

Silent No More

Coming Out About Lesbians and Cancer

THE LESBIANS AND BREAST CANCER PROJECT TEAM

Des recherches qualitatives lues en public ont donné lieu à un forum afin de dégager les différents niveaux des histoires recueillies auprès des participantes d'une recherche. Cet article est le reflet des histoires de 26 lesbiennes de l'Ontario qui ont été interviewées au sujet de leur cancer du sein, des traitements, des soins reçus, du support social et de leur perception et sentiment au sujet de leur identité, de leur corps, de leur sexualité et de leurs amitiés.

—In memory of Pauline Bradbrook, a founding leader, a courageous advocate, an inspiring colleague, a loving friend

Developing effective dissemination strategies for community-based research studies is often a multi-step process wherein the project team decides: 1) who one wants to reach with the information collected; 2) how best to reach these “target” audiences; and 3) what one wants to convey. Important throughout all of the decision-making is to think about what kind of impact one’s findings will have on one’s audience. Utilizing creative and arts-based media to communicate research results is becoming increasingly common, as project teams advocate for knowledge transfer strategies that engage audiences more fully than do traditional presentation forms.

Performance-based scripts are one such strategy which is gaining in popularity as a dissemination tool for qualitative social science research (Gray and Sinding). Utilizing scripts as a way of presenting participants’ quotes and narratives is a powerful way of reaching a diverse audience with a wide-range of material. Central to the purpose behind performance-based scripts is the desire to create “emotional engagement” (Ellis and Flaherty) with one’s audience in order to ensure that the messages heard “move people to moral action” (Denzin).

Given the incredible courage shown by research participants and their desire to make a difference for other lesbians with cancer, our team wanted to present their

stories in a form that transmitted passion, and was widely accessible. The following script is drawn from one-on-one interviews which were conducted with 26 lesbians from across Ontario about their experiences of being diagnosed with breast and/or gynecological cancer (see hyperlink at the end of the article for the full report, including demographic information). Two reader voices: Reader 1 (R1) and Reader 2 (R2) are utilized to make it clear that a “new” woman is speaking, even though it’s always more than two women’s voices that are being integrated. A narrator voice (NR) is the voice of the project team, offering analytical commentary on the main research themes.

Reader 1: Telling other people that you have cancer is like coming out, again... People sit there and go, “oh my God you have cancer,” like you have cooties.... People back away. They still do.

Reader 2: You get that look on some people’s faces that, you know, “oh, she’s got cancer, kind of thing.” Some of my friends stopped calling me. Some of them couldn’t deal with it. And that’s when I needed them the most.... It takes a tremendous amount of courage to go through this ... being a gay woman and being with breast cancer, it really does. It takes everything you’ve got.

R1: People back away. It’s true. But the other side is, after I said I had cancer people came forward and said, “my mother had breast cancer, my sister had breast cancer, my grandmother had breast cancer, I had uterine cancer, and I didn’t tell anyone.

R2: As dykes, from a very young age we feel “other,” you know, like “there’s something different about me,” even before you know you’re queer. So it’s not an unfamiliar thing for me to feel, “other.” And I sort of learned to celebrate otherness and that’s okay for me.

Narrator: *Because of its echoes with coming out as a lesbian, dealing with the social consequences of cancer—including shame and rejection—may be especially complicated and painful for lesbians. At the same time, coming out*

about cancer is in some ways like coming out as a lesbian—and many lesbians have experience with that! Coming out also holds possibilities for connection. In fact, some of the women in this project argued that lesbians may be “better off” than heterosexual women when it comes to support.

R1: My partner could be in my position. My partner knows what it’s like to live in our world and have a uterus and ovaries. My partner knows it can be difficult to talk about this. My partner knows what a check-up means and submitting to all that poking. My partner doesn’t make me feel there’s something wrong with me because I cry.

who died were the leaders of the community, they were the ones who coordinated the dances, coffee houses, and everything like that. They were very visible so it scares women.

