

Homophobie et hétérosexisme dans la prestation des soins contre le cancer : l'expérience des lesbiennes

Christina Sinding, Lisa Barnoff et Pamela Grassau

Cette étude participative et qualitative examine la particularité de l'expérience des lesbiennes en ce qui concerne le cancer et la prestation des soins contre le cancer. On a interviewé 26 lesbiennes sur leur expérience en matière de dépistage du cancer, de traitement et de l'aide qu'elle ont reçue ainsi que sur leurs sentiments et perceptions à propos des changements survenus dans leur identité, leur corps, leur sexualité et leurs relations. Le document montre de quelle façon la manière dont l'homophobie et l'hétérosexisme, dans la pratique actuelle des soins infirmiers et comme élément historique du système de soins de santé, façonnent le vécu des lesbiennes atteintes de cancer. Un petit nombre de participantes a été ciblé, s'est vu refuser des soins courants, ou estime que l'on a pas tenu compte d'aspects de leur identité et de leur contexte social importants pour la prestation des soins contre le cancer. La majorité a souligné que les réalités lesbiennes étaient peu prises en compte dans l'aide psychosociale. Un hétérosexisme résiduel semble déclencher des efforts stratégiques pour éviter l'homophobie et donne lieu à de la gratitude lorsque des soins équitables sont fournis. Les infirmières enseignantes, les médecins praticiens et les décisionnaires ont tous un rôle crucial à jouer en matière d'accessibilité aux soins contre le cancer.

Mots clés : lesbienne, cancer, discrimination, accessibilité aux services de santé

Homophobia and Heterosexism in Cancer Care: The Experiences of Lesbians

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This participatory, qualitative study examines “what is lesbian” about lesbians’ experiences of cancer and cancer care. Twenty-six lesbians were interviewed about their experiences of cancer diagnosis, treatment, and support, and their feelings and perceptions about shifts in identity, body, sexuality, and relationships. This paper highlights how homophobia and heterosexism, in contemporary nursing practice and as historical features of the health-care system, shape the experiences of lesbians with cancer. A minority of participants were targeted, denied standard care, or had aspects of their identity and social context relevant to cancer care dismissed. The majority commented on the lack of attention to lesbian realities in psychosocial support. A legacy of heterosexism appears to prompt strategic efforts to avoid homophobia and also appears to foster gratitude for equitable care. Nurse educators, practitioners, and policy-makers have critical roles to play in the accessibility of cancer care.

Keywords: lesbian, cancer, discrimination, health-services accessibility

Literature Review

Lesbians’ risk of cancer is a subject of debate and confusion among health researchers and within lesbian communities. A recent examination of data from the Women’s Health Initiative (WHI), a cluster of studies designed to investigate disease outcomes in older women (Matthews et al., 1997), confirms what has long been suspected — lesbian and bisexual women have higher rates of breast cancer than heterosexual women (Valanis et al., 2000).

Valanis and colleagues (2000) link this finding with other data from the WHI, which suggests that lesbians and bisexual women have somewhat higher rates of “risky” health behaviours than heterosexual women (smoking, alcohol use), consume fewer fruits and vegetables, and are more likely to be overweight. Lesbians’ lower likelihood of ever having been pregnant is also cited.

Yet the prevalence of cancer among lesbians reported in this study is less than what had been previously suggested, with 5.8% of the “lifetime lesbians” and 7% of the “adult lesbians” reporting having had breast

cancer, as compared with 4.9% of the heterosexual women.¹ As well, critics point out that a risk-factor approach often confuses health behaviour (eating vegetables) with identity (being a lesbian) (Yadlon, 1997) and tends to individualize what are essentially social phenomena (Link & Phelan, 1995). Fish and Wilkinson (2003) note that the paucity of research on lesbian health overall makes ascribing socially undesirable characteristics to lesbians as a group problematic.

While studies that link lesbian identity with cancer risk continue to require careful qualification, both the perception of heightened vulnerability to the disease and this new finding of increased prevalence affect lesbians and lesbian communities. Yet there is virtually no research on lesbians' *experiences* of cancer or cancer care (Matthews, Peterman, Delaney, Menard, & Brandenburg, 2002). Our literature review to date has not generated a single published Canadian study.

