. While Jolene had identified as
a butch dyke for many years, after breast cancer surgery (bilateral mastectomy) Jolene felt their body as trans. Jolene noted that this transformation “delighted” them and that their newly fluid sense of embodied gender seemed, following the mastectomy, to have shifted towards a more consistently male presentation; a felt sense of gender expression of freedom in their body that had not been available before cancer.

“I see me as fluid in my gender... Starting to identify myself as trans was more recent and it certainly was around having both breasts removed. Because when that happened, I realized how free I felt, suddenly, from being seen only as female and how delighted I was to be seen more as male and to feel more of that male embodiment...

That's why I suddenly felt like 'Wow.' When I finally got rid of them, I felt like I had freedom in a way that I hadn't felt since I was eleven years old, just before I hit puberty, which was just great... If I had to go back in now, if I wanted reconstructive surgery, it would be to have a guy's chest, with nipples.” Jolene (ON, 59, Caucasian, genderfluid, transgender, breast cancer)

For some gender nonconforming participants, the widely available perception of the overlap of cancer surgery (e.g., bilateral mastectomy) and gender affirming surgery (e.g. top surgery) made decision-making concerning the mastectomy extraordinarily fraught. For example, uppermost in Jake’s mind was the problem posed by the fact that a prophylactic mastectomy recommended as part of cancer health care following a diagnosis as a BRCA1 carrier would actually function in such a way as, unintentionally, to intensify her felt sense of masculinity and in so doing, to impose a more normatively coherent gendered body. Jake was troubled, in her cancer health decision-making, by her perception that a prophylactic mastectomy
might impact not only her felt sense of gender nonconformity, but also, the complex ways that she relates to the world as a gender nonconforming person. Jake would rather take on the genetic risks of breast cancer as a BRCA1 carrier than the risk that mastectomy surgery would erase her felt sense of gender nonconformity.

“I feel like I would almost become (trans) by default, if I had a mastectomy... I feel like if I do that I will have bought into a binary gender system.... It comes down to some kind of gender identity thing... I don't feel like the word woman fits on me—I'm not super attached to that... I get seen as a man 90% of the time. I don't know if I want to feed into that and give people that out—that I'm just a guy. I like that who I am makes people think and sometimes be uncomfortable. I think there's a value in that. And I am hesitant to give that up.” Jake (BC, 53, Caucasian, butch dyke, ovarian cancer)

3.3.2 “Women’s Cancers” and the Experiences of Trans and Gender Nonconforming Cancer Patients

The common designation of breast and/or gynecologic cancers as “women’s cancers” (Klawiter, 2004), and relatedly, the ways that this designation is taken up by and mobilized by cancer treatment contexts, influenced many of the ways that trans and gender nonconforming people experienced their cancer health and care generally, and their identity as cancer patients more specifically. For trans and gender nonconforming cancer patients, the normatively restricted gendering of cancer patient care environments can cause a significant amount of distress in an already challenging period of cancer treatment.

Participants reported that they were highly aware of binary and essentialized discourses of gender as these shape the organization of cancer treatment, and that they undertook specific
actions and behaviors in order to access services by mobilizing and practicing gendered practices and modes of comportment that would locate them as “in the right place”. James knew that he needed to mark himself as “woman” in some recognizable way in order to receive treatment for his “women’s cancer”. When a clinic that provides breast or gynecologic cancer health services is de facto branded and designed as a “women’s clinic”, the treatment environment is not set up for trans and gender nonconforming patients, nor are they welcoming. The trans and gender nonconforming patients interviewed talked about being asked to leave a treatment space or waiting room.

“I showed up for my appointment and I was immediately told I was ‘in the wrong place, sir’. I had my leather jacket on; I rode a motorcycle in those days. I had my leather jacket and my jeans, and I just opened my jacket and pulled up my shirt. I had no words. I just said, ‘I’m in the right place.’” James (BC, 58, Caucasian, trans man, cervical cancer)

Being unwelcome in clinic waiting rooms was an experience echoed by numerous participants. John described being asked to leave the treatment area by staff and Max recalls feeling uncomfortable interacting with the other patients in the waiting area.

“They told me that I had to wait in the hall, but my girlfriend could sit in the waiting room... ‘Well, you should wait outside and she can come in’... I wish I could have said, “No, I am a patient here. I also lived the first twenty-five years of my life as a woman. I would like to sit in the waiting room.” But I didn't want to make a scene at the time... It didn't come together until afterwards... We are talking about patient care in a
“They call it the pavilion of women. So when I get there, I’m a man in the
women’s pavilion. While I was waiting for the operation, there were two women with me
asking “Are you having an operation”? I didn’t feel like explaining.” Max (QC, 54,
French Canadian, trans man, breast cancer)

Jake described her experience of being a gender nonconforming person in a waiting room
as one of feeling unwelcome and Max describes his discomfort in the gendered clinic. Jake
responded to the sense of being unwelcome by attempting to “be as invisible as possible” and
darting quickly into the consultation room with the surgeon to avoid being in the waiting room—
which resulted in her partner being left in the waiting room when she had accompanied Jake to
the appointment with the intent of being present to support Jake during the surgical consultation.
This gives a direct example of how the cisnormative organization of cancer care into gendered
notions such as “women’s cancers” structures environments in which trans and gender
nonconforming cancer patients struggle to access care and support.

“(My partner) came with me, and when they called out my name, she had
intended to go with me. But I just shot in there so fast. I try to be as invisible as possible
in those kinds of settings, because I don't feel welcome there. I just jumped up and ran in
to see the surgeon. I was in the room with the door closed before she even realized what
had happened.” Jake (BC, 53, Caucasian, butch dyke, ovarian cancer)
3.3.3 Trans Cancer Care as Disorienting, Uncoordinated Bodies of Knowledge

Trans and gender nonconforming people experience cancer care as disorienting and uncoordinated with their gender affirming care. Gender affirming care (e.g. hormone therapy or surgery) is often uncoordinated with cancer care needs (e.g. hormone-related cancers or surgical reconstruction). Trans and gender nonconforming breast and gynaecologic cancer patients report that their cancer care providers are not able to offer options for cancer care that are simultaneously informed by gender affirming care and practices.

“I'd also like to see surgeons who would respect your chest reconstruction, so they would ask. Instead of saying 'You want breasts put in? Implants?', they would say, “Do you want breast implants or do you want to look like a guy's chest?' Surgeons would ask that automatically, instead of me just having to take what I got.” Jolene (ON, 59, Caucasian, genderfluid, transgender, breast cancer)

For participants in this study, the uncoordinated quality of the bodies of knowledge relative to gender affirming treatments and cancer health made it difficult for them to make informed decisions about whether or not to begin or to continue hormone gender affirming treatments. The lack in availability of evidence-based knowledge relative to the intersection of cancer care and gender affirming care makes it difficult for trans and gender nonconforming cancer patients to make informed decisions about both cancer health and gender affirming care.

“I've totally, totally considered (taking hormones). But, (my partner's) approach is: 'Prove to me that taking testosterone will not give you cancer.' It's very hard. The jury's out on that. So, I haven't done it.” Blake (BC, 57, Caucasian, trans man, ovarian cancer)
“Could I even begin my transition or was it a hormonally-based cancer?... It was, ‘Well, we don’t know.’ I just kept running into that again and again.” James (BC, 58, Caucasian, trans man, cervical cancer)

The systems of knowledge that inform cancer care and trans care are not linked and health care providers working within these particular systems of care appear not to share or coordinate knowledge and practice information. Cancer care providers are unable to inform trans and gender nonconforming patients about how their cancer care might be impacted by gender affirming hormone treatment, and gender affirming care providers are unable to inform patients about how their cancer health treatments might impact their gender affirming care, and in particular, future options for gender affirming surgery.

“If I hadn't had cancer, I would have gotten the fully functioning model of the phalloplasty. But because of the radiated tissues, I had to take that into consideration for my surgical choices.” James (BC, 58, Caucasian, trans man, cervical cancer)

3.3.4 Online Knowledge-Seeking

One of the striking aspects of the knowledge-seeking behaviours of trans and gender nonconforming people in this study was the notable divide in the availability of online health-related knowledge. Participants reported extensive knowledge-seeking, research, and online engagement.
“I did research... I got online. I went to the library. And I talked to a lot of cancer survivors.” Liwayway (BA, 50, Native American, Filipino, Two-Spirit, genderqueer, trans, butch, ovarian cancer and uterine cancer)

“It didn't mean anything to me at the time. That's when research kicked in... That's when I went on the internet.. Everybody was saying 'Your choice, what do you want to do?'... So, I did a lot of research.” Blake (BC, 57, Caucasian, trans man, ovarian cancer)

However, participants also reported extraordinary gaps in terms of the availability of cancer health knowledge in relation to support websites tailored for trans and gender nonconforming cancer patients. While numerous participants reported consulting the internet for information, very few were able to find information that they felt was helpful to them in terms of informing their cancer care, and no participants reported finding any information specific to trans or gender nonconforming cancer patients and their support networks.

“There’s certainly no trans stuff—not even online—that I could find or that was what I needed.” John (ON, 33, Asian-Canadian, trans man, breast cancer)

Some participants reported finding more general cancer resources online that they felt were useful and these resources came in the form of either, a) access to medical research—highlighting the need for accessible information and research on trans populations and cancer, or b) in the form of interpersonal connections with other cancer patients—highlighting the need for further engagement of peer experience and connections with other sexual and gender minorities.
Indeed, knowledge-seeking performed an emotional support role for a number of patients who were seeking cancer health information online.

“Ultimately, what I wanted to know was unknowable. I wanted to know if I was going to live or if I was going to die of this… I wanted to know that I was going to be okay, and I wanted enough real facts, not bullshit, that would tell me that. And so I'm looking for it.” Dario (BA, 50, Latinx, genderqueer, breast cancer)

“I remember going to the library and pouring through it, and just completely in my own little horrified world… But that was a way for me to cope too, and take some control.” James (BC, 58, Caucasian, trans man, cervical cancer)

3.3.5 Peer Support Groups and Erasure

Participants in this project reported that peer networking was a primary source of cancer health information relevant to them as a trans or gender nonconforming person—these networks functioned both as support networks and as knowledge networks to inform decision-making. While peer networks are a key source of information for trans and gender nonconforming people, peer cancer networks are often structured by canonical deployments of sex, sexuality, and gender, which structure the systemic invisibility and erasure of trans and gender nonconforming cancer patients.

Blake chose to access an ovarian cancer support group, and reported discomfort and a sense of inauthenticity as a result of this engagement, but felt it would be his only choice to access peer support since Blake was well aware that there was an extremely limited likelihood that he would be able to access a relevant gender affirming cancer support group.
“I very much had that sense of being in this—stealth. Here am I with these people who have given me the big group hug here. As if we’re all ‘women’… I felt inauthentic… I'm thinking, ‘OK, I'm here because there isn't going to be any trans ovarian cancer group, is there?’” **Blake** (BC, 57, Caucasian, trans man, ovarian cancer)

John attempted to access a support group and made extensive efforts to find someone at the cancer peer support program who would be a good match for him. He attempted various avenues of fit with institutional deployments of sexuality and gender, asking questions about their record taking and trying to navigate the available information in order to find a peer support that was helpful to him. Despite his efforts, John was ultimately unable to find a relevant peer support person. The peer support program was able to make some recommendations for support based on sexual marginality, but the institutional knowledge divides left them unprepared to support trans and gender nonconforming cancer patients.

“I did access their peer support program—I tried. I said ‘Can you look, can you key word search for FTM or trans, anybody trans?’ They're like ‘No, we can't. Nothing came up. Do you want a lesbian or do you want a gay?’ I said, /I don't want to talk to a lesbian. That's a different thing. And I don't want to talk to a gay man.’ And they ask, ‘Well, do you want a man or a woman?’ So, you have to choose all these things and none of them fit. It was so uncomfortable… there’s the lesbian group, and the gay group but I didn’t really feel like I fit into any of those.” **John** (ON, 33, Asian-Canadian, trans man, breast cancer)
3.3.6 Intersectionality and the Cancer Treatment Experiences of Trans and Gender Nonconforming People

Race, ethnicity, socio-economic status, age, dis/ability, sexuality, and gender are intersectional and interrelated axes of complex identities and histories; intersectional identities and histories that shape the breast and gynaecologic cancer treatment experiences of trans and gender nonconforming people. Trans and gender nonconforming breast and gynaecologic cancer patients report complex political knowledge about their intersectional social locations.

“*My politics around lots of things, not just gender and sexuality certainly includes an understanding of privilege and oppression that's wrapped up in things like indigenous sovereignty... privilege around class and race... understandings about different types of ableism... and things around poverty and charity... around drug use and discrimination around different mental health stuff.*” John (ON, 33, Asian-Canadian, trans man, breast cancer)

While trans and gender nonconforming cancer patients report very complex intersectional analyses, they also report that they have difficulty determining how it is that each of their multiple social locations shapes their experiences of breast and gynaecologic cancer care and support. For instance, trans and gender nonconforming cancer patients who were people of color or people with disabilities were unsure how their experiences of breast and gynaecologic cancer were shaped by particular elements of their social location (e.g., sexual marginality, gender marginality, race, ethnicity, or dis/ability).

Dario chose to attend appointments and create a rapport with their oncologist without their partner present, detailing the specific strategies that they employed in their attempts to
remove intersectional layers of complexity that were shaping how they were interpreted and interacted with by the oncologist. By removing the presence of their partner in future appointments, they were attempting to alleviate the influences of compounding intersectionalities that were influencing these interactions by removing a visible element of sexual marginality and racialization—in this case, their queer partner who was also a person of color.

“I think it’s layers of invisibility... It felt like we were these radical lesbians of colour. I don't even know if that's how they read us or not. That really wasn't where we were coming from, but that's how we felt like we were being treated... After that I didn't let my partner come to my appointments anymore.” **Dario** (BA, 50, Latinx, genderqueer, breast cancer)

Simplistic assumptions and constructions of social locations or identities or groups leads to the erasure of important parts of trans and gender nonconforming cancer patients’ lives.