NR: *The fear generated by cancer, and the lack of dialogue about the illness in lesbian communities, contributes to the isolation of lesbians with cancer. Our “phobia” about cancer affects the support lesbian communities can offer. For lesbians who were dating after a cancer diagnosis, it was easy to think that other women would not risk a relationship with them.*

R2: You want to be confident and you want to be sure

“You think no one’s ever going date you, and you don’t want to take your shirt off in front of anybody and you certainly don’t want to tell some hot date that you had cancer because they all look at you like, ‘oh, you’re going to drop dead in two years, I can’t date you.’”

R2: The lesbian community is three inches by five, so if you need X, that might not be in your immediate circle but somebody you know slept with somebody who knows somebody who can get X, you know what I mean? It’s what I like to refer to as the great lesbian chart.

R1: Our community is really good about figuring out how to organize support, I guess because we’ve had so many young men with AIDS who’ve had to be cared for within the community.

NR: *It was clear that support for lesbians with cancer can be emotionally engaged, competent, well organized and immensely meaningful. Yet this wasn’t always the case.*

R2: I did not feel that I had a lot of support from the lesbian community. I think that the lesbian community has to wrestle with body stuff, aging stuff. I think we did a terrific job in terms of the HIV/AIDS epidemic, but, you know, how do we care for each other, rather than how do we care for the boys.

R1: In my town all gays and lesbians are mostly invisible. There are no gay and lesbian resources up here. And so ... well, that simply makes me sad in terms of, you know, good grief, there are still parts of Ontario that are completely in the closet.

R2: My friends just didn’t have the information and the experience to be able to have the kinds of conversations with me that I needed to have. So I think I just took care of myself, mostly.

NR: *The main reason lesbians felt they didn’t always get what they needed from other lesbians was fear.*

R1: Cancer scares the shit out of people, and they don’t know what to do with you. It’s really weird. And that part I didn’t expect.

R2: There’s five lesbians in my small city with breast cancer and two have died in the last 12 months, so people are scared. What makes it scarier is the fact that the women

of yourself and say, “if you don’t find me attractive because I have a scar or my one nipple doesn’t stick out anymore, [laughs] then I don’t have time for people like you.” You can say those things, but it’s different when... You know, I’m 36 ... and you’re out cruising, and your first concern is, oh my God, you know, “what happens if I end up with this woman naked, and how’s that going to be?”

R1: It’s very scary. You know, you do think you’re the ugliest thing on the planet and no one’s ever going date you, and you don’t want to take your shirt off in public, and you don’t want to take your shirt off in front of anybody and you certainly don’t want to tell some hot date that you had cancer, or whatever because they all look at you like, “oh, you’re going to drop dead in two years, I can’t date you.”

R2: I didn’t bring my diagnosis to the group because my lesbian partnership was breaking up and I remember thinking, if I bring this diagnosis to the group then I’m bringing the potential that I may never find anybody else. Because why would somebody want to start up a new relationship with somebody who may have breast cancer? I’m not stupid, it gave me pause for thought, so I hid it for a while, on purpose, because it is a small group and I didn’t want to get labeled.

NR: *Lesbians’ worries about finding partners after cancer occur in a context where dating can be a serious challenge. Heterosexism limits lesbians’ capacities to be out and visible and makes it harder to find or identify potential partners—especially in small communities. Even in a city as huge as Toronto, lesbian communities can feel small. One research participant referred to “the great lesbian chart” which plots, among other things, who has slept with whom (this woman was amazed and delighted to find a partner with whom she had no previous connections—by which she meant, actually, that they had no ex’s in common).*



Dr. Christina Sinding and Sarah Emery. In the background is a framed copy of a picture and article from the Toronto Star on Thursday, September 30, 2004 which features Sarah talking about her experience as a lesbian diagnosed with cancer.

And then there's sexuality. With breast and gynecological cancer, sexual parts of a woman's body have disease; they are screened, monitored, and repeatedly examined. These kinds of experiences and feelings can become linked with sexuality. And this is something we don't much talk about.

R2: It was very emotional for me to be sexual for many, many years... I felt very protective of my body, my cervix, my vagina. I was afraid, sort of, you know, if I got fucked too hard.... In some totally irrational part of my brain I was thinking, "it's going to activate the cancer", that's where the crazy place was.

R1: I know what it's like to take a woman's breast into my mouth and feel that visceral response in my body and her body. This breast cancer thing has contaminated and invaded all of that for me. It has become my enemy, when it comes to that piece of my sexuality.

