Meaningful Support for Lesbian and Bisexual Women Navigating Reproductive Cancer Care in Canada: An Exploratory Study

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Abstract

Health inequities for sexual minorities are well documented, but there is a gap in nursing research addressing the specific experiences faced by lesbian and bisexual women with reproductive cancers. This critical feminist study explored interactions between sexual minority women with reproductive cancers and their health care providers and how these interactions enable and create barriers to meaningful support. Purposeful convenience sampling was used to recruit lesbian and bisexual reproductive cancer survivors from Ontario, Canada and providers who have cared for this population. Five lesbians and one bisexual woman who were reproductive cancer survivors participated, as well as one registered nurse who was not a survivor but who has cared for sexual minority women with reproductive cancers. Face-to-face interviews were conducted and conventional content analysis was used to analyze the data. The authors report on findings related to meaningful support, interactions with providers, and organizational environments. Narratives showed that an understanding of gender norms influenced women's perceptions of supportive and inclusive care, such as the acknowledgement of social supports, and barriers to supportive care that included disclosure of sexual orientation. There are implications for nursing education and policy change to enhance inclusive interactions and environments for diverse sexual minority women with reproductive cancers.

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Background

The experience of cancer and receiving clinical treatment can be a difficult period in a person's life that requires an abundance of physical and social support. Unfortunately, members of lesbian and bisexual communities may face barriers that obstruct access to care and meaningful social support. For sexual minority women—including lesbians and bisexuals (LB)—barriers related to interactions with providers and organizations and related health inequities are well documented (IOM, 2011). Homophobia and biphobia describe the irrational fear of lesbians, gays and bisexuals (IOM, 2011), while heterosexism is defined as "a belief that heterosexuality is the only form of sexuality, the only acceptable form of sexuality, or a superior form of sexuality" (Sinding, Barnoff & Grassau, 2004: 176). Providers who lack accurate information about LB women's specific health needs can create barriers to care. Heterosexist policies and provider attitudes that reflect the prevailing homophobia, biphobia and heterosexism in health organizations contribute to discrimination and exclusion of sexual minorities and what is known as heteronormativity (Beagan, Fredericks, & Goldberg, 2012; Fish, 2010). Bisexuals can face marginalization from both heterosexual and gay and lesbian communities, often reporting even less support

from family and friends and services that assume their needs are the same as those of lesbians or heterosexuals (Dobinson, MacDonnell, Hampson, Clipsham, & Chow, 2005). LB women of diverse cultures, classes, abilities, and gender identities may face even greater barriers to equitable care, yet limited research addresses their needs (Fish, 2010).

For LB women with cancer, such barriers create challenges to receiving equitable and quality clinical cancer care (Boehmer & Case, 2004, 2006; Sinding et al., 2004) and can limit meaningful support provided to women. Specifically, reproductive cancers, those that "start in the organs related to reproduction" (U.S. Department of Health and Human Services, 2013: 1) will account for 36.8% (breast and gynecologic cancers combined) of all new cancers for Canadian women in 2015 (Canadian Cancer Society, 2015). Although there is no percentage for how many LB women will develop reproductive cancers, there is literature to suggest that sexual minority women are at an increased risk for development of these cancers when compared to heterosexual women (Brown & Tracy, 2008; Zaritsky & Dibble, 2010). This increased risk is often attributed to the heteronormativity embedded in health systems that limit their use of early screening and clinical services (IOM, 2011). As a result, LB women may lack meaningful support from their providers affecting not only the quality of care received and the frequency of visits, but also their overall health outcomes (Dehart, 2008).

Currently there is a Canada-wide study underway by Mary Bryson and her research team exploring lesbian, gay, bisexual, queer, trans, and two-spirited individuals sharing of cancer knowledge and the health experience of breast and gynecologic cancer care. Despite a similar field of study, there remains to be few studies addressing the experiences of women with a range of reproductive cancers in terms of how they define meaningful support from providers. There is an overall gap in nursing research focused on sexual minorities (Beagan et al., 2012; Eliason, Dibble, DeJoseph, & Chinn, 2009; Eliason, Dibble, & Dejoseph, 2010; MacDonnell, 2014), yet nurses account for the largest group of health professionals in the Canadian health care system, engaged with patient care across all sectors (CIHI, 2015). It is important for nurses to understand the particular needs of LB women who experience reproductive cancers. In response to this gap in nursing research, this study explored interactions between sexual minority women with reproductive cancers and health providers, with a focus on understanding factors that enable and create barriers to care and meaningful support.