“The white woman was treated better than me... I didn't know if it was because of the colour of my skin. My suspicion is because of how I look: being masculine, being queer... If you had to send a Native ambassador—why didn't you send me? They said they didn't think about it—all they thought is that I was gay. So, I said, ‘Are you trying to tell me I'm a white woman? Just because I'm gay, you put me in the category of white... But, I'm not just one thing’... All the boxes, right?” **Liwayway** (BA, 50, Native American, Filipino, Two-Spirit, genderqueer, trans, butch, ovarian cancer and uterine cancer)
3.4 Discussion

This study contributes new understandings about gender minority populations that advances knowledge concerning the provision of culturally appropriate care. This is the first study of that focuses specifically on trans and gender nonconforming peoples’ experiences of cancer care and treatment, support networks, and access to and mobilization of knowledge. The findings reported here support the assertion that cisgender models concerning changes to the body that occur as a result of biomedical treatment for breast and/or gynecologic cancer are wholly inadequate in order to account for trans and gender nonconforming peoples’ experiences of cancer health and treatments, and related knowledge and decision-making. A common thread in the narratives of trans and gender nonconforming cancer patients’ accounts of health and care was that treatments for breast and/or gynecologic cancer had significant and persistent long term impacts on gender identity and expression. The overlap of breast and gynecologic cancer treatment surgeries (e.g. mastectomy) and gender affirming healthcare surgeries (e.g. top surgery) is very significant for trans and gender nonconforming cancer patients. This overlap represents an unanticipated aspect of current cancer health treatment protocols.

*Cancer’s Margins* interviewees reported significant differences in the types of knowledge that inform cancer health, and the types of knowledge that trans and gender nonconforming patients have about their felt sense of self, gender expression, and embodiment. Cancer treatment and cancer peer support environments are often structured by normative deployments of sex, sexuality, and gender. Thus, cancer treatment and support environments are not only inadequate to treat and support trans and gender nonconforming cancer patients, but also contribute to structuring the systemic invisibility and erasure of trans and gender nonconforming cancer patients. Participants reported significant gaps in the availability of gender affirming cancer
health knowledge. While some participants were able to access gender affirming care, their
cancer health services provision, typically, was utterly uncoordinated with their access to gender
affirming health service provision.

Cancer’s Margins project findings reported here suggest that models of culturally
competent provision of cancer care do not take into account the biopolitical constraints that
operate to produce the trans cancer patient as a knowing subject. In fact, models of culturally
competent care may operate in order to obscure discursive disease regimes (Kumas-Tan et al.,
2007) that shape cancer knowledge and care for trans and gender nonconforming people. Models
of culturally competent care risk obscuring the complex relationality that treats gender as “a web
of relations in ongoing tension and negotiation” (Heyes, 2007, p. 1112). Where cancer care
provision for breast and/or gynecologic cancers relies on biomedical discourses that organise
these disease regimes as “women’s cancers”, then care provision tends to produce and to regulate
cisgender modes of embodiment which cannot account for trans and gender nonconforming
people’s felt sense of gender identity or expression and relatedly, knowledge about the self and
the body.

3.5 Conclusion

Cancer’s Margins’ research represents an original and important contribution to advance
knowledge at the intersection of trans and gender nonconforming people and cancer health.
However, the data reported here represents a small sample. More research is needed to document
and analyze the overlap in embodied experiences of trans and gender nonconforming health care
and cancer health care. This analysis reports on various experiences of gender marginality and
cancer care. Participants were keenly aware of and reported complex relationships to various
intersectional social locations of age, race and ethnicity, dis/ability, gender, and sexuality.

Research into the specific experiences of subgroups of trans and gender nonconforming people by gender, age, race and ethnicity, or sexuality may provide further knowledge relevant to build population-based models of cancer health and treatment that reflect the diversity of trans and gender nonconforming people.
Chapter 4: Access to Knowledge and Its Mobilization by LGBQ/T Cancer Patients

4.1 Introduction

The design of culturally competent and medically effective cancer treatment and care is dependent upon understanding both sexual diversity and gender diversity as key elements of the body of knowledge that shapes minority population health. Research has revealed a number of cancer health disparities for members of sexual and/or gender minority populations, including: avoidance of cancer screening, longer time between follow-up appointments, less screening reliability, issue with service provision and refusal, poor healthcare provider communication, and lower self-rated health (Boehmer et al., 2013; Burkhalter et al., 2016; Jabson et al., 2015; Peitzmeier, Reisner, et al., 2014; Tabaac, Sutter, Wall, & Baker, 2018; Taylor & Bryson, 2016). Recently, there have been calls in the field of oncology for better information about the cancer health experiences of gender and sexual minority populations (Burkhalter et al., 2016; Griggs et al., 2017). Critical perspectives on breast and gynecologic cancer and the organization of health care and knowledge have also prioritized a reorganization and rebranding of these cancers so as to move away from the problematic and reductive categorical representation of these cancers as “women’s cancers” (Jain, 2007a; Klawiter, 2004; Sulik, 2011; Taylor & Bryson, 2016).

Recently, the American Society of Clinical Oncology released a position statement outlining the importance of addressing cancer health disparities and the suboptimal care that

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sexual and/or gender minority patients experience across the cancer trajectory (Griggs et al., 2017). While many cancer care providers have supportive attitudes towards sexual and/or gender minority populations, they lack training and knowledge about the unique health needs of LGBQ/T populations. A recent survey of cancer care providers found that only 47% of cancer specialists assessed themselves as being well-informed on LGBQ/T health (Tamargo et al., 2017). Additionally, less than half of cancer specialists correctly answered questions about specific LGBQ/T cancer health needs and disparities, including: quality of life and sexual activity, differences in cancer risk profiles, and disclosure and health outcomes (Tamargo et al., 2017).

Medical education and training for working with sexual and gender minority populations is woefully inadequate (Banerjee, Walters, Staley, Alexander, & Parker, 2018; Obedin-Maliver et al., 2011), and results in cancer care providers who are not prepared to treat a wide diversity of sexual and gender minority patients (Tamargo et al., 2017). The importance of sexual and gender minority health knowledge among health providers cannot be underestimated as qualitative research has shown that increased LGBQ/T health knowledge is directly associated with increased willingness and capacity to provide culturally competent cancer care (Banerjee et al., 2018). However, the inclusion of sexual and gender diversity in cancer treatment and related knowledge-seeking and health communication and decision-making remains a profoundly understudied area of research (Burkhalter et al., 2016; Watters et al., 2014).

The advent of easily accessible cancer health information online has changed the ways that patients make decisions about their health (Ziebland & Herxheimer, 2008). However, claims of the positive contributions made to consumer health knowledge by online access have been curtailed by extensive evidence of knowledge-access divides (e.g. Bryson & Stacey, 2013;
Jabson, Patterson, & Kamen, 2017; Newman, Biedrzycki, & Baum, 2012; Orgad, 2006) that are linked to the lack of “structural competency” that produces population-level marginalization (Donald, Dasgupta, Metzl, & Eckstrand, 2017; Metzl & Hansen, 2014). Public access to structurally competent health knowledge for members of minority populations remains an under-researched social determinant of health disparities (Newman et al., 2012). In particular, marginalized patient groups have uneven access to online cancer health knowledge and are excluded from the online knowledge ecologies proliferated by cancer support programs and organizations (A. Gibson, Lee, & Crabb, 2016). Conceptualizations of accessing information online as a key component of media literacy include not only the technical skill required to access media, but also a measure of cultural knowledge and competency (Orgad, 2006).

Research has shown that online knowledge-seeking can assist patients to become increasingly more informed about their health (Wald, Dube, & Anthony, 2007). Recent research has confirmed that when patients have a positive relationship with care providers, online health information seeking can improve relationships with providers because of greater opportunities for discussion (Tan & Goonawardene, 2017). However, additional research on clinical interactions suggests that there are barriers to patient/provider interactions and communications between cancer care providers and sexual and gender minority patients (Agenor, Bailey, Krieger, Austin, & Gottlieb, 2015; Bryson et al., 2018; A. W. Gibson et al., 2017). Specifically, problematic communication between providers and patients exacerbates already-existing population-based health disparities. In North America, most cancer care is organized around the model of “shared decision-making” (Grabinski et al., 2018), which only works well when there is a strong evidence base to inform care decisions coupled with a high degree of cultural competence that informs patient-provider communication (Grabinski et al., 2018; Kirby et al.,
Sexual and gender minority cancer patients face a doubled health disparity in terms of, first, having less positive relationships their providers (Boehmer & Case, 2004; Matthews, Breen, & Kittiteerasack, 2018) which then, secondarily, prevents them from being able to take advantage of the improved health decision-making that might otherwise result from online health information seeking and subsequent patient-provider interactions.

Quantitative research suggests that LGBQ/T folks are likely to go online to seek health information, and, when seeking health information for themselves and others, have a higher probability of being exposed to incidental health information online than heterosexual populations (Jabson et al., 2017). When sexual and gender minority people are gathering health information online, their risk of being exposed to and utilizing inaccurate health information is increased (Jabson et al., 2017). Therefore, understanding how sexual and/or gender minority people with cancer access, navigate, and coordinate cancer knowledge both online and in face-to-face communication will inform the design of culturally and medically competent web-based information and support systems. No previous research to-date has specifically addressed the need for evidence concerning online knowledge-seeking and access by LGBQ/T cancer patients. The Cancer's Margins project directly addresses the need for research concerning LGBQ/T health informatics. The analysis presented here is intended to advance knowledge concerning cancer health knowledge access and the mobilization of support by LGBQ/T people diagnosed with breast and/or gynecologic cancer.

4.2 Method

The design of the Cancer's Margins research methodology is informed by theoretical frameworks from the Social Study of Medicine (SSM) that deploy sociocultural and post-
structural approaches to an analysis of subjectivity, the mobilization of knowledge, and experiential narratives of health and wellbeing (e.g. Bryson & Stacey, 2013; Diedrich, 2007; Mol, 2002). When applied to sexual and gender minority population health issues, SSM methods allow analyses to take into account both subjective experiences of participants as valuable and credible sources of knowledge, while also simultaneously considering the larger structural and historical contexts shaping those experiences. This analysis of the role of knowledge access in varied discursive contexts pays particular attention to online knowledge ecologies, including in particular, the specific roles of biomedical and biographical knowledge (Bryson et al., 2018) that patients navigate and coordinate in the flux of cancer health decision-making. This analysis seeks to identify both kinds of knowledge and also, access and mobilization techniques that are typical for sexual and gender minority cancer patients. Where the context of cancer treatment is organized around cisgender and heterosexual narratives of treatment and support, the biographical and embodied knowledge of sexual and gender minority patients is discordant relative to the ubiquitous “women’s cancer” narratives of femininity, gender, embodiment, identity, and decision-making.

This analysis asks: What types of knowledge and social support are sexual and/or gender minority breast and gynecologic cancer patients seeking in the multiple contexts of cancer health decision-making, including online and elsewhere? Cancer’s Margins also investigates how sexual and gender marginality, both distinctly and intersectionally, discursively and materially shape access to and mobilization of knowledge and support for cancer patients.

Cancer's Margins participants were recruited from urban, suburban, and rural locations in 5 Canadian provinces: British Columbia (BC), Manitoba (MB), Ontario (ON), Quebec (QC), and Nova Scotia (NS). The sample also includes pilot interviews with LGBQ/T people diagnosed and
treated for breast and/or gynecologic cancer living in the San Francisco Bay Area (BA). Using non-random, purposive recruitment methods—such as snowball sampling—that are considered optimal for use with “hard-to-reach” populations (Bonevski et al., 2014), a diverse sample of LGBQ/T participants was recruited (see Table 4.1). The sample (n=81) varied in age, sexual and gender identity, race, ethnicity, dis/ability, socio-economic status, as well as in the type of cancer and stage. Many studies of LGBQ/T health exhibit a problem of unrepresentative samples in terms of race and also, gender diversity (Meyer & Wilson, 2009). Cancer’s Margins’ deployment of proactive and focused recruitment practises resulted in a sample that is broadly representative of the Canadian population regarding race and ethnicity (Statistics Canada, 2017). Since there are no national demographic data concerning gender diversity, it is hard to say what a representative sample should look like. Participants were asked directly if they identified as transgender or gender nonconforming in any way; 10 participants answered affirmatively, and 71 participants answered “no”. Of the 71 who answered “no” to this question, 31 self-identified as “cisgender” or “woman”. The other 38 of the 71 participants (who did not self-identify as transgender or gender nonconforming) nevertheless used a variety of non-normative identity terms to describe their gender (e.g. kinky femme, genderqueer, butch, etc.) that indicated a more complex relationship to gender than what arises in cisgender narratives. Participants ranged in age from 33 to 75 and all had been diagnosed with and treated for breast and/or gynecologic cancer. Interviews focused on eliciting information about participants’ understanding of intersectional elements of their identities and histories, as well as their experiences along the trajectories of cancer care from screening, to diagnosis, treatment, and ongoing surveillance and/or metastatic care, including their access to knowledge and the mobilization of knowledge, as these relate to support networks, treatment decision-making, and experiences of care and
information-seeking. Research ethics approval was received from the research ethics review boards at each of the investigators’ home universities.

This qualitative data analysis of *Cancer's Margins* interview transcripts focuses on participants’ experiences with seeking knowledge or support and the knowledge mobilization practices and techniques employed by sexual minority and gender minority cancer patients. Data analysis included initial coding of all transcripts using MAXQDA qualitative data analysis software, as well as the refinement of the coding system for consistent inter-coder reliability across the dataset of 81 transcripts.
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4.3 Findings

4.3.1 “What it Really Meant, What We’re Dealing With”: Patient-Provider Communication, Disclosure, and Online Biomedical Knowledge-Seeking by Sexual and/or Gender Minority Cancer Patients

A cancer diagnosis typically precedes an intensive engagement with medical systems and providers. Participant accounts of the complex and laborious coordination of biographical and biomedical knowledge sources during cancer health and treatment decision-making reveal significant use of online knowledge-seeking for themselves and for/by people in their support networks. Informational support was a key driver in online knowledge-seeking activities. For example, Dana talked about a friend, a primary member of Dana’s cancer support network and also a sexual minority community member diagnosed with cancer, who provided Dana with research she had done on breast cancer.