In a US study, Fobair and colleagues (2001) compared heterosexual and lesbian women's psychosocial responses to a breast-cancer diagnosis. The picture that emerged was "mixed in terms of strengths and vulnerabilities" (p. 47). The lesbians in the study tended not to struggle with body image to the same degree as heterosexual women. They tended not to have the same degree of social support from given families, yet often had broad networks of relationships, "chosen families," from which to draw practical and emotional support.

Importantly, Fobair and colleagues (2001) report that lesbian breast-cancer patients were less satisfied than heterosexual patients with their physicians' care and the inclusion of their partner in discussions about medical treatment. Similarly, Matthews and colleagues (2002), in exploring similarities and differences in lesbian and heterosexual breast-cancer survivors, note that lesbians reported lower satisfaction with care received from physicians, and describe a trend towards lower satisfaction with the availability of emotional support from health-care providers. These findings are consistent with those of several other studies that highlight lesbians' difficult health-care experiences and their worries about interactions with health professionals. In a Health Canada survey of client satisfaction with care received, lesbians reported dissatisfaction across health disciplines (Jalbert, 1999; Ryan, Brotman, & Rowe, 2000). A 1995 province-wide survey of the health and social service needs of sexual minorities in Ontario (Mulé, 1999) highlighted the importance of hospital staff being comfortable in acknowledging a patient's sexual orientation, yet 44% of the respondents who had been hospitalized in the

¹The media used the results of a study that mapped lesbians' reported health behaviours onto known cancer risks (Haynes, 1992) to claim that lesbians' lifetime risk for breast cancer was one in three — three times that of women overall.

5 preceding years were uncomfortable being open about their identity. Specifically in relation to nursing, a literature review (Brogan, 1997) concluded that significant numbers of nurses are uncomfortable providing care for lesbians, some even refusing to do so.

The Lesbians and Breast Cancer Research Project (LBCRP) was designed to redress gaps in knowledge in cancer care and clinical literature, and to break the silence in lesbian communities about lesbians' experiences with cancer and cancer care.

Methods

The methodology used in the LBCRP reflected a Participatory Action Research (PAR) model. PAR is "systematic inquiry, with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or affecting social change" (Green et al., 1995). It emphasizes the goal of "liberating oppressed groups through research as praxis" (Gatenby & Humphries, 2000, p. 89) as well as dialogue and collaboration; researchers are positioned not as "separate, neutral academics theorizing about others, but [as] co-researchers or collaborators with people working towards social equality" (Gatenby & Humphries, p. 90).

The LBCRP was undertaken by a Project Team, made up of lesbians directly affected by cancer, along with staff and volunteers at agencies in the cancer, queer, and women's health communities. Members of the Project Team were actively involved in every aspect of the research process.

While the focus of the study was lesbians' experiences of breast cancer, the Project Team speculated early on that lesbians with gynecological cancers might face very similar issues. Both for this reason and to increase the number of potential participants, we recruited lesbians with breast or gynecological cancer. In promotional material, we defined lesbians as women whose primary emotional and sexual relationships were with women.

The study was promoted across Ontario by staff and members of the Project Team (and, eventually, also by the research participants). Posters advertising the study were mailed to key contacts, including agencies listed in a province-wide directory of lesbian and gay resources. E-mail notices were circulated to service and advocacy agencies in the women's health, feminist, queer, and cancer communities. We also asked our personal and professional contacts to transmit the information through their networks. The project attracted media attention across the province, including print, radio, and television. Potential participants were asked to

contact the Research Facilitator, either by phone or e-mail, for further information.

Recognizing the diversity that exists among lesbians and aiming to ensure that the study reflected this diversity, the Project Team developed a set of goals that specified the multiple groups of women we hoped to attract as participants. Our intention was to recruit a diversity of women with regard to age, time since diagnosis, geographic location, socio-economic status, race/ethnicity, health status, ability, and family status. To support our diversity goal the Project Team developed specific promotional materials for specific communities (e.g., for lesbians of colour and for lesbians with disabilities).

Interview topics were developed in consultation with the Project Team. Participants were asked about their treatment, their cancer-care and support experiences, and their feelings about any changes in identity, body, sexuality, and relationships. To offer participants a role in defining the scope and the focus of the research, we included the following question in the interview guide: "If you had planned this study, what questions would you have wanted to ask?" Responses to this question largely confirmed our approach, yet where participants suggested new directions (encouraging, for instance, an increased focus on the impact of cancer on partners and children), these were incorporated in subsequent interviews.