Methods

There is a need to examine barriers of meaningful support from providers and their influence on LB women's cancer care from a lens that will allow for exploration of heteronormative practices that may render these women invisible within the health care

system, and how these can be improved to help promote structural change. A critical feminist lens was used as a framework for the qualitative design of this study and underpinned the methodological decisions throughout the research process. A critical feminist lens incorporates the principles of both feminist and critical theory to uncover how the historical and political contexts that contribute to social dominance and gender play a role in the creation of unrecognized barriers by health care systems or institutions (Eliason et al., 2009; Fontana, 2004). The ontological and epistemological views present within critical feminist methodology differ greatly from these traditional frameworks used in nursing research and value subjective insight. As a result, the use of one-on-one interviews, conventional content analysis, and a collaborative research process was used.

Recruitment

Purposeful convenience sampling was chosen as a means to target and recruit a specific population of women based on predetermined inclusion criteria (Polit & Beck, 2012). The populations of interest for our study were both self-identified lesbian and bisexual women who have experienced a reproductive cancer and health providers who have provided care to these women. Recruitment occurred through disseminating calls via online social networks and LGBTQ listservs, as well as paper postings placed at LGBTQ-positive agencies and cancer support groups across Ontario. Participants were not recruited

in hospital, from clinical settings, or referred by clinicians, as the researchers did not want to place increased burden on women currently undergoing cancer treatment. The postings were aimed at women who had completed treatment or providers who have worked with this population and included information on the study, an email address, and a phone number to contact the researchers if individuals were interested in participating.

Data collection

Data collection occurred during a period between November 2013 and April 2014. A total of seven participants completed individual, audio-recorded interviews lasting approximately 60 to 90 minutes. Six interviews were conducted in person and one was conducted over the phone. An interview guide with broad, open-ended questions was used to uncover aspects of reproductive cancer care and health care interactions, with the potential for new questions to emerge based on topics that arose. This approach was also aligned to the collaborative nature of critical feminist methodology guiding this study, allowing participants a chance to express their insights both verbally and non-verbally and feel more connected to the research process. All interviews were conducted at a setting and time mutually agreed upon by the participant and interviewer.

Ethical considerations

This study explored the barriers that exist during reproductive cancer care interactions for a marginalized group of women who are often discriminated and persecuted, and therefore ethical consideration and confidentiality was of the utmost importance. Using a critical feminist methodology demands the need for scrutiny in maintaining ethical research practice that does not further contribute to oppression for participants (Preissle, 2012). Approval was received by the institution's ethics review board before recruitment or data collection began and the voluntary nature of the study was stressed. The study was described in detail to participants prior to starting the interviews and informed consent was obtained. In order to maintain confidentiality and anonymity, no names or identifying information were included in the transcribed interviews, all participants were assigned a pseudonym for discussion of findings, and all data including audio-recorded interviews were stored on a password protected, encrypted USB key.

Data analysis

Conventional content analysis using a critical feminist lens was applied to determine codes, categories, and ultimately themes that emerged from the data. All interview transcripts from participants were read and coded line by line, allowing the researchers to become immersed within the data (Hsieh & Shannon, 2005). Data analysis

occurred simultaneously with data collection in order to effectively modify the interview guide to delve deeper into early emerging concepts. To account for researcher bias, which could influence validity and trustworthiness in the findings, a reflexive journal was used throughout the research process to avoid the unintentional influence of researcher's assumptions on the data analysis (Finlay, 2002). To further ensure trustworthiness, reporting reflected verbatim excerpts from the interviews and participants' choice of language to describe their identities (Hall & Stevens, 1991).

Participants

Seven women participated, whose demographics are described in Table 1. Five female cancer survivors in the study self-identified as lesbian, one self-identified as bisexual, and the female Registered Nurse (RN) who was not a cancer survivor identified as heterosexual. The reproductive cancers represented within this research were breast cancer (n=4), ovarian cancer (n=1), and cervical cancer (n=1). Two participants were single. One was dating a female partner, and three were either living with or married to a female partner. At the time of the interview, two women had been diagnosed within six months to a year ago, three women received their diagnosis one to three years ago, and one woman was diagnosed five to ten years ago. Four of the six survivor participants also worked as health or service providers, ranging from registered therapists to health advocates.

Although their work was not specific to oncology or sexual minorities, their experiences as providers and patients influenced their own journeys throughout their role as patients within the health care system.

Results

The findings illustrate that gender normativity shaped the experiences and care of LB women with reproductive cancers with implications for the meanings women attributed to social support as well as interactions with providers and organizations.