“She was on the Internet, and she's a very smart cookie. So she was looking at just about anything she could find, including medical research.” Dana (BA, 64, Caucasian, gentlemanly butch, breast cancer)

Many participants reported that both they and their support network members spent more time online subsequent to their cancer diagnoses, and that accessing information online had become a primary source of knowledge. They recalled being online for “many hours”, or

4 The demographic information following each quote from the transcripts includes the participant pseudonym as well as those particular words that each participant used to communicate the specificities of their locations relative to categories of location, age, race and/or ethnicity, modes of gender identification and sexual identification, and type of cancer diagnosis.
spending the “whole day online”, pointing to a consistently high pattern of Internet use related to cancer diagnosis and treatment decision-making.

“I get on the Internet for many hours every day now.” Heather (BA, 54, Caucasian, kinky femme, femme dyke, breast cancer)

“I would always use the Internet for research.” Barbara (BA, 54, Caucasian, femme, queer, metastatic breast cancer)

“I would spend a whole day online, looking at things, and then I would get a bit burned out from that. But then I would do it (again) because I would get reassured, by finding out different things, and just knowing what's what, a little bit.” Paula (BC, 48, Japanese Canadian, gender nonconforming, queer, breast cancer)

“It was like breastcancer.org, the discussion boards on chemotherapy, side effects in treatment kind of things, was like my bible; my go-to. I would go there and read and read and read and read.” Holly (BA, 44, Jewish, femme, queer bisexual, breast cancer, BRCA1 gene)

Participation in shared decision-making models is directly affected by the quality of patient-provider communication that, for sexual and gender minority patients, is often encumbered by power differentials between patients and providers and also, by the existence of mistrust and a very high level of vigilance by patients about the possible impacts of disclosure related to either minority sexuality or gender. Additionally, there is a significant impact of the
lack of evidence pertaining to LGBQ/T cancer patients on the quality of patient-provider interactions about cancer health decisions. While online information seeking is performed by many cancer patients of all sexualities and genders to seek further clarification of biomedical information, the increased barriers to communication and knowledge access in relation to care providers experienced by sexual and/or gender minority cancer patients makes the use of online resources to make sense of biomedical information all the more crucial as a source of information for cancer health decision-making. Gender and sexual minority patients have an already hindered access to knowledge based on barriers present in the patient-provider relationship. Patients who are marginalized in the clinic will seek the information they need from other sources, and the internet is consistently found to be an increasing source of health knowledge. Participants reported that clarification of medical knowledge took place throughout the trajectory of their cancer experiences and identified the period of diagnosis and staging to be particularly significant.

“It wasn't until I actually saw the pathology readout that I got some of those things explained. And what I did is, I sat there with the pathology report, and an online guide to the pathology 'Your Pathology Report' and tried to sort of match it up.” Holly (BA, 44, Jewish, femme, queer bisexual, breast cancer, BRCA1 gene)

“I was wanting to learn more about the stages and the grades of cancer—to try and understand the levels and the scales... I did a bit of research about that, just to understand my (diagnosis)... It was to explain and to confirm for me what it really meant.” Diane (NS, 39, Caucasian, femme, lesbian, uterine cancer)
“Then (I) started going on the Internet too. Started looking at things. I think (I) just started with basically a Google search. You could go on to some of the medical sites; it was here in Canada… The one I found was actually very good because it explained and showed diagrams and explained all the pieces of it. So it was like, 'Oh okay, so that's what it is. And that's what we're dealing with’.” Donna (MB, 53, Caucasian, lesbian woman, breast cancer)

Disclosure of gender and/or sexual minority identity to health care providers is a key communication issue and is highly related to quality of healthcare outcomes generally, and specifically, cancer health outcomes and quality of life and wellness measures. Cancer care providers frequently neglect to ask about the sexual and gender identities of their patients, which constitutes an increased barrier to communication and rapport, inflating the risk of disparities in care for LGBQ/T cancer patients. With disclosure being directly linked to better experiences of care and wellbeing (Kamen et al., 2015), it is significant to note that Cancer's Margins participants consistently reported that they actively managed the disclosure of their sexual and gender identities—often hiding their identities in online environments—in order to access support and information in cisnormative and heteronormative online environments.

“I don’t talk about it. I'm totally closeted… I keep it undercover in the online group.” Barbara (BA, 54, Caucasian, femme, queer, metastatic breast cancer)

These findings reveal that sexual and gender minority cancer patients perform significant cancer health knowledge-seeking online and suggest that web-based knowledge and support environments could be an effective and efficient way to access both biomedical and biographical
cancer health knowledge and support for LGBQ/T patient populations by reducing the amount of
navigation and coordination that patients need to do to sort through the support and information
online to find what is relative to them. Online resources that provide information specifically for
LGBQ/T cancer patients may partially alleviate the additional knowledge-seeking burden on
these marginalized patients as a result of barriers in their communication and relationships with
care providers.

4.3.2 “It Didn’t Work For Me”: Cisnormativity and Heteronormativity as Barriers to
Online Knowledge Access and Mobilization

Given the lack of competence in working with sexual and gender minority patients that
has been assessed in cancer care providers marginalized patients are positioned to “manage the
unmanageable” (Mason, 2001, p. 40) by being tasked with finding a provider who is both
medically competent and culturally competent. Participants reported that they specifically went
online to find knowledge and information about providers who were, in some way, reputed to be
willing, experienced, and/or “friendly” in working with sexual and gender minorities and used
this information to make decisions about providers.

“They had a list of (care) providers that are quote unquote 'LGBT friendly.'”

Angela (BA, 33, Caucasian, queer, dyke, breast cancer, uterine cancer)

As previous research on online cancer resources has noted (A. Gibson et al., 2016), the
marginalization of sexual and gender minority populations compels many patients to seek out
culturally competent providers—with no suggestion as to how to accomplish this—placing the
responsibility to resist the cisnormative and heteronormative narratives of cancer care onto individual patients.

Sexual and gender minority cancer patients are highly attuned to find biographically relevant knowledge as a key element of the navigation of online knowledge and support. *Cancer's Margins* interviewees talked about what they noticed online and how they made decisions about whether or not a particular resource was a good fit. They paid attention to the language and topics used in order to assess the level of LGBQ/T inclusion in a wide array of knowledge ecologies.

“Really early on in my online reading, I realized that lots of people were praying for other people. And lots of people had a DH (“darling husband”). And nobody in the general threads said anything about my DW (“darling wife”). There is a thread for lesbians. I found it strangely underdeveloped. It didn't work for me. I thought, 'Boy, it's not fair for me to just read and read and not participate... And then I thought I'm not comfortable being out on this. And I can't imagine being in. So I'm not going to join.”

**Holly** (BA, 44, Jewish, femme, queer bisexual, breast cancer, BRCA1 gene)

Ethnographic accounts of cancer care systems and marginalized cancer patient experiences have pointed to heteronormative and cisnormative knowledge systems as organizing factors in cancer care (Jain, 2007a; Klawiter, 2004). The *Cancer's Margins* project findings have also detailed deleterious effects of cisnormativity on trans and gender nonconforming cancer patients (Bryson et al., 2018; Taylor & Bryson, 2016). Participants described at length how cisnormative and heteronormative knowledge systems influenced many aspects of their care, such as support access and patient-provider relationships, and led to substandard care and a lack
of attention to the specific aspects of patients’ experiences that were key aspects of minority sexuality and/or gender identity.

“The thing that was just blatantly absent was the queer element. Nobody talked about it. It was completely absent from discussion on the boards.” **Serena** (BC, 39, Caucasian, punk femme, bisexual, breast cancer)

“I went online and I started to do research... It’s all very mainstream” **Shirley** (BC, 52, Jewish, femme, dyke, cervical cancer)

“I didn’t find information that focused on lesbian women who had cancer. Absolutely nothing. I would have liked it, but I didn't find anything like that.” **Olivia** (QC, 60, Caucasian, lesbian woman, breast cancer)

The pink ribbon branding of breast cancer support sites is also part of the systemic barriers for sexual and gender minority patients seeking cancer information. Participants reflected that the feminized gendering of cancer websites was a barrier to their engagement and inclusion in accessing knowledge or support online. The branding of a website that uses the pink ribbon approach to breast cancer was interpreted by LGBQ/T participants as an effect of heteronormative and cisnormative narratives.

“I was opposed to the pink ribbon effect that was a major marketing tool for non-profit sites focused on women and cancer.” **Olivia** (QC, 60, Caucasian, lesbian woman, breast cancer)
This analysis revealed that the cisnormative and heteronormative narratives that inform patient experiences of biomedical care also shape the representation of online biomedical information, as well as support websites. The cisnormative and heteronormative narratives of cancer that are invoked on cancer websites were perceived as a barrier to online engagement by interview participants who were seeking inclusive locales for knowledge and support.

4.3.3 “Talking on Different Wavelengths”: Gender Minority Patients, Shared Decision-Making, and Structural Competency

The Cancer’s Margins project previously reported on the alarming lack of coordination between gender affirming care and cancer care for gender minority patients (Taylor & Bryson, 2016). In the analysis reported here, gender minority patients reported that online cancer knowledge was uncoordinated with knowledge concerning gender affirming care. Despite extensive knowledge-seeking, none of the transgender participants in the Cancer’s Margins study reported accessing any cancer health information or support online that was specific to gender minority populations and many indicated that they were lacking support.

“I spent a lot of time trying to find information about (transgender cancer patients online). Because the first thing, when you tell people you have cancer, and you're trans, is “Oh, it is because of your hormones?” A lot of people say that, which drives me nuts. Like you did this to yourself. You know, there's zillions of trans people and not all of them have cancer! I don't even think there's any studies to show that the rates are higher. I was looking at all the possibilities and I didn't really find any information.” John (ON, 33, Asian-Canadian, trans man, queer, breast cancer)
While most of the transgender participants reported accessing some form of gender affirming care, their cancer care did not in any way take this into account. The lack of information at the intersection of cancer health and gender affirming medical care prevents the meaningful integration of medical knowledge and culturally competent care for gender minority cancer patients and creates an enormous barrier to informed and shared decision-making. Patient-provider communication was completely stymied by this lack in structural competency for gender minority patients.

“I keep running across that: ‘I'm the unique patient that they don't have any experience with’... And you know, specialists at the best of times don't really want to get their information from their patients. They don't want to be educated by their patients because it tips the power imbalance, doesn't it?” James (BC, 58, Caucasian, trans man, bisexual, cervical cancer)

Particularly in relation to hormone administration, oncologists were unaware of the benefits to the trans cancer patient that would accrue from coordinated care regimens. When attempting to engage in shared decision-making with their care providers, gender minority participants were keenly aware of the lack of available biomedical information about their gender affirming cancer health needs.

“There’s a growing awareness that lesbian and gay people have specialized needs (but) trans healthcare is way, way out there. Even though I think that would be easier to address medically, because there is actually a biological (context)... But, it's so far from people's minds... they couldn’t advise me one way or the other. (My doctor) said, ‘You know, there aren’t really numbers to support, in your case, if it’s going to help
you or not’... But, there's no shortage of information for biological women who are female identified to access information.” John (ON, 33, Asian-Canadian, trans man, queer, breast cancer)

When gender minority cancer patients seek out cancer health information online, they often attempt to coordinate additional bodies of knowledge, such as biomedical knowledge about gender affirming care. However, neither patients nor their providers have the knowledge needed for decision-making about the overlaps in cancer risk, cancer treatment, and trans-related surgical and hormonal care. John directly described how the lack of coordination of online gender minority health knowledge and cancer health knowledge created a barrier in his communication and informed and shared decision-making with his surgeon:

“There's certainly no trans stuff, not even online, that I could find or that was what I needed... I had said to (my surgeon), “In the time that I've been waiting, I've been doing a lot of research online... Are there sources of information that are better than others, in your experience?.' He said “Google breast cancer.” I was like, 'Oh my friend, we are talking on different wavelengths here.' So I realized that he wasn't a source of information. I was waiting for my surgery, and he didn't hook me up with any resources or anything.” John (ON, 33, Asian-Canadian, trans man, queer, breast cancer)

Despite, or perhaps as a result of, the lack of gender minority specific information and support online, gender minority participants had clear and direct ideas about how to make online cancer knowledge and support websites more available and accessible to marginalized communities.
“Each page that you go to is clean looking. In other words, don't have a lot of stuff on each page. Have it so the type is fairly large. And don't put backgrounds like, black with blue lettering. I've seen that on websites. Terrible. You can't read the damn thing, right? For people who are visually impaired, you have to have it really good, right? Make a site that you can also access for deaf people—signing the information. If you put people in, of course, a wide variety of people—not just a bunch of white folks, which drives me crazy when I go to websites. I also want to see culturally-specific information as well. In terms of the website, you just gotta have lots of good information.” Jolene (ON, 59, Caucasian, genderfluid, transgender, queer, metastatic breast cancer)

Cancer support and information websites that are inclusive and accessible for sexual and gender minority people need to show complexity in their portrayals of cancer patients and the kinds of knowledge they might find useful in making cancer health decisions. Transgender and gender nonconforming participants, as well as a significant portion of gender diverse sexual minority participants, showed a high degree of health literacy and media literacy that they used to coordinate various sites of knowledge. These findings suggest that both online engagement and support—in relation to biomedical, biographical, and experiential knowledge—are primary considerations in efforts to address LGBQ/T cancer health disparities. Support targeted specifically to gender minority populations needs to be a key element of health informatics design in order to engage the wider population of LGBQ/T cancer patients.
4.3.4 “People Like Me, People Like Us”: The Credibility of Online Information, Decision-Making, and Experiential Knowledge

Participants in the Cancer's Margins research project reported that they often accessed health knowledge online and that they were concerned about the quality of that knowledge. Participants expressed concern about the accuracy and credibility of cancer health information that might be available online, and Internet sources were generally regarded with some suspicion concerning credibility.

