

# *Cancer's Margins:* Trans\* and Gender Nonconforming People's Access to Knowledge, Experiences of Cancer Health, and Decision-Making

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## Abstract

**Purpose:** Research in Canada and the United States indicates that minority gender and sexuality status are consistently associated with health disparities and poor health outcomes, including cancer health. This article investigates experiences of cancer health and care, and access to knowledge for trans\* and gender nonconforming people diagnosed with and treated for breast and/or gynecologic cancer. Our study contributes new understandings about gender minority populations that will advance knowledge concerning the provision of culturally appropriate care. This is the first study we are aware of that focuses on trans\* and gender nonconforming peoples' experiences of cancer care and treatment, support networks, and access to and mobilization of knowledge.

**Methods:** This article analyzes trans\* and gender nonconforming patient interviews from the *Cancer's Margins* project ([www.lgbtcancer.ca](http://www.lgbtcancer.ca)): Canada's first nationally-funded project that investigates the complex intersections of sexual and/or gender marginality, cancer knowledge, treatment experiences, and modes of the organization of support networks.

**Results:** Our analysis documents how different bodies of knowledge relative to cancer treatment and gendered embodiment are understood, accessed, and mobilized by trans\* and gender nonconforming patients. Findings reported here suggest that one's knowledge of a felt sense of gender is closely interwoven with knowledge concerning cancer treatment practices; a dynamic which organizes knowledge mobilities in cancer treatment.

**Conclusions:** The findings 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 treatments, and access to and mobilization of related knowledge.

**Key words:** access to knowledge, cancer health disparities, illness narratives, population health equity, transgender.

## Introduction

MARGINAL CULTURAL LOCATIONS, specifically in relation to sexuality and gender, have been associated with numerous general health disparities.<sup>1-9</sup> In particular, research regarding trans\* and gender nonconforming people

has identified that gender marginality is associated with health care avoidance overall.<sup>10-12</sup>

In research on cancer health and care, sexual and gender minority populations are locations for multiple "overlooked health disparities;"<sup>3</sup> diverse groups which have been left out of the most basic epidemiological cancer

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\*Our use of the phrase "trans\* and gender nonconforming" in this article is based on the World Professional Association for Transgender Health's Standards of Care, Version 7 that uses the term "transsexual, transgender, and gender nonconforming", which we have adapted to "trans\* and gender nonconforming". In this way, the "\*" in "trans\*" comes to stand in place of "sex" or "gender" as a wildcard for a wide range of identities and expressions, further problematizing the binary applications of sex/gender and, additionally, contributing to systems of knowledge that locate the margins of sex/gender as sites of knowledge production.

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surveillance and other broad-based data collection carried out by national and international health agencies.<sup>13–16</sup> Sexual and gender minority populations are underrepresented in health professional curricula,<sup>6,17</sup> leaving care providers without sufficient education and knowledge to provide relevant and appropriate care. Recent findings show that sexual minority cancer survivors are 60% less likely than heterosexual survivors to rate their health as “good,”<sup>18</sup> 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.<sup>19</sup>

#### *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,<sup>6,5</sup> issues specific to gender minorities<sup>8,16</sup> have often been conflated with concerns specific to sexual marginality.<sup>6,16,20</sup> 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.<sup>8,21,22</sup>

The relatively small body of research in North America that addresses the experiences of sexual minority women and cancer health<sup>3,23–25</sup> has provided evidence about cancer related health disparities.<sup>3,25,26</sup> Sexual minority women are more likely to express dissatisfaction with cancer care provision<sup>27</sup> and underutilize cancer screening.<sup>28–30</sup> 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.<sup>23,24,31</sup> 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 sexual minority identity.<sup>23,24</sup> To date, research on sexual minority women and cancer 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,<sup>23,25</sup> but work in the area of cancer and sexuality and gender tends to assume cisgender embodiment, identity and expression. We know of no studies available to-date that specifically address trans\* and gender nonconforming people’s experiences of cancer health generally, and treatment specifically.<sup>22,32</sup> 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.

#### *Trans\* cancer and the cancer research landscape*

Gender marginality has significant impacts on overall experiences of health and care.<sup>11,20,33–35</sup> However, trans\* and gender nonconforming people have been overlooked consistently in the research on cancer health and care.<sup>22,36</sup> 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.”<sup>37,38</sup> We seek 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.<sup>39</sup> A recent research review<sup>22</sup> 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,<sup>22</sup> often recommending guidelines for screening protocols and/or increased attention to cultural competency.<sup>32,40–46</sup>

Some case studies suggest there may be a possibility that hormones provided as part of gender affirming care increase cancer risks.<sup>42,47–55</sup> In contrast, larger cohort, long-term follow up studies suggest that administration of hormone treatments does not significantly affect overall cancer mortality,<sup>56,57</sup> and that some hormonal regimens may, in fact, have protective factors in relation to cancer risk.<sup>47,58,59</sup> Recent studies of trans\* and gender nonconforming populations and cancer health report underutilization of cancer screening<sup>60</sup> and delays in accessing follow up care.<sup>45,60</sup> 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.