Interviews (approximately 90 minutes in length) were audiotaped and transcribed. Face-to-face interviews (17) were conducted at a time and place convenient for participants, either in their homes or in our research unit. Telephone interviews (9) were conducted with participants living at a distance from our research unit in Toronto, at a time convenient to them and when they were in settings where the conversation could happen comfortably and confidentially. A \$30 honorarium was provided.

Twenty-six lesbians diagnosed with cancer (22 with breast cancer, three with gynecological cancer, and one with both forms of cancer) were interviewed over an 8-month period. Demographic information can be found in Table 1.

Analysis

Once five interviews had been completed, each member of the Project Team reviewed three transcripts. Based on our conversation about these transcripts, and review by the research team of an additional seven transcripts, the research team created a coding framework. Transcripts were coded using the qualitative software program *NVivo* (Bazeley & Richards, 2000). Further interviews were coded as they were completed and new codes were added by the Research Facilitator in consultation with the team. Both to adhere to principles of qualitative analysis (Seale,

Table 1 Demographic Characteristics of Participants

Age	Average 50, range = 36–72		
Time since diagnosis	Three years or more 13, less than three years 13		
Place of birth	Canada 20, United States 2, England 1, Philippines 1, Jamaica 1, Hong Kong 1		
First language	English 24, Cree 1, Dutch 1		
Race / ethnicity (self-defined) ^a	Caucasian/white 7, British 6, Canadian 2, Jewish 2, Indigenous/Native 2, Métis-Ukrainian 1, Euro-Canadian 1, Polish Canadian 1, Italian 1, Asian 1		
Total annual household income (\$) ^b	100,000 + – 6 70–79,000 – 2 40–49,000 – 1 Less than 20,000 – 1 ^c	90–99,000 – 1 60–69,000 – 3 30–39,000 – 4	80–89,000 – 1 50–59,000 – 4 20–29,000 – 2
Education	University degree 19, college diploma 6, secondary school diploma 1		
Disability / health problems aside from cancer	Hearing impaired 1, heart problems / arthritis / psychiatric survivor 1, depression (in past) / fibromyalgia 1, endometriosis 1		
Urban / rural (at time of treatment)	Urban 20, semi-urban 2, rural 4		
Family status (at diagnosis)	Partnered 17, single 9; adult children 5, young children 1, trying to have children 2		
Sexual identity	Lesbian 22, gay 2, dyke 1, bisexual 1		
Family doctor knew of sexual identity	Yes 23, no 2, not sure 1		
^a One woman said the question was impossible to answer as her ethnicity was “too mixed”; one did not respond.			
^b One woman did not respond.			
^c Actual income was \$8,000.			

1999) and to minimize the risk of stereotyping lesbians, we deliberately read for and coded negative cases (instances where participants’ experiences or commentary departed from or challenged an emerging theme).

A draft research report was written describing lesbians’ experiences in each of the key thematic areas outlined in the interview guide. In keeping with our participatory research framework, we asked eight interviewees to join the Project Team for two half-day meetings, in order to review this draft and comment on the emerging analysis. These eight participants were selected on the basis of some of our diversity aims (for

example, we specifically invited women who were from outside of Toronto, and we invited one participant who identified as “poor,” since women from low socio-economic groups were not well represented in the study).

Feedback from this meeting led to substantial revision of the research report. While the first draft described lesbians experiences’ with cancer in a general way, the second draft focused on “the lesbian parts” of the women’s experiences with cancer. We took this direction because it was advocated by the participants and members of the Project Team and because it supported one of the mandates of the project, which was to challenge the invisibility of lesbians as cancer survivors and in cancer care. The consequences of our analytic and representational choices are discussed towards the end of the paper.

In this paper we highlight one of the research themes: lesbians’ experiences of cancer care. A community report summarizing the additional research themes (including support, fallout from treatment, partnerships and dating, families, and finances) is available at <http://dawn.thot.net/lbcp>

Findings

Homophobia and Heterosexism in Cancer Care

The majority of lesbians interviewed said they had not encountered discrimination in their cancer care. While transferability of the findings may be limited (participants were, in the main, well educated and economically privileged), this is an encouraging finding — yet one that requires contextualizing.