The impact of meaningful social support

Survivors' narratives about their experiences of reproductive cancer care and what constituted meaningful social support were implicitly and explicitly linked to gender, sexuality and the meanings they attributed to reproduction at various points of their lives. LB participants varied with respect to what they considered effective social support. Support from their families of origin was mixed. Some had encountered family conflict in relation to their sexual orientation prior to their cancer diagnosis or were not "out" to some family. Although it might have been anticipated that limited family support might increase stress during cancer care, the participants did not express this, as they most often turned to friends or partners during this time. Robyn was the only one of the six participants interviewed who sought support services from a lesbian-specific support group. She

initiated this connection, having found a pamphlet on the group from one of the hospitals where she was receiving treatment, although no health care provider suggested this as an option. Robyn described feeling more comfortable in the cancer support groups that were lesbian-specific, and found that she had difficulty relating to others in the groups dominated by heterosexual women. As she noted, "I just went once [to the general cancer support groups] and then I never went back. I can't relate to any of the women there, they are all about their husbands and their kids." (Robyn, cancer survivor).

Interestingly, several participants felt that meaningful support should be sought through personal support networks, were the responsibility of the patient, and should not be expected from providers themselves. Tasha elaborated further in regards to her perceptions of what nurses were available to assist with. "I didn't really feel like it was appropriate to ask for emotional support from the nurses, especially because it seemed like they were so busy. I didn't really want to bother them with that." (Tasha, cancer survivor). For several participants, meaningful support from providers was characterized only by the quality of physical cancer care received, with less emphasis on providing supportive, therapeutic interactions.

Interactions with providers that influence support during cancer care

Survivors interacted with health care providers at various points and times in the cancer journey, including in hospitals, physicians' offices, and outpatient clinics for chemotherapy and radiation. Frequency of interactions varied from several times weekly to every six months for follow up after surgery. With few exceptions, survivors described interactions and support during cancer care to be positive, identifying providers' acknowledgment and respect for their partners as a key dimension of inclusive, supportive care.

Despite this, their narratives provided a number of ways that heterosexism pervaded health interactions and disrupted the establishment of meaningful support. At times these were subtle examples, such as when Tasha described that her sexual orientation would only come up during interactions with providers when they asked if she could be pregnant. Tasha stated that providers would ask her questions not specific to sexual orientation but rather if there was the possibility she could be pregnant and if she used contraceptives, which created a less welcoming atmosphere to disclose her sexual orientation. Some participants, like Claire, faced more overt homophobic sentiment when a staff member working in reception refused to acknowledge Claire's spouse.

They asked for my emergency contact and I said 'My partner, Theresa'. 'Oh your

> husband?' they asked. I said 'No, my partner, Theresa. This is my partner, and this is her phone number'. But on the sheet the woman wrote 'friend' and highlighted it. So I got rather upset and said 'You need to change that' but she wouldn't change it. 'Nobody needs to know that about you' she said. (Claire, cancer survivor)

This experience had very upsetting implications for her.

According to all six participants, at no point did a health care provider directly ask about their sexual orientation. Participants either opted to disclose this information themselves or chose not to reveal their sexual orientation at all during cancer care. Participants varied with respect to their preferences for providers to explicitly ask questions about sexual orientation. Brenda, a retired health care provider, indicated that a direct question would be a welcome opportunity because otherwise she is constantly weighing when it might be appropriate time to "come out": "We always have to come out. There's never the option to say 'who are you?' so you always feel that it's a heterosexist assumption. It would have been good if it had been [asked]. I would have appreciated that." As a health care provider herself, Brenda felt that sexual orientation was important for provider's to be aware of in order to provide holistic care, and was something she inquired about in her practice as a therapist.

Robyn believed that because her providers did not ask about her sexual orientation, and therefore did not know she was a lesbian, she might have actually received more supportive care than she would have if she had disclosed. A rather disturbing finding was that most participants believed that that disclosure would lead to altered (negative) treatment and support or treatment that was not equal to what heterosexual patients would receive. Neither participant who was single disclosed, while the participants in relationships either formally disclosed or assumed that their provider would be aware given the presence of their same-sex partner.

The RN, Lucia said that it is not in her institution's policy to ask sexual orientation, and that she often discovers this information through inquiry of a patient's substitute decision maker, who may happen to be an individual's same sex partner. She also mentioned her fear of stereotyping lesbian and bisexual patients, and not wanting to be perceived as homophobic or biphobic. "I think that the insecurities of 'how comfortable are they with me?' makes you uncomfortable" (Lucia, RN). As an RN, Lucia did not want her patients to feel as though her awareness of their sexual identity would equate to passing judgments or making assumptions about their actions or appearances.