“You never know what's true and what's not.” Debrah (ON, 72, Jewish, lesbian woman, metastatic cervical cancer).

A number of participants brought up the source of the information as a primary part of their concern. Suzette pointed out that the source of the information is directly part of the issue of credibility.

“Anyone can put anything up there. So, you know, how valid is the information? Where is it coming from?” Suzette (NS, 59, Caucasian, lesbian woman, breast cancer)

In order to mitigate the risks of using erroneous knowledge to guide decision-making, Cancer's Margins participants sought out sexual and/or gender minority-specific knowledge and networks, and prioritized experiential knowledge from other sexual and/or gender minority people diagnosed with cancer.

While many participants reported preferring a face-to-face interaction with other LGBQ/T cancer patients, they were often seeking out peers online because there was a wider
community network to connect with other LGBQ/T cancer patients online than there was for them locally.

Information and experiential knowledge-sharing was seen as less credible and less relevant to decision-making when it was more general and not specifically geared towards sexual and/or gender minority patients.

“When you know that things like this exist, that there are other people that are living the same thing as we are, people like us.” Sylvie (QC, 37, Caucasian, French Canadian, lesbian woman, ovarian cancer)

“When I watched the videos of LGBQ/T cancer patients, it really made me feel better. It was like a breath of fresh air in a period of discouragement. It was really good to see someone who looked a lot more like me.” Olivia (QC, 60, Caucasian, lesbian woman, breast cancer)

For LGBQ/T interviewees, the role of gender and/or sexual minority populations-specific information was important to provide validation and support for identities, embodiments, and lives subjected to the disrepair engendered by a diagnosis with cancer.

“I think it's absolutely critical. I'm old school gay, right? I like having our own stuff. I'm not into integration here. I think we're losing—don't even get me started on this. We have already lost so much. I will always fight for separate LGBT stuff. It's critical.” Emily (ON, 61, Caucasian, femme, dyke, cervical cancer)
4.3.5 “Someone That You Actually Click With”: Locating and Facilitating LGBQ/T Community and Network Support

Given that different types of support are needed by patients undergoing cancer treatment, these findings contribute new knowledge concerning how LGBQ/T cancer patients make extensive use of online tools to counteract the relatively lower levels of support in health decision-making that they experience in person. Participants reported that they also went online in order to organize their support: coordinating, scheduling, and delegating support tasks.

“I put an announcement on the website. My partner, a week after my surgery, needed to go to a conference. There's part of me that wanted people to bring me certain things... So I put it online. And people did stuff (in person to support me).” Ninet (BA, 56, Israeli, radical feminist dyke, uterine cancer)

*Cancer's Margins* interviewees who were seeking people similar to themselves went online to connect with other LGBQ/T people and to facilitate interactions that would not be as easily accessed in person. For participants, especially those who were living in smaller or more remote communities, the ability to reach a wider pool of people for various types of support was essential, but they specifically needed to locate other sexual and/or gender minority cancer patients that they could identify and connect with.

“The circle of gay and lesbians is so much smaller in small communities. Having a hard time to find someone that you actually click with in that small community, because you're different. Having cancer on top of that, I wanted to be able to connect with a lesbian who has breast cancer.” Marianne (ON, 51, Aboriginal Canadian, gay woman, breast cancer)
By going online to seek out community and network support, participants were able to reach a larger/wider pool of potential interlocutors, and thereby increased the probability of connecting with other LGBQ/T people.

A significant sub-group of participants also noted that they were not able to locate support for their partners and that impeded access to support was an added stress during their cancer treatment. Participants were acutely aware of the impact of their cancer on their partners and support networks. Participants identified support for their partners as being entirely lacking in their experiences online. Partner support was highly prioritized by participants and many participants talked about the possibility of their primary support persons getting online support or getting support for their relationships online during treatment.

“What if we did this specifically for lesbians to talk together, especially about how relationships are affected? It could be a chat line.... Often we’re left with information that could be shared and typically is not: feelings, tips, medical and psychological decision-making, and relationships.” Olivia (QC, 60, Caucasian, lesbian woman, breast cancer)

4.3.6 “Information That Could Be Shared”: Blogging and LGBQ/T Cancer Patients’ Contributions to Mobilizing Sexual and/or Gender Minority Knowledge

Cancer patient blogs contain valuable information about people’s cancer experiences and researchers have used blogs by cancer patients as data sources for understanding the role of blogs and communication networks in shaping cancer patients’ experiences. Chung and Kim (2008) looked specifically at the impacts of blogging on cancer patients and found that “emotion
“Would you like to know why I started blogging?... I realized how hard it was going to be on him, to have to constantly update everybody about everything. And I thought if I blogged then his friends and family—I mean, it really was about him first. They could just go somewhere and see it, and he wouldn't constantly have to ask me what's going on and then distribute it... That's why I started it. And then it turned into the life support thing, life saver, I don't know, rope, this thing that was going to carry me through when I was really upset and I could sit down and write about it.” Holly (BA, 44, Jewish, femme, queer bisexual, breast cancer, BRCA1 gene)

Participants also reported that they used blogging to share experiences with others because they felt there was limited information that was specific to them as members of gender and/or sexual minority populations. Blogs, in this sense, were also seen as a form of service or obligation to other patients to fill in the gaps in cancer information that is available and
accessible online for sexual and/or gender minority patients. Blogs allowed participants to create and mobilize experiential cancer knowledge that was specific to them as members of one or more marginalized groups.

“I think my main thing was to provide something for (LGBQ/T) people who ended up in that situation themselves. I couldn't find anything that would tell me what I was about to go through. That's why I decided to put it out there for other (LGBQ/T) people... I wanted (those) people to have some idea what to anticipate.” Jake (BC, 52, Caucasian, butch dyke, ovarian cancer, BRCA1 gene)

Blogging afforded participants an online opportunity to mobilize their own “experiential evidence” (Ziebland & Herxheimer, 2008); that is to say, knowledge that was relevant and specific to their community and support networks. This contribution to knowledge mobilization was taken up by participants as a duty of care to their LGBQ/T community so as to refuse the heteronormative and cisnormative narratives of cancer care, and, simultaneously, to create a culturally appropriate emotional support system.

4.4 Conclusions

The Cancer's Margins project advances knowledge concerning how sexual marginality and gender marginality shape access to knowledge and the processes by which marginalized cancer patients engage with knowledge access and mobilization. This analysis advances knowledge about the ways that sexual and/or gender minority cancer patients access knowledge and support and the implications for cancer health decision-making and patient-provider relationships and communication.
Cancer's Margins participants were highly aware of the need to coordinate their online activity with their face-to-face treatment, knowledge, and support networks. The persistent presence of heteronormative and cisnormative narratives in the organization of cancer care knowledge specifically, and health care more generally, put participants in a position where they needed to perform extra work to compensate for the failure of care systems to respond to their cancer health decision-making needs. Marginalized patients must do a lot of excess labour to manage and coordinate various fields of knowledge in cancer care environments. Research interviewees shared techniques that they used to navigate cancer knowledge ecologies. They reported that knowledge about cancer and relatedly, decision-making was not designed to meet current standards regarding culturally competent care. The specific techniques that participants used to coordinate knowledge access across diverse locations included: managing disclosure, sorting applicable information from cisnormative and heteronormative narratives, and seeking biographical and medical knowledge from other sexual and gender minority cancer patients, in addition to knowledge mobilization techniques such as blogging.

This analysis provides evidence that LGBQ/T cancer patients are making extensive use of online cancer knowledge and support, despite widespread “informational and institutional erasure” (Bauer et al., 2009) of sexual and gender minorities. By going online, participants were able to widen their scope of knowledge access, contribute to LGBQ/T-specific knowledge, while increasing the likelihood of finding other LGBQ/T cancer patients with experiential knowledge. To inform their cancer health decision-making and to account for the lack of communication and structural competency in cancer care, LGBQ/T patients sort through biomedical and biographical knowledge that is shaped by heteronormative and cisnormative narratives so as to glean knowledge that aligns with their experiences. These findings also reflect that LGBQ/T cancer
patients had an altruistic commitment to knowledge-sharing and mobilization with others in LGBQ/T communities and a robust intersectional lens to shape visions of culturally competent online knowledge-sharing. This analysis also provides evidence that LGBQ/T cancer patients have considerable health literacy and media literacy and use LGBQ/T community networks and experiential knowledge to ameliorate the risks presented by cisnormative and heteronormative health knowledge structures.

This analysis supports an argument for the necessity of undertaking a sexual and gender diversity analysis in both online and face-to-face support programming for sexual and/or gender minority cancer patients. The organization of cancer knowledge and support spaces excludes sexual and gender minority cancer patients. The strong overall preference expressed by participants for both sexual-minority-specific and gender-minority-specific online knowledge and support points to particular need for online cancer support that takes into account the unique needs of sexual and gender minority populations. Knowledge and support spaces need to be designed in such a way as to recognize that sexual minority cancer patients and gender minority cancer patients have related, but distinctly different, experiences of cancer health and care.
Chapter 5: Conclusions and Discussion of Implications for Cancer Care

5.1 Overview

The overall contribution of this dissertation is to advance knowledge concerning the ways that sexual marginality and gender marginality shape experiences of cancer health and care. This research aims to contribute an analysis of the intersection between gender diversity and cancer treatment and support for populations that were previously subsumed into the interpretations of sexuality categories and documents participants’ “creative attempts to resist, thwart, and otherwise manage the possibility of discrimination and likewise, the probability of institutional erasure in care settings” (Bryson et al., 2018).

5.2 Summary of Findings

1. Sexual and/or gender minority breast and/or gynecologic cancer patients navigate a complex terrain in negotiating intersectional identities in cancer care.

2. Different generational cohorts of sexual and/or gender minority populations have distinct practices and values around health knowledge.

3. Sexual and/or gender minority cancer patients prioritize communitarian knowledge, population-specific knowledge, and experiential knowledge from other sexual and/or gender minority patients in their treatment decision-making.
4. Normative narratives of sexuality, gender, femininity, reproduction, and embodiment are informing providers’ expectations of patient decision-making. Patient-provider communication is stymied by disparate understandings of the knowledge that informs sexual and/or gender minority patients’ wellbeing and embodiment.

5. Sexual and gender minority breast and/or gynecologic cancer patients are using knowledge of gender diversity to make sense of post-treatment changes in embodiment. Cancer surgeries are being experienced as practices of gender affirming care, yet cancer care and gender affirming care are siloed bodies of knowledge.

6. Organization of cancer care into gendered care systems such as “women’s cancer” results in systems of care that create increased patient vulnerability to stigma and discrimination for sexual and/or gender minority cancer patients.

7. Gender minority patients experience additional barriers, including denial of care. The cisnormative structures of cancer care and peer support groups contribute to the erasure of trans and other gender diverse patients.

The overall contribution of this dissertation is to add an intersectional analysis of sexual and gender marginality to the literature on cancer and minority populations. Where the previous research literature has subsumed gender diversity under categories of sexual marginality, or an umbrella of “LGBT”, this dissertation adds evidence concerning the intersectionality of sexuality.
and gender in the biopolitical production and regulation of health knowledge generally, and cancer knowledge specifically.

The *Cancer's Margins* research in this dissertation also provides the first research data to examine trans and/or gender nonconforming patient experiences of cancer treatment and decision-making. This analysis of the particularities of gender marginalization and cancer care is a new contribution of knowledge that has wide-reaching implications for the organization and implementation of cancer care systems.

Examining the data with a specific intention of identifying the mobilities of gender diverse knowledges has revealed that the organization of cancer care around a binary gender system is not only producing discriminatory environments for patients that identify as trans and gender nonconforming, but also for a significant amount of patients who identify, in some way, as other gender minorities. The substantial portion of *Cancer's Margins* participants who identified themselves, not as transgender, but also as not being coherently gendered along a binary, provide an important insight into the gender diversity and marginalization that occur in a population previously assumed to be easily codified as “sexual minority women”.

Trans and gender non-normative narratives of gender identity and embodiment provide sexual and gender minority cancer patients with an alternative to cisnormative narratives to understand and make sense of changes to embodiment that they experience as a result of cancer treatments. For cancer patients who identify as gender diverse/genderqueer but not necessarily as transgender, these narratives provide a more familiar framework that more appropriately aligns with their values and knowledge of wellness than the cisnormative, heteronormative narratives they experience in biomedical environments.
The overlap in surgical and hormonal treatments for cancer with medical interventions for gender affirming care is significant, not only for trans patients, but for other gender minority patients and provides a context for cancer-related changes to embodiment that is less traumatic than the normative narratives of cancer and embodiment that are ubiquitously endorsed and assumed by medical providers. In some cases, changes in embodiment after treatment also resulted in changes to identity, which were, again, more easily understood by sexual and/or gender minority patients outside of cisgender narratives.

Non-normative narratives of gender and knowledge of gender diversity gives sexual and/or gender minority cancer patients a queered approach that is outside the commonplace cancer narrative available to them whereby breast and gynecologic cancers are conceptualized as “women’s cancers” that only relate to a very limited narrative of womanhood and femininity (Jain, 2007a; Klawiter, 2004; Nielsen, 2018). The findings in this analysis suggest that standardized treatment processes are informed by biomedical and cisnormative models of gender and care that are presumed to be suitable across all patient populations and thus, fall short in terms of facilitating collaborative or informed patient-provider decision-making with sexual and/or gender minority cancer patients.

A specific and interesting finding from the Cancer's Margins project is related to the distinct generational differences among participants in terms of how they engaged with narratives around sexuality and gender. Queer and trans generational values around communitarian knowledge and the prioritizing of experiential knowledge highly influenced how patients made decisions about care and treatment. While there were also distinct differences in terms of how different queer and trans generations engaged with biomedical knowledge and care providers, a consistent theme of this dissertation research is that sexual and/or gender minority
cancer patients across generations of queer and trans knowledge and identities value population-specific knowledge to inform their cancer-related decision-making.