In this section we describe lesbians’ difficult experiences with health professionals. We draw on definitions of homophobia (fear of, aversion to, or discomfort with homosexual people; irrational hatred of homosexual people) and heterosexism (a belief that heterosexuality is the only form of sexuality, the only acceptable form of sexuality, or a superior form of sexuality) adapted from Mihalik (1991) and Mullaly (2002).

Homophobia: lesbians targeted or denied standard care. In detailing her cancer treatment, Paddy² noted that she had a cardiac condition that prevented her from receiving a general anesthetic. As the surgeon performed a lumpectomy, Paddy found the local anesthetic insufficient. “I told him that he was beneath the level of the freezing,” she recalled, “and he told me that I was a dyke, therefore I should be able to tolerate pain.” Theresa said that the nurses in the hospital seemed unable to comprehend her identity as a lesbian:

² Names associated with quotes were chosen by the participants themselves.

I found a lot of the nurses just couldn't get their head around it and were saying, "You're a nice-looking girl, you can find someone..." So it was very hard. And they would pull faces and all different kinds of stuff.

Kate described an interaction with the physician with whom she discussed her unusual vaginal bleeding. The physician pulled herself back in her chair in the middle of a Pap test and posed her first (and only) question to Kate: when had she last had a sexual relationship with a man? Kate responded that it had been about 20 years. The physician then told Kate that she thought there was "something wrong" and that she could either finish the test or refer Kate to a specialist:

I was pretty clear at that point that she was making me uncomfortable. And I was making her uncomfortable. And I don't know which was worse. But at that point I didn't want her to finish the exam, because I felt like she had disappeared on me, because of her anxiety about the fact that — first of all I guess because it wasn't a normal Pap. And secondly the fact that I was a lesbian and I don't think she knew how to handle even talking to me about cervical health... I'm sure everything she's been taught has been about heterosexual women, and if somebody had cervical dysplasia you ask them about their relationships with men.

When a physician who had just learned Lillian was a lesbian examined Lillian's breast, "she stood about as far away as a person could — you know, like she was moving a computer mouse from across the room."

In the situations described, lesbians seeking health care were treated as if they were somehow contagious or so far outside a framework of "normal" that health professionals were unable to act in a professional way (indeed entitled to act in entirely unprofessional ways, expressing disgust and justifying inattention to pain). As well, as a consequence of the history of heterosexism in medicine, Kate's physician did not know how to take an adequate history from a lesbian with cervical changes. The Pap test, which might have provided Kate with more information about her condition, could not reasonably proceed; the physician's discomfort and lack of knowledge were so apparent that continuing would have only made things worse. In the encounter she describes, Kate was essentially denied care. We might also hypothesize that Lillian's breast exam "from across the room" was less than adequate.

Mary Lou spoke about the uniqueness of being a lesbian with cancer, the fear that cancer generates, and the importance to her of having a medical team that would not be unsettled by fear — of cancer or of her. "If my lesbianism is going to provoke fear on their part, that's at my expense," she said.

It was apparent in the interviews that the poor care the women received was sometimes linked to economic class as well as their identity as lesbians. At home with a drain after surgery, Glenda needed nursing care but did not receive it. "Welfare wouldn't pay for it; welfare said Community Care Access should send me somebody...all they did was argue." Later in her treatment, Glenda called to see if she could get a ride to the cancer centre. The agency told her that welfare should pay for her cab. The welfare worker told her that the cancer agency provided the service free to other people, so refused to pay. Glenda ended up walking, every day, for 28 radiation treatments. These incidents demonstrate that lesbians' difficult experiences of cancer care are related to more than their identity as lesbians; other systems of privilege operate in concert with heterosexism to restrict access to care and services.

Heterosexism: lesbian identity and social context ignored or dismissed.

It became clear that aspects of lesbian identity and social contexts directly relevant to cancer care can be dismissed or overlooked by health professionals. A series of encounters experienced by Sarah highlights this point. Sarah spoke, for example, of drawing on her courage to raise the question of a double mastectomy with her surgeon:

And he said, "Oh, well, we'll just cut them off; you'll be fine. If you want to do it, call me in a couple of weeks." And he left. And I just, I just, I just, I crumbled...and then he came back in and he goes... "If breasts are important to you and your husband we can always do implants and we can talk about reconstructive surgery after you do that." And he left. And I remember sitting there thinking, he forgot who I was, you know, and he left, and I just thought, oh my God, I'm never going back to see that guy ever again.