Organizational Barriers to inclusive care and meaningful support

The majority of participants did describe examples of inclusion within health care environments that allowed them to feel safe and welcome as sexual minority women, and most responded that there was never any elements present that would make them feel as though they were unwelcome as a lesbian or bisexual women. While no participants replied in the affirmative to an interview question about dynamics in the health care environment that would make them uncomfortable as a lesbian or bisexual woman, stories of heterosexism, biphobia, and heteronormativity that contributed to unwelcoming care environments still emerged. Tasha described an instance where her health care provider provided information that was not aligned with current recommendations for PAP smears.

Before I'd been diagnosed, I was asking a doctor whether or not I should receive a PAP smear. He asked about my sexual activity and [I said] that I was with a woman. He said 'you probably won't even need to get PAP smears that often, so you don't have to worry about it.' (Tasha, cancer survivor). The same type of experience was recounted by Brenda, who described a similar conversation but with her family physician. "I must admit that my family doctor in doing PAP smears sort of went 'oh well, your partner is female' and I said 'well do it anyway', you know?" (Brenda, cancer survivor). These experiences

reflect barriers within the organization environments that inhibit meaningful support for early cancer screening in sexual minority women.

Lucia also discussed an aspect of the health care environment at her work place that was less than inclusive for lesbian and bisexual women.

> There was a pamphlet I read once for post surgical care after reproductive cancers. It was just about post-op care and resuming sexual activity, but I guess the way I interpreted it was that it was focused towards if you were a female wanting to resume sex with your male partner. (Lucia, RN)

The presence of heteronormative literature within health care environments can further hinder supportive relationships between LB women with providers, as Lucia may have given this pamphlet unknowingly to lesbian or bisexual identified individuals in past interactions.

Discussion

The narratives shared by LB participants on their reproductive cancer care provided insight into what they conceptualize as supportive care during their cancer journeys. The importance of a critical gender lens that accounted for gender normativity in the analysis was crucial to understanding the unique meanings that their reproductive cancer experiences represent for sexual minority women. It is important for health care providers

involved in reproductive cancer care to understand that lesbian and bisexual women's lives are influenced by normative meanings of gender, sexuality, and reproduction. Pervasive heteronormative dynamics embedded in all social institutions contribute to normative and stereotypical gender roles, expressions of femininity and expectations that "real" women bear children, all of which influence the meanings that experiencing reproductive cancer have for LB women (MacDonnell, 2001). Lesbian and bisexual women negotiate these meanings through their interactions with partners, families, providers and their larger social worlds and at any time may resist or accommodate to these dominant discourses.

Therefore, meaningful social support from providers must account for the various ways in which sexual minorities define family beyond family of origin or formal partners (Gabrielson, 2011). Providers must be aware of the need to consider that LB women's key relationships may involve a same-sex or opposite-sex partner and that patients across the age spectrum may be single or living alone (Dobinson et al., 2005). Findings align with literature on breast cancer support for sexual minorities that described the importance of patients having their partner with them and acknowledged by providers (Boehmer, Linde, & Freund, 2005; White & Boehmer, 2012). Making information available about lesbian-specific and bi-inclusive cancer support groups can enhance support for patients who are

not partnered or who are struggling with relationship concerns and is consistent with strategies to create a welcoming environment for sexual minorities.

The findings show that sexual minority women may be reluctant to disclose their sexual orientation, even if providers ask, for fear of receiving less than optimal care or encountering hostility, fears that are well documented in the literature (IOM, 2011). For this reason, nurses and other providers cannot assume women are in heterosexual relationships if they are to provide responsive and relevant care. There are implications for nurses across settings and clinical areas working with a range of individuals and families dealing with reproductive cancers to understand meaningful support, from preventive care to clinical palliative care settings, in both older and younger women (Peate, 2015; Rawlings, 2012).

Our findings suggest that providers are not consistently inquiring about sexual orientation, which is consistent with findings from an American study on breast cancer and sexual minority women (Boehmer & Case, 2004). Although several LB cancer survivors felt that physical cancer care was the most important aspect of their relationship with providers, there remained an emphasis on receiving care and support that mirrored what heterosexuals would receive. Narratives from the RN in our study also suggest that there are concerns from providers about stereotyping sexual minority patients by acknowledging their sexual orientation. This was consistent with other Canadian findings that found that

RNs commonly associated the acknowledgment of differences in patients, such as sexual orientation, to be discriminatory rather than helpful in therapeutic relationships (Beagan et al., 2012). These findings raise point to a larger gap in nursing education on sexual minority women's health, in which the focus may be from a problem-based perspective with emphasis on avoiding discriminative care and assumptions that sexual minority health concerns are limited to mental health, addictions and HIV (Daley & MacDonnell, 2011), rather than focusing on ways to provide supportive, inclusive care. An increasing literature base calls for comprehensive organizational change that includes policy change in addition to provider education in order to create environments that can support inclusive care in individual patient-provider interactions (Gay and Lesbian Medical Association, 2006; IOM, 2011).