Participants were highly aware of the types of specific knowledge that they needed, but simultaneously also highly aware of the lack of population-specific cancer information available to sexual and/or gender minority patients and their support networks. Where no population-specific knowledge existed, Cancer's Margins participants reported active engagement in creating and providing wide access to such knowledge.

Sexual and/or gender minority cancer patients make extensive use of the internet in order to connect with other patients for both support and information. From conducting extensive research, to creating robust informal support networks, to blogging their experiences, sexual and/or gender minority cancer patients value not only the receiving of communitarian knowledge, but also the contribution of their experiential cancer knowledge to provide specific and relevant narratives of experiences of cancer treatment and decision-making in the intersectional context of sexual and gender marginalization.

When the biomedical knowledge available to them fails to fit with their biographical self-knowledge, sexual and/or gender minority patients are taking on extensive effort to both access and contribute population-specific cancer knowledge for future patients and generations. In contexts of both formalized cancer care and health, as well as in online knowledge ecologies, Cancer's Margins participants spoke strongly about the need for community-based knowledge and social support that is specifically tailored to sexual and/or gender minority patients.
5.3 Cultural Competency, Cultural Humility, and Cultural Safety in Health Care

“Cultural competency” (Williams, 2006) has been defined as the ability to provide appropriate care to a person of a particular cultural, racial, or ethnic population. This approach assumes that most care providers provide care to diverse patients and is “defined by the capacity to work across multiple paradigms to find ways to engage with (patients)” (Williams, 2006, p. 209). While approaches to culturally competent practices usually refer to cross-cultural practice situations, it is also accurate to use this concept in reference to culturally competent practices within one's own social group/location. Measurements of cultural competency have been criticized for neglecting power relations of racism and difference and measurements of cultural humility have been suggested to better measure the preparedness of providers to provide culturally-specific care (Kumas-Tan et al., 2007).

“Cultural humility” has been defined as the awareness that social, cultural, institutional care is provided relationally—and often between people of disparate social locations—and describes a need to maintain curiosity, lack of judgement, and awareness of the power dynamics between patients and providers from different social locations (Rajaram & Bockrath, 2014). A value of this concept is for practitioners to try to maintain an awareness that they may need to learn more about their patients’ social and cultural contexts in order to provide adequate care.

“Cultural safety” approaches, founded by Maori nurses, build further on these concepts by ascribing to theories and practices of patient-centred care that contextualize power, history, bias, and social inequity (Kirmayer, 2013). “Cultural safety” bears many of the same resemblances to care that are represented by “cultural competence” and “cultural humility”. A difference is that “cultural safety” de-centres the experience of the providers and re-centres the experiences of patients, by focusing on the patient’s definition of the interaction. Whether or not
a patient feels safe is a different measure than whether or not providers believe they are providing effective care (Kellett & Fitton, 2017).

Research reviewing the qualitative measurements of “cultural competency” practice assessments has found multiple issues that plague the narrative of “cultural competency”. A particular problem is for intersectional frameworks that, contrary to common intention, inadvertently reify the hierarchical ideologies that their practitioners may intend to dispel (Kumas-Tan et al., 2007). Baker and Beagan (2014) have critiqued discourses of “cultural competency” using a queer framework and suggest that using a framework of “cultural humility” may be more appropriate for creating medically competent and culturally safe/r environments for sexual and/or gender minority patients and creating environments of care where patients and providers work together to communicate and make decisions about care and treatment. Cancer's Margins findings also suggest that the knowledge of trans-identified patients regarding culturally competent health care practice and provision is unique and different from the knowledge and perspectives of LGBQ women (Taylor & Bryson, 2016). Trans people may even experience worse health care experiences with providers who claim to be culturally competent in gender affirming care than they do with providers who do not lay claim to any sexual and/or gender minority cultural competency (Baker & Beagan, 2014). This differentiation between the experiences of sexual minority and gender minority patients is indicative of the critical challenge that an analysis of gender marginalization and diversity adds to the critiques of “cultural competency”. Distinctions between “competency”, “humility”, and “safety” may be challenging to ascertain in terms of measurements (Kumas-Tan et al., 2007). Providers who prioritize patient-centred care and undertake professional development and research to improve their skills and
knowledge may be more equipped to provide care to marginalized populations than those who may label their practices as being “culturally competent”.

Discussions of various approaches to culturally appropriate care—from cultural humility to cultural competency—have been a consistent part of the debate and conversations around ethical care provision practices (Tervalon & Murray-Garcia, 1998). Cancer health care treatment and support needs to go above and beyond a politics of inclusion (Epstein, 2007a) and focus not solely on knowledge access, but also on patient access to the capacity and opportunity to mobilize cancer health knowledge and to modify and distribute knowledge (Bryson & Stacey, 2013; Kapczynski, 2008). One of the aims of the overall analysis in this dissertation is to provide useful evidence to inform the provision of cancer care, and the frameworks that undergird both practices and communications between patients and providers, as well as systems of care.

Canadian research on perceptions of cultural competence among both patients and health care providers has found that sexual and/or gender minority patients have “strikingly low expectations” (Baker & Beagan, 2014, p. 591) of the cultural competency their providers will have in working with them in terms of appropriate knowledge, skill, and practices—and generally being equipped to attend to their unique health needs as a marginalized population. Bauer and colleagues in the Trans PULSE project (Bauer et al., 2009) found that trans patients were likely to express gratitude for finding a provider that, regardless of whether or not they even understood their health needs, at least expressed tolerance for their gender diversity.

Sexual and/or gender minority cancer patients anticipate their risk of experiencing discrimination such as homophobia and transphobia in health care environments and interactions, and so they bring a heightened level of and awareness of that risk and its attendant vulnerability in health care interactions and environments. This vigilance is largely the result of accumulative
experiences of discrimination in health care environments, contributing to avoidance of care (Bauer et al., 2014; Li, Matthews, Aranda, Patel, & Patel, 2015; Reisner, Gamarel, Dunham, Hopwood, & Hwahng, 2013) and delay in cancer screening and follow up (Matthews et al., 2013; Peitzmeier, Reisner, et al., 2014). Disclosure of sexual and/or gender minority status/identity is closely related to the quality of patient-provider relationships experienced by sexual and/or gender minority patients, (Boehmer & Case, 2004; Cruz, 2014; Quinn, Schabath, Sanchez, Sutton, & Green, 2015), which is important to note, given that they are also related to patient population health outcomes during and after receiving cancer care and treatment (Fish & Williamson, 2016; Kamen et al., 2015). The current research showing cancer health disparities among sexual and/or gender minority populations is a material manifestation of the unequal social positioning and disadvantages measured by the social determinants of health (Matthews et al., 2018). Issues related to both access to health care and health literacy, as social determinants of health, need to be addressed in the specific context of cancer care in order to reduce cancer health disparities for sexual and/or gender minority patients.

* Cancer's Margins * has found that the lack of safety that sexual and/or gender minority cancer patients experience in health care environments generally will shape and inform their access to cancer care specifically (Bryson et al., 2018; Taylor et al., 2019; Taylor & Bryson, 2016). When patients feel they are unable to trust and disclose their identities and biographical knowledges to their cancer care providers, the risks of receiving suboptimal care rise accordingly (Griggs et al., 2017), further institutionalizing cancer health disparities.

Numerous studies have looked at health outcomes generally, and specifically among sexual and/or gender minority cancer patients and found that patient perspectives on safety and culturally effective care provision have direct effects on their perceptions about the quality of
that care (Boehmer et al., 2013; Fish, 2016; Kamen et al., 2015). In order to provide the best care possible, a patient-centred approach is vital to developing care and treatment protocols that can address patients’ needs (Joint Commission, 2011). The context required to develop care and treatment planning includes not only the medical diagnosis and cancer-specific information such as staging and grading, but also includes social contexts and issues around knowledge access and health literacy and population-based health disparities (Matthews et al., 2018; Schilder et al., 2001). An argument made throughout this dissertation is that the provision of ethical, patient-centred care requires medical providers generally, and cancer care providers specifically, to engage with patients’ social positions and biographical knowledge.

5.4 Connecting Culturally Effective Care with Medical Competency in Cancer Care

Issues of appropriate and effective practice have been theorized and examined under the interrelated and interdependent, yet distinctly nuanced frameworks of medical competency, cultural competency, structural competency, cultural humility, and cultural safety. I refer to each and all of these frameworks in varying degrees throughout the dissertation. Each of these models of competency describes a nuanced and particular aspect of understanding the intersection of the “fields of knowledge” (Foucault, 1975) that produce social, cultural, community, and institutional contexts. While I use each of the concepts individually, as appropriate, I refer to this assemblage of measurements collectively as “culturally effective” practices.

No matter the specific conceptualization or measurement being used, the underlying ethic of culturally-specific care is to reduce population-based health disparities and provide care that improves health and maintains wellness among a given population—through means of culturally-specific care that is effective. Understanding the care experiences of patients is
important to increasing the efficacy of care provision. In order to understand the experiences of marginalized cancer patients and, ultimately, be informed enough to be able to ensure the provision of ethical and effective care, practitioners need to be aware of the intersectional contexts in which patient experiences of care are shaped and produced.

Medical competency and culturally effective care are interrelated aspects of health care, and cancer care specifically. Effective cancer care cannot exist without care that is simultaneously medically effective and culturally effective. For instance, while the commonplace practice of placing a rainbow sticker/flag on a door of a clinic is intended to point to the element of cultural safety in care, the reality for many people in the very population that the clinic is intending to increase access for is that this symbol does not represent their unique experiences and intersectional social locations and is not necessarily a reliable tool for identifying and navigating safe and supportive spaces (Wolowic, Heston, Saewyc, Porta, & Eisenberg, 2017). Likewise, the proverbial rainbow sticker on a door of a medical clinic, regardless of the number and colour of stripes and attempts at a politics of inclusion (Epstein, 2007a), does little to attest to the medical skills of the providers involved. Simply put: all the medical competency in the world won’t make a difference for patient health if patients are avoiding health care environments (Bauer et al., 2014), but likewise, cultural competency in a cancer clinic without medical competency is useless in the face of a cancer diagnosis.

A strong research base is necessary to inform medical practices and the organization of care. Creating care that simultaneously engages both medical competency and care efficacy issues surrounding cultural and social locations requires research evidence that takes up multiple knowledge bases and can then inform care. The conceptual, contextual, and clinical practice locations where medical competency and culturally effective care intersect are areas where
cancer care can be improved—and reducing cancer health disparities may translate to improving cancer outcomes.

5.5 **Implications: Advancing Intersectional Health Approaches with Sexual and/or Gender Minority Cancer Patients**

5.5.1 **Medical Education**

The “ informational and institutional erasure” (Bauer et al., 2009) of sexual and/or gender minority populations from the realm of health care knowledge has deathly consequences—and especially so in relation to cancer health and population differences in access to care and knowledge. Medical providers are not prepared by medical school curricula for the sexual and gender diversity of the patients they will encounter (Obedin-Maliver et al., 2011; Parkhill, Gainsburg, Fearing, & Mathews, 2011). Pedagogical approaches to medical education have largely failed to assist providers in understanding the role of sexuality and gender in shaping their patients’ access to appropriate knowledge, their biographical narratives, and their experiences of health and care (Murphy, 2018). “The messiness of the social, culture, context and subjectivities often are obscured in physician education because of a medical regime that dictates that an objective, scientific gaze trumps all others” (Macleod & Frank, 2010, p. 800). Nonetheless, health care providers have moral and ethical obligations (Taylor, 2013) to understand the social determinants of health and the associated social positioning and related health knowledge that will assist them in addressing health disparities and health inequities (Awosogba et al., 2013).

Sexual and/or gender minority cancer patients experience varying forms of discrimination and/or service refusal and medical professionals need to be aware of the existence of population-
level health disparities. Providers can access multiple opportunities to a) interrupt practices and narratives that are harmful to marginalized patients, b) to ameliorate the engagement with patients narratives in decision-making, c) to address social determinants of health on individual patients and patient populations, and d) to engage in the values of health equity that align with ethical provision of medical care.

The data presented here consistently identify that participants report communication difficulties with their cancer care providers—and particularly in those situations when patient decision-making contravened providers’ normative expectations of identity or of embodiment.

Trans and other gender minority Cancer's Margins participants reported that their gender affirming care providers and their cancer care providers were not coordinating care, that they were often refused or excluded from care environments, and that they were consistently told by their care providers that there is no research evidence to support health care best practices for trans and other gender minority patients. This research points to a need for collaboration and continuity of care between cancer care providers and gender affirming care providers, as well as a widespread need for both research evidence and training to include cancer risk profiles in assessments for gender affirming care, and to include gender affirming care options in cancer risk assessment, care, and treatment.

Cancer care providers do not typically undertake a comprehensive view of knowledge to understand how their patients make decisions about health and care. Cancer's Margins participants reported that practitioners seemed: a) unaware and ill-equipped to understand the important role of communitarian knowledge in sexual and/or gender minority patient decision-making, and also, b) completely unprepared for non-normative narratives of gender. Medical treatment providers require training to understand the overlaps in biographical knowledge and
medical decision-making. Health care providers at all levels require training to include both sexuality and gender identity in patient histories and in cancer health treatment and decision-making.

Recent studies with cancer care practitioners indicates that cancer care specialists have a false sense of competency in working with sexual and/or gender minority patients—they believe they know more than they actually do (Schabath et al., 2019; Shetty et al., 2016; Tamargo et al., 2017). Along with the qualitative context of the findings presented here, such research identifies that there are particular training and education needs for cancer care and other medical providers for working with sexual and/or gender minority cancer patients and points to a lack of preparedness for working with these populations. While further research is needed to establish a more robust research base about marginalized cancer patient experiences, this dissertation provides initial evidence that can inform the design and implementation of culturally effective and medically competent LGBQ/T training for providers that is evidence based.