In failing to acknowledge Sarah as a person and as a lesbian, this physician jeopardized her cancer care. Sarah cancelled her next appointment and seriously considered not going back at all. As she put it, "If I have to battle this one emotionally, I'd rather die physically." Other studies have concluded that lesbians sometimes avoid routine health care, or delay seeking care for health problems, because of worries about homophobia and heterosexism (Trippet & Bain, 1992). Sarah's case illustrates that heterosexism can affect a woman's capacity to *continue* with care. When the care is treatment for cancer, heterosexism can threaten survival. As an additional consequence of this interaction, Sarah's connection with an important nursing support, a nurse navigator, was lost: "I haven't called her. I couldn't call her. I know she has left messages on my phone, but I can't call her, because I'm so angry and I'm so lost."

A genetic counsellor sought Sarah's permission to contact her older sister for testing, to see if she had the genetic mutation associated with hereditary breast cancer. When Sarah refused, the counsellor pressed the point:

I finally broke down and said, "I'm lesbian and my RC [Roman Catholic] family makes it difficult for me to be that person, you know..." She didn't get it; she fought me on that one for a half hour and I finally stood up and said, "I'm leaving," and I walked out.

The counsellor essentially forced Sarah to come out, and then failed to appreciate (or even to learn about) the salience to the situation of being a lesbian in a homophobic family. The reality of a heterosexist social context was central to this cancer-care situation, and yet it was dismissed. Clearly, the care — and the woman — suffered for this.

Heterosexism: lack of lesbian-positive psychosocial support. Considering the blatant homophobia in cancer care, one might think that the lack of lesbian-specific support services, or explicitly lesbian-positive services, would be less of an issue. Yet it became clear that the lack of attention to lesbian realities in psychosocial oncology can have the same consequences: the exclusion of lesbians and the denial of standard care.

Jessica's social worker had told her about a support group at the hospital and asked if she would like to join. The social worker posed the question casually, as if it were an easy decision. But it was not an easy decision. Jessica was fairly certain she would be the youngest woman in the group, as well as the only lesbian. She spoke specifically about her reluctance to be part of a group where she might encounter homophobia:

You have enough on your plate to deal with, with your diagnosis or your treatment, that you don't want to deal with [homophobia]... And you sort of feel, like, a bit of camaraderie with other women who are going through the same thing and you don't want to be shunned away from the only place that you can go... You know what I mean? Like, what if you got into a support group, came out [as a lesbian], and then had to deal with homophobia on top of everything else? Then you'd be left with no place to go. So it's almost better to go and hide, or not go at all, than deal with the stigma.

Jessica made the point that joining a support group and encountering homophobia may be more difficult than doing without the support. She spoke of a longing for connection and "safe space" with other women experiencing cancer and suggested that homophobia, in severing that connection, could negate the benefit of the group.

Joining a cancer support group can be a difficult step for any woman. Jessica's comments point to the need for cancer-care professionals to appreciate what it takes for a lesbian to join a support group or service. Lesbians, like marginalized women generally, face particular risks, and the decision to join a group is often more complicated than health professionals might suspect.

Experiences reported by two other participants, Paddy and Theresa, showed that Jessica's worries about coming out and having to endure painful reactions within a support group were well founded. Even when responses were not blatantly negative, the feeling of being "not quite part of it," not quite "there" in the group, was common. Anticipating such experiences, some of the women never made an attempt to access existing services.

In a few instances the participants attempted to have their needs as lesbians met within mainstream support services. After a session in which members of Theresa's group had reacted negatively to her coming out, Theresa asked the facilitator to speak to them about the importance of relationships — including lesbian partnerships — to one's ability to cope with cancer.

[The facilitator said], "Well, it's really not my mandate...it's for the group to talk on its own and for me to give guidance." And I go, "So, what you're saying is, you're not willing to help me integrate into the group, right?"