The participants' reports of heterosexism and homophobia, manifested as assumptions that patients are in heterosexual relationships or excluding or denying a same-sex partner during cancer care and health care interactions are not isolated incidents and examples of limited support from providers. Studies within the past ten years exploring both homophobia and heterosexism that exists for lesbian women undergoing cancer treatment provide similar findings (Boehmer et al., 2005; Boehmer & Case, 2004, 2006; Brown & Tracy, 2008; Dibble et al., 2008; Sinding et al., 2006).

Although all participants generally felt that areas where they received cancer care were welcoming, none could provide specific examples of how they were inclusive or welcoming. Narrative findings showed that heteronormative elements were relevant to all participants' interactions with providers and organizations, consistent with literature that calls for comprehensive attention to creating inclusive and welcoming environments for diverse sexual minorities (IOM, 2011; McIntyre, Szewchuk & Munro, 2010).

Limitations

The small sample size and limited diversity of LB reproductive cancer survivors from one province in Canada makes it difficult to classify these findings as transferable. However, the findings gathered from the interviews with these women do provide insight to some of the concerns that may be expressed by other survivors and leave opportunity for further research on reproductive cancers. There was also a notable lack of response to our extensive recruitment efforts for providers. There is recent literature that suggests that despite increased visibility of LGBTQ health in North America, nurses and physicians are often still not aware that their patients may identify as members of LGBTQ communities (Abdessamad et al., 2013; Beagan et al., 2012). Recruiting providers with specific experience caring for sexual minority women with reproductive cancer created even more challenges.

Conclusion

Findings from this exploratory study support the need for development and implementation of comprehensive organizational change including nursing education that promotes inclusive care interactions and cancer care environments that support sexual minority women. Lesbian and bisexual women contextualize their experience with reproductive cancer in ways that are unique and shaped by normative meanings of gender, sexuality, and reproduction with implications for the ways that they understand meaningful social support. Nurses interact with sexual minority women with reproductive cancers in all domains of practice, and have the opportunity to promote both individual and organizational level change and continually enhance care. Further research is needed to address the needs of diverse lesbian and bisexual women in order to support inclusive and meaningful care.

Key points for policy, practice and/or research

- Research shows that sexual minorities consistently face barriers to health care access and equity that can be perpetuated by health care interactions.
- There is limited nursing research focusing on reproductive cancer care among lesbians and bisexual women.

- Meaningful social support for sexual minority women experiencing reproductive cancer must account for the fact that they may not disclose their sexual orientation even when asked and also that they may define family beyond family of origin or formal partners.
- It is important for nurses involved in reproductive cancer care to understand that lesbian and bisexual women's lives are influenced by normative meanings of gender, sexuality, and reproduction.
- Nurses can enhance high quality reproductive cancer care for sexual minority women by exploring the meanings that reproductive cancer, acknowledging diverse forms of social support and promoting comprehensive organizational change to promote inclusive practices.

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Declaration of conflicting interest

The authors declare that there are no conflicts of interest.

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Table 1: Participant Descriptions

Participant	**Description**
Robyn (health advocate and survivor)	Self-identifies as a black, lesbian woman in her early 50s. She is a survivor of breast cancer and was single during her cancer care.
Tasha (health provider and survivor)	Self-identifies as a Canadian lesbian woman in her early 20s. She is a survivor of ovarian cancer and had a female partner during her cancer care.
Brenda (health provider and survivor)	Self-identifies as a Canadian and Caucasian lesbian woman in her late 60s. She is a survivor of breast cancer and was married to her female partner during her cancer care.
Claire (survivor)	Self-identifies as a Canadian lesbian woman. She is in her mid 40s and a survivor of breast cancer. She was married to her female partner during her cancer care.
Anna (service provider and survivor)	Self-identifies as a Canadian bisexual woman in her early 50s. She is a survivor of breast cancer and was single during her cancer care.
Dani (survivor)	Self-identifies as a black, lesbian woman in her early 20s. She was recently diagnosed with cervical cancer and has a female partner.
Lucia (Registered Nurse)	Self-identifies as Eastern European heterosexual woman in her mid 20s.

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