5.5.2 Cancer Systems

The current organization of cancer care institutions into “women’s cancers” or “men’s cancers” is informed by cisnormative narratives of a binary model of gender that assume normative relationships between sexuality, gender, embodiment, and identity. The findings in this dissertation provide robust evidence that reductively gendered cancer “regimes” (Klawiter, 2004) are ineffective, and unethically insufficient at providing care to sexual and/or gender minority cancer patients. There is a major revision needed in terms of the gender-binary-based organization of care and screening protocols for breast and gynecologic cancers that are currently categorized as “women’s cancers.” While “patient navigators” are often used to bridge gaps
between marginalized populations and health care system design, this approach has not been shown to be effective at improving patient experiences with cancer care and may in fact reify the disparities in care for marginalized patients (Wells et al., 2016). Such an approach fails to address the larger systemic organization of cancer care which is organized by fields of knowledge that are incommensurable with the knowledges that shape patient decision-making (Bryson et al., 2018). The findings from Cancer's Margins’ research suggest that an alternative organization of cancer care would be far more effective and efficient in providing care to marginalized patients (Bryson et al., 2018; Taylor et al., 2019; Taylor & Bryson, 2016).

Advances in biomedical technologies are developing in a time where the social study of medicine and other qualitative research approaches are increasingly generating and establishing an abundance of research evidence that documents the social determinants of health and health inequities among marginalized populations (Marmot & Allen, 2014; Polite et al., 2017). As such, the ethical imperative of patient-centred care and the importance of simultaneously considering both medical competency and culturally effective care are becoming increasingly linked through the evolution of personalized medicine. Cancer care that is both medically competent and culturally effective care is ethical care that may improve cancer care and save lives.

Where all breast cancers had previously been considered diseases of the breast, genomic approaches are shifting the attention off the particular body part where the cancer cells are located and onto specific genomic mutations (Tomczak, Czerwińska, & Wiznerowicz, 2015; Vogelstein et al., 2013). This restructuring of cancer knowledge provides an excellent opportunity for the excision of “men’s” and “women’s” cancer regimes (Klawiter, 2004). This may provide a step towards care that is personalized and considers intersectional social locations. Given the ongoing attention to patient-provider communication and relationships as a predictor
of marginalized patient outcomes, advances in the organization of cancer care that increase patient-provider communication and collaborative decision-making are likely to benefit sexual and/or gender minority cancer patients.

Marginalized patients do extra work to fit themselves into a cancer care system that has not been designed with their needs in mind. Patients are tasked with strategically navigating a gap between what matters to them about their lives or identities, and the medicalized notions and narratives of populations that makes sexuality and gender diversity invisible or irrelevant (Baker & Beagan, 2014).

Since decisions about disclosing sexual or gender identity are linked with perceptions of safety and the possible impact of disclosure on quality of cancer care (Bryson et al., 2018; Fish & Williamson, 2016; Jabson & Kamen, 2016), cancer care systems need to ensure that clinical protocols, treatment environments, and patient-provider relationships focus on improving patient perceptions of safety in care and support environments.

Cancer care systems need to ensure that they have visible and accessible information for sexual and/or gender minority patients, and that electronic health records reflect the presence and health needs of patients whose sexual or gender identities are non-normative. In order to address the “informational and institutional erasure” (Bauer et al., 2009, p. 348) of marginalized patients, visibility for sexual and/or gender minority patients needs to be taken up in all forms of electronic health records, patient history documentation and cancer tracking, including forms, educational campaigns, research projects, and clinical settings as well as national cancer surveillance databases. Care systems need to make concerted efforts to engage in the visibility and positive recognition and affirmation of sexual and/or gender minority patients in order to
increase patient perceptions of safety and engagement and positive experiences of cancer care and support.

Cancer surveillance systems and record keeping also need to specifically ensure that cancer data collection, cancer research designs, and national cancer epidemiological registries include both sexual orientation and gender identity as distinct factors and cancer-related social determinants of health. While sex is currently a collected field of cancer surveillance data, public health policy should consider the benefits of adding sexuality and gender to cancer surveillance data and electronic health records (Deutsch et al., 2013). The organization of electronic health records uses reductive ideas of gendered embodiment and the “crude proxy” (Roberts, 2015) of “sex” to organize patient groups, and thus, overlooks more important health factors. Electronic medical records should, instead, separately record embodiment, sexuality, and gender as demographics in cancer surveillance and research data. It is imperative to the measurement of health equity that categories of sexual marginality and gender identity are represented in cancer surveillance data (Matthews et al., 2018)—and this information needs to be based in the biographical narratives of patients.

Instead of using “sex” as a crude proxy, a set of descriptors, demographics, and relevant biographical details should be gathered that more specifically records relevant health information. Additionally, in order to ensure that medical records are increasingly more accurate, a system of record keeping that takes an inventory of organs (Deutsch et al., 2013) as part of recording patient demographics around embodiment would a) increase the accuracy and effectiveness of cancer risk assessment and care planning, b) increase the accuracy and applicability of epidemiological surveillance, and c) increase the possibilities and efficacy of personalized genomic approaches to cancer treatment.
5.5.3 Patient-Centred Care and Decision-Making

The particular significance to practitioners of these analyses is the evidence to support a need for further coordination of care. First, as has been noted, is the need for the coordination of cancer care with gender affirming care; patient care cannot be truly patient-centred unless the various systems of care are coordinated around them (Joint Commission, 2011; Macleod & Frank, 2010). However, the need for coordinated care goes beyond the clinics of care. Cancer care, “if it is to be truly patient-centred, must move beyond patient meta-narratives and acknowledge the multi-layered diversity of patients, and the complex intersections of social issues and culture” (Macleod & Frank, 2010, p. 800). The evidence in this dissertation strongly supports the need for cancer health care that pays attention to the significance of the effects that cancer, and accompanying care and treatment, has on the intersectional identities of patients.

For sexual and/or gender minority cancer patients, gender is a primary site of knowledge and identity that shapes decision-making around treatment. Since many Cancer's Margins participants did not identify as trans or gender nonconforming, but still narrated very complex identities and relationships to gender, practitioners should be aware of and engaging their patients in conversations about gender, embodiment, and the shifts to embodiment and gender identity that may occur after cancer-related surgery or treatments.

Given the overlap between treatments for cancer (i.e. mastectomy, hysterectomy, hormone therapy) and gender affirming medical care (i.e. top surgery, bottom surgery, exogenous hormone administration), some patients make sense of these changes in embodiment as a form of gender affirming care, and practitioners need to centre the biographical narratives of their patients in making these life-altering decisions about their bodies and identities.
Given the known risk and burdens of minority stress on sexual and/or gender minority populations (Meyer & Frost, 2012; Miller & Grollman, 2015), particular attention needs to be paid to tailoring appropriate cancer support to assure safety and respect for human rights in cancer care. Cancer care practices and protocols need to reflect and maintain an awareness that sexuality and gender identities and embodiments are complex, multilayered, and intersectional; there is no monolithic “LGBT”, “queer”, or “trans and/or gender nonconforming identity”.

Individual, patient-centred cancer care needs to address not only patient identity, but the social locations and accompanying health equity issues that that are being faced by individual patients, who are always already living within complex social and cultural systems of wellness and disease (Epstein, 2007a; Matthews et al., 2018; Patton, 2007).

5.6 Future Research Approaches

This dissertation undertakes an intersectional approach to sexuality and gender. Future research could replace the banners of “LGBT Cancer” or “SGM Cancer” as catch-all population identifiers in order to increase specificity and to avoid the ongoing conflation of sexuality and gender and to maintain a focus on the intersectionally located lived experiences of marginalized patients.

While this dissertation research reports and contributes valuable evidence about knowledge access and mobility, decision-making, and care experiences, further research into the lived experiences of cancer health and decision-making by sexual and/or gender minority patients is needed to form a robust knowledge base. Provider education and training needs to be based in research on patient experiences, and well as research evidence on the experiences and needs of care providers providing care to marginalized populations. Ongoing research could
consider the intersectional locations and social determinants of health for cancer patient populations, and research into sexual and/or gender minority patients needs to take a disaggregated view of sexuality and gender, along with considering the fluid and relational nature of sexuality and gender with other intersectional locations of race and ethnicity, class, dis/ability, generational cohort, etc.

Future research contributions into the effects of hormone therapy on trans and other gender minority people’s cancer risks and treatment processes will be helpful in establishing an evidence base to inform cancer care decision-making that is gender affirming, and also to inform gender affirming care decision-making that usefully considers cancer risk profiles.

5.7 Significance and Contributions

This dissertation contributes new knowledge about how it is that sexual marginality and gender marginality operate to shape experiences of cancer for minoritized breast and/or gynecologic cancer patients. This dissertation considers cancer health and knowledge mobilization issues relative to sexual marginality—as well as and alongside of issues relative to non-normative gender identity, expression, and embodiment—thereby adding a more nuanced and intersectional approach to understanding cancer and the lived experiences of marginalized patients.

An additional important aspect of this research is in its contributions to the cancer research landscape that focuses on the significance of communitarian knowledge. The methodological rigour and specific analytical frame of this dissertation amplifies the knowledge and voices of marginalized communities and increases the status of biographical knowledge from being seen as merely anecdotal, to a level of credibility wherein lived experience and
communitarian knowledge is regarded as “experiential evidence” (Ziebland & Herxheimer, 2008).

Health care providers tend towards a politics of inclusion (Epstein, 2007a), emphasizing that they are compassionate and “LGBT-friendly” and/or “trans-friendly” in their care provision (Lim et al., 2014). Recent research of American oncologists reports that 92% of oncologists agree that they are comfortable treating sexual and gender minority patients and that they support increased training and education about the unique needs of sexual and gender minority cancer patients (Tamargo et al., 2017), while over 70% of oncologists report being highly interested in receiving such education about working with these patient populations (Schabath et al., 2019). However, despite reporting generally positive attitudes toward treating sexual and/or gender minority patients, only 47% of oncologists report that they feel adequately educated and knowledgeable about their specific health needs (Tamargo et al., 2017). There is limited research on sexual and gender marginality and experiences of cancer health and decision-making, and so it is not surprising that cancer health care providers report that they are not generally using research to inform their practices with sexual and/or gender minority patients (Shetty et al., 2016). The research in this dissertation may provide new insights that can inform patient-centred treatment decision-making, improve patient-provider communication, and guide effective systemic approaches to cancer care provision.

This dissertation, and the research findings reported here, may contribute new knowledge and research evidence to undergird an informed approach to cancer care, treatment, and support for marginalized patients by providing a disaggregated look at how sexuality and gender independently and interdependently shape cancer care experiences. The evidence from the Cancer's Margins project contributes to the expanding field of research on cancer health and
treatment and the emerging pool of research on the health, health care experiences, and health
decision-making of sexual and/or gender minority populations, providing specific qualitative
research evidence that providers can engage with in shaping their professional practice.

This research also contributes evidence that might inform the design and provision of
ethical and culturally effective cancer systems and organization, and improve access to culturally
appropriate knowledge and support for sexual and/or gender minority patient populations. By
documenting and identifying the relationship between cancer health, and the experiences of
sexual and/or gender minority patients, this research contributes knowledge that may inform the
design of cancer care delivery, clinical education and training, care protocols, and the provision
of cancer information and support.

This dissertation research will be of interest to scholars in fields of Critical Studies in
Gender and Sexuality, Population and Public Health, Health Literacy and Knowledge
Translation, cancer care, and interdisciplinary health fields such as Social Work, Nursing,
Counselling Psychology, and Medical Education.
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Appendices

Appendix 1: Interview Protocol

*Cancer’s Margins: Interview Protocol for LGBQ Women and Transgendered People Diagnosed and Treated for Breast and/or Gynecologic Cancer*

(Approved by the UBC Behavioral Research Ethics Board March, 2011 and renewed February, 2012: H11-00275)

**NB:** This protocol is not a script. The protocol includes a pool of potential questions and follows a cancer trajectory, from screening, through a cancer diagnosis, surgery and treatment decision-making, and health practices following a period of urgent treatment.

**Pre-Interview Review:** Before the interview, email and ask the Interviewee about (1) when and what was the diagnosis/diagnoses of cancer, and (b) what – if any – are the URLs for websites they used during treatment to gather knowledge (specifically, did they Google or also consult cancer sites, or health sites, or access medical journal databases) and likewise, what are the URLs for sites they used to share knowledge (like a blog or MyLifeLine.org) during the processes of cancer diagnosis and treatment, and post-treatment. Ask them to identify the URLs of sites they visited, blogs they wrote, followed or participated in, PubMed, or any other online source of knowledge they used.

**1.0 Consent & Reminder:**

Open-ended questions and not a script
1.1 Introduction:

*Cancer's Margins* interviews ask:

- How do we experience cancer health, support and knowledge-seeking across the spectrum of gender and sexuality?
- How do we care for ourselves and each other in networks of support, communication, and health?
- Where do we access and share knowledge about cancer health, support and care?

2.0 Demographics:

- Where were you born?
- Where do you live?
- How long have you lived in XXX?
- How old are you?
- Are you employed – what?
- Level of Education completed?
- Race/Ethnicity?
- Relationship status?
- Any children?

2.1 Demographics, Intersecting Identities:

In this interview, most of my questions are about specific phases of the cancer trajectory, like diagnosis, surgery and treatment decision-making. But first, understanding the context for your experience of cancer health and knowledge is important, so let’s start with a few questions.
about identity – how you see yourself – how other people see you – how society classifies you – how you may or may not classify yourself. If we took a kaleidoscope as a metaphor for your sense of self, different colored bits of glass that come together to make a whole image, I want to understand what are the different and important parts that together, make up a picture of what is critical to know about your sense of self.

2.1. A Gender.

1. Do you consider yourself to be transgender/gender nonconforming in any way?

   IF YES:

   1a. What does “transgender/gender nonconforming” mean to you? What gender do you currently live as in your day-to-day life?

   1b. What was your assigned sex on your birth certificate?