#### *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.<sup>61</sup> The theoretical model for *Cancer’s Margins*<sup>61,62</sup> 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.<sup>63,64</sup> In these accounts, both “cancer” and “trans\*” are constituted by means of knowledge and practices wherein people, places, and practices produce narratives relative to a set of biographical norms that shape gendered modes of knowing and of embodiment.<sup>62</sup>

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.<sup>65</sup> In this mode of analysis, then, it is perhaps unavoidable that the very terms by which we discursively constitute participants as trans\* and/or gender nonconforming, are the same terms by which we may reinscribe the limitations of gender 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”<sup>66</sup> that seek to inscribe new understandings and knowledge relative to gendered practices of self knowledge, embodiment, and expression.<sup>66</sup>

## Methods

### *Doing and knowing: The Social Study of Medicine 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.”<sup>67</sup> Tracing the genealogical movements of knowledge, how it is accessed, used, and mobilized, can help us 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.<sup>68,69</sup> We must look “behind and beyond” accounts of experience<sup>68,70</sup> 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. 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,<sup>64,71,72</sup> 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.”<sup>73</sup> Fields of cancer knowledge construed as “disease regimes” can be examined so as to document and examine the institutionalized practices, authoritative discourses, and social relations that produce the categories of “gender minorities” and “cancer patients,” and to identify and question the mechanisms through which cancer treatment simultaneously produces cancer patients and disciplines their bodies in relation to gender discourses.

### *Logic of participant inclusion*

Sampling for *Cancer's Margins* was informed by previous Canadian research with gender minority patients<sup>74</sup> 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.<sup>75</sup> 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.”<sup>75</sup>

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 the 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, disability, 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.<sup>76</sup>

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).<sup>75</sup> 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 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.

### *Data collection*

Approval for 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.

### *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

TABLE 1. PARTICIPANT DEMOGRAPHICS

	Dana	Liwayway	Dario	James	Jake	Blake	John	Jolene	Logan	Max
Age	64	50	50	58	53	57	33	59	56	54
Pronoun	They	They	They	He	She	He	He	They	He	He
Cancer Diagnosis	Breast cancer	Ovarian and uterine cancer	Breast cancer	Cervical cancer	Ovarian cancer	Ovarian cancer	Breast cancer	Breast cancer	Ovarian cancer	Breast cancer
Race/Ethnicity	Caucasian	Native American, Filipino	Latina	Caucasian	Caucasian	Caucasian	Asian-Canadian	Caucasian	Caucasian;	French Canadian
Gender Identity	Butch	Genderqueer, trans, 2-spirit, butch	Genderqueer	Trans man, trans male	Butch, gender nonconforming	Female-to-Male	Female-to-Male	Gender fluid, transgender	Trans man	Trans man
Sexual Orientation or Identity	Butch	Queer	Queer	Attracted to gay men	Butch dyke	Married to cisgender lesbian	Queer	Butch, queer, dyke	Queer	Attracted to women
<b>Cancer Treatment:</b>										
Radiation Therapy	X	X		X			X			X
Chemotherapy	X	X			X	X	X			
Hormone Therapy	X	X	X				(Testosterone discontinued)			
Mastectomy		Tamoxifen	Tamoxifen, Aromasin					X		X
Lumpectomy			Bilateral					Bilateral		Partial
Hysterectomy	X				X	X		X	X	
Tumour Debulking		X			X	X			X	
Conization									X	
<b>Gender Affirming Care:</b>										
Hormone Therapy		Testosterone		X						X
Bilateral				X			Testosterone			Testosterone
Mastectomy (Typically with chest contouring)				X			X			X
Genital Surgery or Reconstruction				X			X			X
Hysterectomy (typically with bilateral salpingo-oophorectomy)				X			X			X
Phalloplasty				X						

and other modes of support. Our thematic analysis prioritizes the production of an account of what trans\* and gender nonconforming cancer patients actually “did”—the “doing cancer”<sup>72</sup> and “doing gender”<sup>77</sup> reported to us by *Cancer’s Margins* participants.

**Results**

*Cancer surgeries experienced as practices of gender affirming care*

While not all trans\* and gender nonconforming people undergo surgery as part of gender affirming health care, 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 our 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 health care 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 (Table 2) 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.

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.

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

TABLE 2. CANCER SURGERY EXPERIENCED AS PRACTICES OF GENDER AFFIRMING CARE

Blake (57, Caucasian, ovarian cancer, female-to-male)	<i>“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.”</i>
Jolene (59, Caucasian, breast cancer, genderfluid, transgender)	<i>“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.”</i>
Jake (53, Caucasian, ovarian cancer, butch, gender nonconforming)	<i>“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.”</i>

TABLE 3. "WOMEN'S CANCERS" AND THE EXPERIENCES OF TRANS\* AND GENDER NONCONFORMING CANCER PATIENTS

Max (54, French Canadian, breast cancer, trans man)	<i>"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."</i>
Jake (53, Caucasian, ovarian cancer, butch, gender nonconforming)	<i>"(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."</i>
James (58, Caucasian, cervical cancer, trans man, trans male)	<i>"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.'"</i>
John (33, Asian-Canadian, breast cancer, female-to-male)	<i>"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 clinic that doesn't need to be gendered."</i>

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.