The "not our mandate" comment was reported by more than one of the lesbians with cancer. It conveys the idea that providing care and support to lesbians is above and beyond what the service does. The "not our mandate" line was heard in relation to additional dimensions of lesbians' lives and social realities:

[The health professional] said to me, "I can only work with you and your cancer; you've got too many things going on." I was too poor, I was too busy figuring out what I was going to eat. [Glenda]

The notion that lesbians and poor women are "not our mandate" clarifies the position of many psychosocial support services: they do not intentionally exclude anyone, but, lacking a critical perspective on their own mandate, they do end up excluding lesbians and other marginalized women. This process of exclusion is much more subtle than outright homophobia. Service providers can easily claim that lesbians are welcome, and some can even claim that lesbians participate in their services. Yet it is the realities of heterosexual, middle-class, white, able-bodied women that define the scope and landscape of many cancer care and support programs.

Lesbian-Positive Care in a Context of Homophobia and Heterosexism

Although the majority of lesbians said they had not encountered homophobia in cancer care, they had clearly put a significant amount of effort into avoiding homophobia. Comments about positive experiences with cancer services can say as much about a history of disentanglement to equitable health care as about lesbian-positive services.

Screening for homophobia. “Early detection strategies” took on new meaning as the participants sought to detect homophobia in cancer care, and to avoid it. For instance, when Maureen went for her first appointment with the primary nurse assigned to her care, she asked about the nurse’s values:

I just said, “You know, my partner’s a woman — do you have a problem with that?” And she said, “Absolutely not.” So it was okay. Because if she had said [she had a problem], then I would say, “Send someone else in,” because I don’t have time to have this be an issue at all.

As Maureen and others pointed out, a strategy that includes coming out usually assumes that lesbians have other options for care. Of course, this is not always the case.

Mary Lou’s family physician tried to ensure that specialists to whom she referred Mary Lou were lesbian-positive. Mary Lou appreciated her physician’s efforts, believing that this kind of commitment by a health professional represents progress. Yet the fact that a health professional perceives the need to protect a patient from the homophobia of colleagues reveals the salience of homophobia to health-care interactions.

Being out and not being out. It became clear that both coming out and remaining closeted are strategies lesbians use to influence the quality of their health care. Sarah, for example, came out to a nurse and explained what her breasts meant to her as a lesbian, indicating just how difficult it would be for her to lose them. She felt it would be impossible for the nurse to adequately support her without understanding this. Coming out was often described by the participants as a deliberate effort on the part of lesbians with cancer to communicate with oncology professionals about what, for them, constituted “good care.”

On the other hand, several of the women deliberately remained closeted in order to avoid having to deal with homophobia in cancer care. Laura, for instance, kept her sexuality to herself over the course of her cancer treatment. She was out to her family physician, but that physician was based elsewhere, in a city. “Had I come out here, in my town, I don’t think it would have gone over so well.”

A few participants explained that the cancer-care system was one of the few places where they were *not* out as lesbians. This was partly

because they feared it would compromise their care. However, they also spoke about how draining it was to deal with heterosexism, to come out over and over, to anticipate and deal with awkward or homophobic reactions, to explain what it means to be a lesbian. Because dealing with cancer is itself extremely energy-depleting, lesbians with cancer may not be willing or able to risk expending further energy battling homophobia.

Both Glenda and Kate made the point that to be safe in the cancer-care system, women may conform to norms and expectations, not only around sexuality but also around class, gender, and “patienthood.” “Of course, I didn’t say I was lesbian,” said Glenda. “I was just an aging, nice lady — not a woman, a lady. I did all I was supposed to do, didn’t raise any questions or whatever.” Kate spoke about masking her working-class background when interacting with health professionals, being sure to “talk the talk...act in a certain way to get what you need, which is stressful due to the situation.”

The efforts of the lesbians with cancer to get good care and avoid bad care were often strategic, creative, and defiant. The fact that lesbians feel the need for such behaviour calls attention to the legacy and reality of homophobia and heterosexism in cancer care.

Gratitude for receiving equitable care/readiness to fight for equitable care. Several participants spoke warmly about health-care workers and support staff who had accepted and related to their partners. Paula B.’s surgeon could have spoken first with her mother or father but instead chose her partner:

It made such a difference to me that she went to [my partner] first. Just that, in legitimatization of who we are, because she would have for sure gone to my husband if I were married, right? It just normalizes it, and you’ve got so much to deal with emotionally.

The physician clearly acted in a lesbian-positive way, and Paula B.’s appreciation was genuine. Yet as Paula B. herself suggests, a heterosexual woman would not even have to think about the possibility of a physician overlooking her spouse. What is normal treatment for heterosexual women was something that the lesbians remarked on and even praised.