   1c. Some people are very specific about how they identify in terms of gender and their gender expression, and they use words like femme, butch, genderqueer, woman, trans man … What is your felt gender identity or expression? What does that mean, for you? (e.g., feminine, masculine, butch)

   1d. What have you undertaken to medically transition – Y/N?

      F>M: hormone therapy, mastectomy, chest reconstruction, hysterectomy, oophorectomy, metoidioplasty, phalloplasty, or

      M>F: hormone therapy, hair removal, breast augmentation, orchiectomy, vaginoplasty?

   IF NO:
2. What is your gender identity?

3. Some people are very specific about how they identify in terms of gender and their gender expression, and they use words like femme, butch, genderqueer, woman, trans man … What is your felt gender identity or expression? What does that mean, for you? (e.g., feminine, masculine, butch)

2.1. B. Sexuality. Some people are very specific about how they identify in terms of sexual orientation and they use words like straight, bisexual, queer, dyke, lesbian, gay woman – do you use any of these words in particular to refer to your sexuality? What does that mean, for you? (identity vs. kinship networks vs. sexual attraction and behaviors vs. politics etc. . . .)

c. Race, ethnicity, and Socioeconomic status. How are race and or ethnicity part of how you see yourself, and how others see you? What about class? What does that mean, for you?

d. Other. Is there any other social or cultural aspect of how you see yourself, your family, your social network, that may impact on what health knowledge you find of value? What does that mean, for you?

3.0 Health Care and Insurance

1. Do you have access to health coverage?

2. Do you have access to extended health benefits and health coverage?

3. Do you have a regular health care provider? Briefly, what was important in how you selected your GP?
4.0 Cancer Screening and Knowledge about Risk/s

Before your Cancer Diagnosis,

1. What access to/participation in cancer screening PRE diagnosis? (e.g., paps, mammograms) What did you know then, about your specific cancer risks and screening priorities and practices?

2. There is some consensus that [insert lesbians, or bi women, or trans people] have higher than average cancer risks… like this advertisement by Ovarian Cancer Canada that asks Lesbians to think about their particular gynecologic cancer risk? Before your diagnosis, what did you know then about cancer risks and screening priorities for [insert lesbians, bisexual women, trans people]?

5.0 Your Cancer Experience: Access to Knowledge

We would like to learn about what are the various kinds of knowledge, knowledge providers, and knowledge sites, that played a role in your access to and/or contribution to health knowledge prior to, during, and after cancer diagnosis, surgery and treatment and ongoing? We are especially interested in how you located knowledge and then used that knowledge related to decision-making about care providers and treatments, related to getting support and related to advocacy for yourself as a patient who identifies as XXX (e.g., bisexual) and as YYYY (e.g., man or trans or femme) and as VVVV (e.g., working class).

5.1 Cancer diagnosis
1. What kind of access to health care did you have at the time of diagnosis? Was your sexual or gender identity relevant to your selection of an HCP at that time – family physician?
2. When was the diagnosis, and how did that unfold – regular or diagnostic screening?
3. What kinds of knowledge were part of the cancer diagnosis context?

Imaging >> Ultrasound?>> Bloodtests? >> Biopsy

**NOTE** that with Ovarian cancer there is no Biopsy and patients typically move from vague symptoms to ultrasound to surgery with no Biopsy or report.

**Biopsy Report? What did it mean to you? What did you KNOW?**

1. How did you seek out support during the Diagnosis – QLGBT or not?
2. What did your support and care network look like at the time of diagnosis? Who played a key role in that support network? (knowledge-sharing, or seeking, or note-taking w medical appts)
3. How did you seek out and access knowledge in the Diagnosis phase?
   a. Probe: Ask about each of these kinds of knowledge – what, how, so what, and how was it shared and mobilized? Specifically, probe about the particular role of internet searches, online knowledge-sharing sites vs. Google searches, and also, sharing of knowledge by anyone in the person’s care/support network.

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<tr>
<th>Biomedical Knowledge</th>
<th>How located?</th>
<th>What significance?</th>
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<td>Knowledge by HCP?</td>
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<td>Knowledge peer-to-peer</td>
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<td>Knowledge – narratives</td>
<td>How located?</td>
<td>What significance?</td>
<td>Shared, Assessed and utilized?</td>
</tr>
</tbody>
</table>

Did you seek a second opinion during the Diagnosis?

5.2 Cancer Surgery

- When was the surgery, and what was the surgery?
- Did you have a choice about a surgeon? What knowledge was relevant for your choice?

Was your sexual or gender identity relevant to your selection of an HCP during diagnosis - surgeon?

- Did you have a choice about the kind of surgery (e.g., lumpectomy vs. mastectomy total vs. subtotal hysto)? What knowledge was relevant for your choice?
- Was your sexual or gender identity relevant to your selection of surgical treatment – e.g., mastectomy/lumpectomy?
- How was your sexuality or gender identity impacted by the surgery?

1. How did you seek out support during the Surgery phase – QLGBT or not?
2. What did your support and care network look like at the time of surgery? Who played a key role in that support network? (knowledge-sharing, or seeking, or note-taking w medical appts)
3. How did you seek out and access knowledge in the Surgery phase?
a. Probe: Ask about each of these kinds of knowledge – what, how, so what, and how was it shared and mobilized? Specifically, probe about the particular role of internet searches, online knowledge-sharing sites vs. Google searches, and also, sharing of knowledge by anyone in the person’s care/support network.

<table>
<thead>
<tr>
<th>Biomedical Knowledge</th>
<th>How located?</th>
<th>What significance?</th>
<th>How shared, assessed and utilized?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge by HCP?</td>
<td></td>
<td>What significance?</td>
<td>Shared, Assessed and utilized?</td>
</tr>
<tr>
<td>Knowledge peer-to-peer</td>
<td>How located?</td>
<td>What significance?</td>
<td>Shared, Assessed and utilized?</td>
</tr>
<tr>
<td>Knowledge- ResourceCen</td>
<td>How located?</td>
<td>What significance?</td>
<td>Shared, Assessed and utilized?</td>
</tr>
<tr>
<td>Knowledge – narratives</td>
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</tr>
</tbody>
</table>

Did you seek a second opinion during the Surgery decision-making? Was any knowledge part of seeking that second opinion? How access knowledge? How access HCP for second opinion about surgery?

Pathology Report? What did it mean to you? What did you KNOW?

5.3 Cancer Treatment – i.e.: chemo or radiation

- When and what?
- What kinds of access to Treatment were made available to you?
- Was there anything in particular that would make your sexual or gender identity – your chosen support network, relevant to your experience of cancer treatment, or your decision-making about cancer treatment and treatment HCP’s
• What kinds of knowledge were part of the cancer treatment decision-making context?

Was your sexual or gender identity relevant to your selection of treatment – e.g., chemo or radiation?

How was your sexuality or gender identity impacted by the chemo or the radiation?

How did you seek out support during the Chemo/Radiation phase – QLGBT or not?

1. How did you seek out support during the Chemo/Radiation phase – QLGBT or not?
2. What did your support and care network look like at the time of treatment? Who played a key role in that support network? (knowledge-sharing, or seeking, or note-taking w medical appts)
3. How did you seek out and access knowledge in the treatment phase?
   a. Probe: Ask about each of these kinds of knowledge – what, how, so what, and how was it shared and mobilized? Specifically, probe about the particular role of internet searches, online knowledge-sharing sites vs. Google searches, and also, sharing of knowledge by anyone in the person’s care/support network.

<table>
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<td>How located?</td>
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</tr>
<tr>
<td>Knowledge – narratives</td>
<td>How located?</td>
<td>What significance?</td>
<td>Shared, Assessed and utilized?</td>
</tr>
</tbody>
</table>
Did you seek a second opinion during the Treatment decision-making? Was any knowledge part of seeking that second opinion? How access knowledge? How access HCP for second opinion about cancer treatment? How was your sexuality or gender identity impacted by the cancer treatment/s?

Complementary Therapies? What did you know about that therapy and your health decision-making?

5.4 Living With Cancer After Treatment. (What some folks call, Survivorship or Thriving – or Living with Metastatic Cancer post-active-treatment)

NOTE: A person living with metastatic disease may never be living “after” treatment and so be careful that you are asking about the person’s relationship to the concept/label of “survivor”…

- Ask about use of “survivor” terminology
- What kinds of knowledge are part of living with cancer or thriving? (nutrition, cancer prevention, toxins, exercise, alcohol, regular screening)
- What did/does your support and care network look like at the time of survivorship or living with metastatic cancer post-active-treatment? Who played a key role in that support network? (knowledge-sharing, or seeking, or note-taking w medical appts)

How has your sexuality been impacted by living with cancer after treatment <or living with metastatic cancer>?
How has your gender identity been impacted by living with cancer after treatment, <or living with metastatic cancer>? 

How has your support network been impacted by living with cancer after treatment, <or living with metastatic cancer>? 

Probe: Ask about each of these kinds of knowledge – what, how, so what, and how was it shared and mobilized? Specifically, probe about the particular role of internet searches, online knowledge-sharing sites vs. Google searches, and also, sharing of knowledge by anyone in the person’s care/support network. 

<table>
<thead>
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<td>Knowledge – narratives</td>
<td>How located?</td>
<td>What significance?</td>
<td>Shared, Assessed and utilized?</td>
</tr>
</tbody>
</table>

- **Now**, do you seek out or locate knowledge about [insert key identity terms here] and cancer treatments specifically?
- Do you seek out online sites that target QLGBT communities in particular?
- Do you seek out offline sites, like a Cancer Resource Center, that target QLGBT communities in particular?
6.0 Concluding Thoughts about Culturally Competent Support and Care for an LGBT Cancer Patient and Post-Treatment

1. Looking at yourself as a [XXX XX] person diagnosed and treated for cancer,
Are there particular aspects of your treatment as a [lesbian/bisexual/trans person] with [breast or gynecological] cancer that went especially well, and things that could have happened differently?

2. If you had to give advice to someone like yourself who will lend support to a [XXXXX] person with cancer, what you tell this person? What should s/he watch out for with respect to providing cancer support?

7.0 Design of a LGBT Cancer Hub

HealthTalkOnline.org http://www.healthtalkonline.org/ and/or Trans PULSE Project
http://transpulseproject.ca/ websites.

Design of a LGBT Cancer’s Margins Hub. What public educational support (such as schools and libraries) is available and/or should be available in building LGBT cancer health knowledge and general health knowledge literacy in discovery, comprehension, assessment, and utilization strategies? What would you value in a LGBT cancer site? How to support care networks? Use as example, the Health Talk Online site, where people share experiences of decision-making about cancer and treatment, or Trans PULSE community-based project website, where researchers and community members and service providers share knowledge and engage in dialogue and joint planning initiatives to build capacity.

1. What would you value in a LGBQ/T cancer site?
2. If there were an online group for LGBQ/T people who are supporting someone with cancer, would you participate?

3. What would you be looking for when you visited a LGBQ/T cancer site?

4. a. What would matter to you about how this site was designed?

   b. What do you think about LGBT Cancer Hub as a name for this site?

8.0 Designate a Support Person for Cancer’s Margins Interview?

   The Cancer’s Margins project is also interviewing support people designated by folks we interview. Is there a trusted other – a key person in your support network at the time you were diagnosed and treated for cancer, who we could approach to interview? We would – of course – in that interview, respect your confidentiality and not share ANY information that we have learned in this interview with you.

   Name:

   Email:

   Phone:

9.0 Providing Participant Closure, Access to Supports and Acknowledging Contribution.

   Thanks for a really great interview. “I was particularly interested in…” or “Your experience with X will be very helpful as we try to answer the question Y”, or etc. etc.

   You may find after this interview that talking about your cancer experiences kicks loose feelings or memories you haven’t thought about for some time. This is a really natural reaction to the process of being interviewed. You might want to consider talking to someone who was there for your experience with cancer, or someone that you trust.
Some people have told us after their interview that they felt judged. We want to be clear that we are not judging your experience. On the contrary what you have told us is very valuable information that we hope will help other LBQ women and trans people and their support people, and health care practitioners in the future.

**Down the road, we will contact you about participating in a no-cost Micro-Documentary Workshop?** Cancer’s Margins is going to hold a free two-day workshop next year, where people we have interviewed are invited to learn how to produce a short documentary, that can be shared online – if you participate, the video and audio records of today’s interview will give you some really good raw materials for that workshop that of course, you can augment with anything else that matters to how you want to tell your story.

We will also contact you when there are published reports of our findings, or if we would like to ask you about putting a short clip from this interview online.