#### *"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," and relatedly, the ways that this designation is taken up by and mobilized by cancer treatment contexts,<sup>73</sup> 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 (Table 3) 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 is it welcoming. The trans\* and gender nonconforming patients we interviewed told us about being asked to leave a treatment space or waiting room.

Being unwelcome in clinic waiting rooms was an experience echoed by numerous participants. Jake described her experience of being a gender nonconforming person in a waiting room as one of feeling unwelcome. 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. This 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 us 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.

#### *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 gynecologic 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. For participants in our study (Table 4), 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 gender affirming hormone 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.

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.

TABLE 4. TRANS\* CANCER CARE AS DISORIENTING, UNCOORDINATED BODIES OF KNOWLEDGE

Blake (57, Caucasian, ovarian cancer, female-to-male)	<i>“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.”</i>
James (58, Caucasian, cervical cancer, trans man, trans male)	<i>“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.”</i> <i>“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.”</i>
Jolene (59, Caucasian, breast cancer, genderfluid, transgender)	<i>“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.”</i>

*Online knowledge seeking*

One of the striking aspects of the knowledge seeking behaviors 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, and 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 (Table 5), 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.

Some participants reported finding more general cancer resources online that they felt were useful and these resources came in the form of either, i) access to medical research, highlighting the need for accessible information and research on trans\* populations and cancer, or ii) 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.

*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 (Table 6). 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.

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.

TABLE 5. ONLINE KNOWLEDGE SEEKING

John (33, Asian-Canadian, breast cancer, female-to-male)	<i>“There’s certainly no trans* stuff—not even online—that I could find or that was what I needed.”</i>
Liwayway (50, Native American, Filipino, ovarian cancer and uterine cancer, genderqueer, trans, two-spirit, butch)	<i>“I did research... I got online. I went to the library. And I talked to a lot of cancer survivors.”</i>
Blake (57, Caucasian, ovarian cancer, female-to-male)	<i>“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.”</i>
Dario (50, Latina, breast cancer, genderqueer)	<i>“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.”</i>
James (58, Caucasian, cervical cancer, trans man, trans male)	<i>“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.”</i>

TABLE 6. PEER SUPPORT GROUPS AND ERASURE

Dana (64, Caucasian, breast cancer, butch)	<i>“A woman who I had dated had breast cancer, was diagnosed, and had gone through this whole rigmarole of getting knowledge and researching it... She was my single most provider of research information... So, she gave me that gift, going through mine... I said, ‘That’s what I need from you, is that information.’ And she gifted it all to me.”</i>
Blake (57, Caucasian, ovarian cancer, female-to-male)	<i>“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?’ ”</i>
John (33, Asian-Canadian, breast cancer, female-to-male)	<i>“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.”</i>
Logan (56, Caucasian, British, Jewish, ovarian cancer, trans man)	<i>“But, my experience as someone of non-normative gender, it’s affected the way I’ve experienced my care and the way I make sense of my cancer. And the mourning I have for the body parts is different... I’m trans and that does affect my experience, my cancer journey.”</i>

*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 gynecologic cancer treatment experiences of trans\* and gender nonconforming people. Trans\* and gender nonconforming breast and gynecologic cancer patients report complex political knowledge about their intersectional social locations, but also report that they have difficulty determining how it is that each of their multiple social locations shapes their experiences of breast and gynecologic 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 gynecologic cancer were shaped by particular elements of their social location (e.g., sexual marginality, gender marginality, race, ethnicity, or dis/ability) (Table 7).

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

TABLE 7. INTERSECTIONALITY AND THE CANCER TREATMENT EXPERIENCES OF TRANS\* AND GENDER NONCONFORMING PEOPLE

Dana (64, Caucasian, breast cancer, butch)	<i>“Being queer is who I am. That’s all of me, that’s every core in my cell in my being... my whole self. Cancer is something that I experienced for a period of time that came into my life. But it’s not my whole self.”</i>
John (33, Asian-Canadian, breast cancer, female-to-male)	<i>“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.”</i>
Dario (50, Latina, breast cancer, genderqueer)	<i>“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.”</i>
Liwayway (50, Native American, Filipino, ovarian and uterine cancer, genderqueer, trans, 2-spirit, butch)	<i>“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?”</i>



interactions by removing a visible element of sexual marginality and racialization; in this case, their queer partner who was also a person of color.

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.

## Discussion

Our study contributes new understandings about gender minority populations that advance knowledge concerning the provision of culturally appropriate care. This is the first study we are aware of that focuses 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 health care 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\* and gender nonconforming cancer patient as a knowing subject. In fact, models of culturally competent care may operate in order to obscure discursive disease regimes<sup>65</sup> 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."<sup>61</sup> Where cancer care provision for breast and/or gynecologic cancers relies on biomedical discourses that organize 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.

## Conclusions

*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 represent 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. Here we have reported on various experiences of gender marginality and cancer care. Our 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.

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