The narratives reveal that legacies of homophobia and heterosexism leave lesbians in the position of being grateful for things that heterosexual people take for granted. And if gratitude for equal treatment is a consequence of marginalization, so too are anticipation of problems and readiness to fight for care. Rosalie said, “I always felt respected as a woman and a lesbian... And I always felt that [my partner]’s position as my partner was respected. *I think she would’ve clobbered anyone that didn’t.*”

Lesbian-Positive Cancer Care

A few of the women had felt very well supported as lesbians by oncology professionals and by their family physicians. In speaking about these instances, and also in articulating what was missing in their interactions with health professionals, they defined some of the features of lesbian-positive cancer care. One participant, Teagan, received “incredible” support from her primary nurse:

She knew of my relationship, and when I would do my chemo it would be her and I in an isolated area, and we would be talking about how the situation is playing at home, you know, how comfortable is Mom that [participant's partner] is there sleeping with you every night...those kinds of things. So she was awesome. Awesome, awesome.

More commonly, however, lesbian-positive care was articulated in terms of the absence of homophobia, in some ways from a position of disentitlement to equitable care. Marcia's comment captures the tension inherent in this position:

There was no glitches, there was no hiccups, there was...certainly no...I mean they were very nice about it... I don't think there was an awkward moment ever when I said, “This is [my partner] and she will be here.” It was, “Oh, of course.” [pause] But I will also still tell you, I felt extremely invisible...it's a sense that you're always alone.

This comment, and the form it takes, echoes those of other participants. Kate, for instance, had to use a dilator several times a week after receiving internal radiation for cervical cancer. Her physician and primary nurse offered her a pamphlet, and nothing more:

[They] said nothing to me. Said nothing in the whole experience about how I deal with my sexual life, said nothing about the effects this might have on my life. Absolutely zero, nothing about that... I don't know if she would have said more if I was heterosexual... It's not like [the nurse] didn't answer my phone calls if I had to call and I had a problem here and there. But there was absolutely no real patient-focused care or contact that allowed me to talk about my life at all. And she really was the point person. So if your point person can do that for you, you can...deal with a lot of other things. That didn't happen.

As Kate and others noted, it was sometimes difficult to discern whether less-than-satisfactory health-care experiences were the result of usual health-care practices or stemmed from health professionals' discomfort with lesbians. Yet the more general points are clear: while both Kate and Marcia were at pains to state that health professionals had not

discriminated against them as lesbians, they also perceived that health professionals had failed to engage meaningfully with their lesbian selves and realities. Marcia said, “I never got beyond ‘How are you doing?’”

Recent research by Dibble and Roberts (2002) comparing the diagnosis and treatment of lesbian and heterosexual women generated an unexpected finding: lesbians reported more side effects from chemotherapy than heterosexual women. In considering explanations for this finding, the researchers note that informal talk — often about husbands and (heterosexual) families — is a feature of cancer care and commonly results in a bond between patients and nurses administering chemotherapy (Jarrett & Payne, 2000), and that such talk may be awkward or non-existent between lesbians and health professionals. They speculate that lesbians may be reluctant to report problems, and that nurses may block patients from divulging worries and concerns when communication is problematic. Comments made by participants in the present study certainly show that nurses’ engagement with lesbian identities and social contexts can facilitate a valued bond, and that lack of such engagement can undermine or preclude such a connection. This finding takes on particular relevance in light of Dibble and Roberts’ suggestion that the quality of the relationship between women with cancer and nurses may mediate — for better and for worse — women’s experiences of treatment side effects.

Discussion

A persistent tension in the literature on the illness experiences of women in particular social locations, with particular identities, is the extent to which identity is the centre of analysis and representation. In this study, one of the consequences of focusing on “what is lesbian” about lesbians’ cancer experiences is that those lesbians for whom “lesbian” was less at the fore in terms of identity and social life tended to be less well represented. As well, highlighting aspects of the cancer experience linked to lesbian identity means that other aspects of having cancer — aspects that might in fact be important to an individual lesbian’s experience — receive less attention. For instance, one participant said that people who focus on hair loss as the most difficult aspect of chemotherapy “just don’t know about all the other stuff — mouth sores...all the other stuff that comes with it...all the suffering that goes on.” In this paper, as in other reports of findings from this research, we have indeed overlooked some of the suffering that was endured, and we have missed some of the joys that lesbians discovered after the cancer experience — the positive life changes they underwent. Yet we trust that the bases of our analytic and representational decisions are clear: the persistence of homophobia and

heterosexism in cancer care calls for focused attention to lesbians' experiences "as lesbians" with cancer.