**Gift Cards.** There is no way that Cancer’s Margins can compensate interview participants for the huge gift of offering so freely a look at a very intimate time in your life. But we offer a small gift card as a token of our appreciation…

If questions occur to you, or there are more things you want to tell me, please feel free to email me. Here is my card.
### Appendix 2: Coding Scheme

<table>
<thead>
<tr>
<th>MAJOR CODES</th>
<th>SUB-CODES</th>
<th>CODE DEFINITIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity &amp; Expression</td>
<td>Age</td>
<td>How participant's age (generational cohort) affects their identity and expression (lesbian vs. queer identity), especially in relation to diagnosis and treatment for breast and gynecologic cancers. For younger participants, how diagnosis may lead to genetic testing.</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td>Within our study, how gender identity and expression affect those participants diagnosed and treated for breast or gynecologic cancer. Identity refers to innate and deeply felt gender while expression refers to how we express our gender to others.</td>
</tr>
<tr>
<td></td>
<td>Gender Fluidity</td>
<td>Flexible range of gender expression, unrestricted by stereotypical female or male roles. Not limited to a fixed identity or expression.</td>
</tr>
<tr>
<td></td>
<td>Parent</td>
<td>Identity and expression as a parent</td>
</tr>
<tr>
<td></td>
<td>Race</td>
<td>Race/ethnicity identity and expression</td>
</tr>
<tr>
<td></td>
<td>Religious or Spiritual Beliefs</td>
<td>When religious or spiritual beliefs played a key role in the patient's understanding of living with cancer</td>
</tr>
<tr>
<td></td>
<td>SES</td>
<td>Socio-Economic Status (SES) identity and expression</td>
</tr>
<tr>
<td></td>
<td>Sexuality</td>
<td>Sexuality - identity and expression</td>
</tr>
<tr>
<td></td>
<td>Stigma</td>
<td>Always cross code with the ID/Express related to stigma, like Age or Race etc. Recognition of/Experiences of cultural norms that are deemed “different” or “deviant” in certain geo- or sociopolitical or historical contexts and that are related to myriad forms of discrimination and/or institutional erasure and/or informational erasure.</td>
</tr>
<tr>
<td></td>
<td>Trans and/or Gender Diverse</td>
<td>Gender diverse/Transgender people whose gender identity or expression differs from cultural norms relative to natal sex.</td>
</tr>
<tr>
<td>Cancer Trajectory</td>
<td>Cancer Generations</td>
<td>Patients speak about cancer diagnosis of close family members: mother had breast cancer/aunt had ovarian cancer. Diagnosis before age 50 may introduce testing for BRCA gene or other genetic factors</td>
</tr>
<tr>
<td>Event Type</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Cancer Risk</td>
<td>Discussion of increased risk factors for cancer. Also strategies for risk reduction</td>
<td></td>
</tr>
<tr>
<td>Screening: Participation</td>
<td>Describes process of participating in screening; may be coded with Decision-making. Also include barriers to participation in screening.</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Includes going to HCP because “something is wrong” – not always a lump, could be a fever or abdominal discomfort. Indicates high degree of self knowledge. Or partner found lump or urged patient to see HCP in response to acute symptoms.</td>
<td></td>
</tr>
<tr>
<td>Diagnosis: Biopsy</td>
<td>Biopsy testing for breast cancer; include other forms of diagnostic screening tests ordered by HCP including MRI and diagnostic mammogram</td>
<td></td>
</tr>
<tr>
<td>Diagnosis: HCP</td>
<td>When health care provider diagnoses cancer through regular screening (if ordering tests in response to acute symptoms, double code with Diagnosis)</td>
<td></td>
</tr>
<tr>
<td>HCP Incompetence</td>
<td>Participant states that HCP was incompetent. For example, cancer would have been diagnosed at a much earlier stage if health care provider(s) had been more inquiring or less dismissive of symptoms; also, news of diagnosis delivered in a disrespectful manner. Double code with specific Treatment Provider code.</td>
<td></td>
</tr>
<tr>
<td>Surgery: Lumpectomy</td>
<td>Discussing lumpectomy surgery, cross code as needed</td>
<td></td>
</tr>
<tr>
<td>Surgery: Mastectomy</td>
<td>Discussing mastectomy surgery, cross code as needed</td>
<td></td>
</tr>
<tr>
<td>Surgery: Reconstruction</td>
<td>Discussing “breast” reconstruction surgery, cross code as needed</td>
<td></td>
</tr>
<tr>
<td>Surgery: Pathology report</td>
<td>Discussing pathology report, stage and grade, cross code as needed</td>
<td></td>
</tr>
<tr>
<td>Surgery: Ovarian Cancer</td>
<td>Discussing surgery as treatment for ovarian cancer, cross code as needed</td>
<td></td>
</tr>
<tr>
<td>Surgery: Uterine Cancer</td>
<td>Discussing surgery for uterine cancer, cross code as needed</td>
<td></td>
</tr>
<tr>
<td>Treatment</td>
<td>General cancer treatment code - use when other codes do not fit</td>
<td></td>
</tr>
<tr>
<td>Treatment: Chemo</td>
<td>Discussing chemo treatment generally; cross code with Side Effects if appropriate</td>
<td></td>
</tr>
<tr>
<td>Treatment: Complementary Treatment</td>
<td>Discussing use of complementary therapies, such as massage, acupuncture, yoga, vitamins, herbal treatments, Traditional Chinese Medicine (TCM)</td>
<td></td>
</tr>
<tr>
<td>Treatment: Radiation</td>
<td>Discussing radiation treatment generally; cross code with Side Effects if appropriate</td>
<td></td>
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</tr>
<tr>
<td>Treatment: Hormone Therapy</td>
<td>Being on Hormone Therapy, as treatment for cancer (Tamoxifen) or as gender therapy. Include side effects, issues, sexuality, sex drive, pushing back, risk, etc.</td>
<td></td>
</tr>
<tr>
<td>Treatment: Side Effects</td>
<td>Discussing side effects of treatment: surgery, chemo, radiation, pharmaceuticals etc.</td>
<td></td>
</tr>
<tr>
<td>Recurrence</td>
<td>Fear of cancer returning; dealing with metastatic cancer</td>
<td></td>
</tr>
<tr>
<td>Post treatment: Interactions</td>
<td>With HCP and support network. Participating in studies. Especially important code for patients living with metastatic cancer</td>
<td></td>
</tr>
<tr>
<td>Post treatment: Monitoring</td>
<td>Lifetime of genetic risk monitoring; 5+ years routine monitoring.</td>
<td></td>
</tr>
<tr>
<td>End of Life</td>
<td>Discussing preparation for end of life care</td>
<td></td>
</tr>
<tr>
<td><strong>Care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affirmative Care</td>
<td>Affirmative care not only in terms of gender, but other forms of affirmation – such as LGBT representation and affirmation of sexual orientation, ethnic/cultural identity</td>
<td></td>
</tr>
<tr>
<td>Being Managed</td>
<td>Forced or required encounters with health care in order to get what you want or need. For example: trans women have to see endocrinologist regularly for monitoring; lesbians who want to get pregnant often have to work with health care provider.</td>
<td></td>
</tr>
<tr>
<td>Decision-making</td>
<td>Always cross-code with either Treatment Provider codes and/or with Cancer Trajectory code and/or Knowledge code or Support or other codes</td>
<td></td>
</tr>
<tr>
<td>Gender affirming care</td>
<td>Healthcare practices that are (a) cultural competent and that (b) affirm gender identity or expression and that (c) may or not include biomedical treatment options</td>
<td></td>
</tr>
<tr>
<td>Pathways to Health</td>
<td>Best practices for health promotion. Include individual pathways to health (exercise, health eating etc.), policies that provide structural support and advice for healthcare workers on providing culturally competent care to sexual and gender minorities. Include examples of competent or incompetent HCP behaviour. Potential material for medical curriculum.</td>
<td></td>
</tr>
<tr>
<td>Self-Management</td>
<td>The ‘work’ of ensuring quality health or health care. The energy expenditure or effort that goes into negotiating to protect one's well-being, but will sometimes go beyond healthcare. Managing a care situation to get what you need, managing self presentation, disclosure, information, HCP encounters etc. It may be coded in conjunction with</td>
<td></td>
</tr>
<tr>
<td>Systemic/Institutional Factors</td>
<td>Include lack of resources such as not enough doctors – having nurses perform physician duties, having to travel from rural areas to access services</td>
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</tbody>
</table>

### Feeling Cancer

<table>
<thead>
<tr>
<th>Acceptance</th>
<th>Accepting diagnosis and moving forward</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>When age is discussed within the context of cancer - feeling old after diagnosis or younger than most people who have been diagnosed.</td>
</tr>
<tr>
<td>Body changes</td>
<td>How patient feels changes in body, positive or negative, as a result of cancer diagnosis or treatment. Includes pain or discomfort before, during or after treatment.</td>
</tr>
<tr>
<td>Cancer Culture Identity</td>
<td>Being a person with cancer had become part of the person's identity. Includes cancer activism</td>
</tr>
<tr>
<td>Economics</td>
<td>How patient's economic situation has changed as a result of cancer diagnosis or treatment, including loss of income or opportunity. Include instances when treatments were provided through social programs, or when a loss of energy reduced one's ability to earn an income</td>
</tr>
<tr>
<td>Emotions</td>
<td>How patient feels about cancer treatments and post-treatment. Depression, anger, changes in perspective.</td>
</tr>
<tr>
<td>Fertility</td>
<td>Participants discuss not wanting kids but then having the choice taken away - related to gyne surgeries/recurrence risk/Tamoxifen/lack of knowledge/research</td>
</tr>
<tr>
<td>Gender</td>
<td>Influence of gender on treatment. For trans person or butch lesbians, being alone in a waiting room of cis-gendered people.</td>
</tr>
<tr>
<td>Humour</td>
<td>Code when humour is used as a coping tool to deal with uncertainty, insecurity and fear. Cross code with Excellent Anecdote or Quotable Quote when appropriate.</td>
</tr>
<tr>
<td>Language, Poeticizing, Metaphor</td>
<td>Discussing cancer treatment and care in a poetic or metaphorical way</td>
</tr>
<tr>
<td>Mortality</td>
<td>Discussion of emotions felt when considering fear of death and facing one's mortality</td>
</tr>
<tr>
<td>Parenting</td>
<td>Discussion of how living with cancer diagnosis and choosing treatment is influenced by being a parent</td>
</tr>
<tr>
<td>Relationships</td>
<td>How being diagnosed with, treated for and recovery from cancer influences relationships with partner, friends, and social network</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Sexuality</td>
<td>How being diagnosed with, treated for and recovery from cancer influences sexuality and sexual relationships</td>
</tr>
<tr>
<td>Temporal</td>
<td>Waiting time for cancer treatment, waiting for test results. Cross code with Trans and/or Gender Diverse if waiting time for gender surgery or other types of treatment</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Knowledge</strong></th>
<th><strong>Access: Sources</strong> Where people go to find info on health, healthcare, queer realities, etc.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Access: Seeking</strong> Seeking to know more re health, cancer health, alternative therapies</td>
</tr>
<tr>
<td></td>
<td><strong>Biomedical</strong> Knowledge perspective that is limited to biological factors in clinical medicine; include online sites that explain technical terminology and treatment options to patients</td>
</tr>
<tr>
<td></td>
<td><strong>Biopolitics</strong> People discussing how they feel about being a survivor, identifying with the term, not identifying with the term, not feeling like they survived, fear of recurrence, etc.</td>
</tr>
<tr>
<td></td>
<td><strong>Expert</strong> Being an expert; or seeking/having access to expert advice</td>
</tr>
<tr>
<td></td>
<td><strong>Lack of</strong> Absence of knowledge. This can refer to specific people lacking knowledge; that there is little information available; that little research is done on a particular topic.</td>
</tr>
<tr>
<td></td>
<td><strong>Misinformation</strong> When HCPs talk re misinformation proliferating re queer health, or where HCPs actually are providing misinformation. Primarily the participant’s perceptions re: misinformation, rather than the coder’s perceptions that a participant's info is erroneous.</td>
</tr>
<tr>
<td></td>
<td><strong>Self</strong> One's own knowledge about their body; knowledge the interviewee brings to the encounter.</td>
</tr>
<tr>
<td></td>
<td><strong>Sharing Experiential</strong> Peer support groups, writing blog, talking to others with similar experiences for their input. Both sharing and accepting experiential knowledge.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Locations/Spaces</strong></th>
<th><strong>Cancer Care Provider</strong> Interactions at Cancer Care Provider Office. Cross code as needed.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Clinic</strong> Interactions at clinic. Cross code as needed.</td>
</tr>
<tr>
<td>Location</td>
<td>Description</td>
</tr>
<tr>
<td>-------------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>GP Office</td>
<td>Interactions at GP’s office. Cross code as needed.</td>
</tr>
<tr>
<td>Home</td>
<td>Interactions at home. Cross code as needed.</td>
</tr>
<tr>
<td>Hospice</td>
<td>Discussion of interactions in hospice; cross code with Decision-Making and End of Life when appropriate</td>
</tr>
<tr>
<td>Hospital</td>
<td>Interactions at hospital. Cross code as needed.</td>
</tr>
<tr>
<td>Online</td>
<td>Support from friends online, especially for those who live in rural communities or who do not have peer support in their geographic community</td>
</tr>
<tr>
<td>Support Group</td>
<td>Interactions at support group, in addition to Knowledge - Sharing Experiential. Cross code as needed.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Support</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community/Generational</td>
<td>Social support from peer groups (beyond partner, friends, family)</td>
</tr>
<tr>
<td>HCP</td>
<td>HCP who help patient navigate the cancer trajectory</td>
</tr>
<tr>
<td>Lacking</td>
<td>Support lacking for the patient or partner or their support network</td>
</tr>
<tr>
<td>Network</td>
<td>Discussion of partner, friends, family, homecare workers – interactions with the support network</td>
</tr>
<tr>
<td>Partner</td>
<td>Support from a partner</td>
</tr>
<tr>
<td>Seeking</td>
<td>How and where and why participant looks for support. When participant has found a support group or network, code shifts to Knowledge - Sharing Experiential</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Treatment Provider</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complementary and Alternative Medicine</td>
<td>Interactions with naturopath, acupuncturist, Chinese Traditional Medicine practitioner, massage therapist etc.</td>
</tr>
<tr>
<td>Counsellor</td>
<td>Interactions with Counsellor, cross code as needed</td>
</tr>
<tr>
<td>GP</td>
<td>Interactions with General Practitioner or primary care doctor; cross code as needed</td>
</tr>
<tr>
<td>Intern</td>
<td>Interactions with Intern or Resident, cross code as needed</td>
</tr>
<tr>
<td>Nurses and Care Workers</td>
<td>Interactions with Nurses and other support staff; cross code as needed</td>
</tr>
<tr>
<td>Oncologist</td>
<td>Interactions with Oncologist (chemo); cross code as needed</td>
</tr>
<tr>
<td>Radiologist</td>
<td>Interactions with Radiologist (radiation); cross code as needed</td>
</tr>
<tr>
<td>Surgeon</td>
<td>Interactions with Surgeon; cross code as needed</td>
</tr>
<tr>
<td>---------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>Excellent Anecdote or Quotable Quote</td>
<td>Portion of transcript that may be suitable for one minute clip on Cancer's Margins website or for data summaries (always cross-code with the substantive focus code)</td>
</tr>
</tbody>
</table>