While the majority of participants said they had not encountered discrimination, a minority had been targeted or had been denied standard care; in a few cases, aspects of lesbian identity and social context directly relevant to cancer care had been ignored or dismissed. The participants also commented on the lack of attention to lesbian realities in psychosocial support. However, the historical failure of health professionals to respect lesbians or grant legitimacy to lesbian relationships means that lesbians with cancer sometimes do not *expect* that they or their partners will be offered equitable care. This was the context in which gratitude, readiness to fight, and steps to identify and avoid homophobia occurred.

Nurse policy-makers, educators, and practitioners have critical roles to play in determining the extent to which cancer care and support are accessible to lesbians. Elsewhere (Barnoff, Sinding, & Grassau, submitted), we consider recommendations for new programs and services that emerged from this study (for instance, support and wellness groups that enable connections between lesbians with cancer and their partners and families; resource materials that integrate lesbian realities). Further discussion of lesbians' access to health care can be found in Hudspith and Bastedo (2001), McNair (2003), and Peterkin and Risdon (2003).

In relation to treatment settings, lesbians who took part in this study called for oncology professionals to actively create welcoming space for all of their identities. Specific suggestions for change included:

- intake procedures that make it clear that all identities are welcome; use of the word "lesbian" so that lesbians do not have to come out in order to access appropriate services. *Suggested wording: "In order for us to best support you, I'm going to ask a few questions. Some of the questions won't relate to you, but I want to make sure I'm connecting you with all the services and resources that make sense." Then ask: "Do you identify with a particular ethnic or cultural group, are you a lesbian or bisexual or transwoman, do you have a disability, do you have financial needs, what is your housing situation, your age..."*
- forms that allow for self-identification as a lesbian. *When a woman identifies as a lesbian, discussion about the meaning of her identity in relation to cancer and cancer care; and choices offered about how and with whom the information is shared.*
- "positive space" campaigns, including, for instance, stickers on doors or nametags indicating that this professional is lesbian-positive; beyond the value of the actual sticker, this practice promotes dialogue in the setting. *Could also include specific sections in patient resource centres identifying lesbian material, and having the word "lesbian" or a rainbow symbol on the Web site.*

- intentional support for lesbian partnerships and lesbian families
- lesbian and gay health professionals coming out (*recognizing that this requires workplace support*)

At the broadest level, the institutionalization of positive change for lesbian patients requires policy development: specifically, a commitment to equitable treatment for lesbians should appear in organizational mission statements, providing strategic direction for ongoing efforts to increase accessibility, and anti-discrimination policies should specifically prohibit heterosexism. As with all “living” policies, lines of accountability for implementation and processes to address instances of discrimination should be clear.

Nurses at all levels have an opportunity to forge partnerships with lesbian community agencies, actively supporting processes by which lesbians articulate their own health-care concerns and needs and have a role in shaping health-care services. Participants in this study advocated such partnerships, encouraging lesbian community organizations to attend more actively to cancer and urging cancer-care agencies to attend more actively to the realities of lesbians’ lives. The latter is facilitated when lesbians are represented (and thus safely “out”) at all organizational levels and in all nursing sectors.

Education and training are obvious and critical means of intervention. It is important that nurses be aware of the range of ways that lesbian identity may be relevant to cancer and cancer care. Yet, as Beagan (2003) points out, a “difference perspective” — learning about how “others” experience a particular health condition — is inadequate and risks stereotyping. Educational strategies, then, should focus on challenging the assumption that all service users are heterosexual; on unpacking assumptions, myths, and stereotypes about lesbians; and on exposing the ways in which heterosexism affects lesbian health. Securing these understandings among nurses working at all levels should result in the commitment upon which every other effort at change ultimately rests. Ultimately, however, nurses must understand that nursing care can itself be complicated and compromised by systemic oppression, and must be prepared to examine their own complicity in — and to challenge — homophobia and heterosexism.

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