R2: There's very little if next to nothing out there about the effect of losing your breasts on your sexuality. Which made me think, "what no one plays with anyone's nipples anymore?"

NR: *The loss or changes in a breast, or the changes sexual organs that can come with gynaecological cancer, are a kind of double loss to lesbians. The sameness of bodies in a lesbian relationship makes the treatment effects from a "woman's cancer" especially present, and especially complicated and difficult. Women talked about what helped them with this.*

R2: Even when I was having chemo my partner and I still made love and loved each other. I was worried when I was bald but then, she didn't mind my bald head, so, I felt good about myself.

R1: A casual lover I had was amazing in terms of not being afraid to touch me, and not freaking out, moving slowly with me, making sure I was okay as we progressed into lovemaking, giving me as much time and room as I needed.

R2: I get dressed in the morning and I look at myself in a full-length mirror and I look at my breasts and I think, "oh, you're lingering in there, you breast cancer and I hate you for that." Then I try to remind myself that I love my breasts, you know. So then I touch my breasts and I feel them and I try to get reconnected with them.

R1: I was one of those people for whom the nipple was the triggering factor. Then it's not there, what do you do? You have to figure out some other way, another way to have sex. [with playful sarcasm] We've had to train really hard and practice a lot.

NR: *The lesbians we interviewed talked about other consequences of cancer treatment. First, hair loss.*

R1: I have a wonderful butch lesbian friend who taught me how to do my hair with one of those hair clipper things. I had never done that before in my life. [laughter] And as a professional, I always struggled with, "Okay, so, how dykey can my hair go and still pass, still be acceptable...." So it was the first time I could have a legitimate absolute dyke haircut. And so for me it was liberating.

R2: The cutting of my hair essentially was my way of saying to the world, "I'm still a butch" in the face of the threat from cancer.

R1: On Church Street they're like, "yeah, you go girl..." I still have one waiter at this restaurant who always

says, "when are you going to shave your head again, I love that, you look so great." I finally told him a couple of months ago why I didn't have hair then, he went, "really, well you still look fabulous" and I thought, "love you." That was the kind of support we got, you know.

NR: *Lesbian identity seems to allow some women to resist the difficult impact of hair loss, and even to find power in it. But hair loss can be disempowering for lesbians.*

R2: You feel like in a way you've died and been reborn. Your hair goes right down below the skin line. It takes months for it to even come back, I'd never seen my bare

"'No! You couldn't be a lesbian,' she said. And I go, 'well, last time I checked, I am a lesbian.' And I was even more isolated from the group because I confirmed it for them."

head since I was a baby, and ... oh, it was dreadful. I hid away from people. I hibernated. I was away from everybody. If they would have said, "what's the worst time of your life?" I would say, "when I was on chemo."

NR: *Lesbians had a range of experiences around the loss of their hair. They also had a range of experience—and different beliefs—about breast loss.*

R1: I think a woman wouldn't drop a woman partner because she lost her breasts. It's more of an emotional love than a physical fixation. If I had a mastectomy or had some disfigurement of my breast, it would be more acceptable with another woman than it would be with a man.

R2: At the time of my surgery I had that lesbian belief in my head, it doesn't matter what I look like, lesbians are going to love me anyway. So I had that in my head, no problem, no matter what I look like. I'm strong and this isn't going to bother me. But it does matter to some women. Some women don't even want to look at that breast. Some women don't even want to touch that breast. Some women you never hear from again.

R1: I think lesbians really identify with their breasts, you know, as a sexual thing....

NR: *In this research we heard that breast loss isn't so hard for lesbians because lesbians reject society's ideas about what women should look like, and because women partners are more accepting. Sometimes this felt true for the women we interviewed; other times it was not. But, we also heard that breasts matter more to lesbians than they do to heterosexual women and so breast loss is especially difficult for lesbians. It is not a problem, of course, that some lesbians think breasts matter more to us, and some think they matter less, than they do to straight women. What becomes a problem is when we start to make rules for lesbians with breast cancer. Here, one woman gets the message that she can't be a proper lesbian (at least not a proper femme) without breasts, while another hears*

that she can't be a proper lesbian if she chooses to have breast reconstruction.

R2: For a lot of my friends, Pride Day and stuff like that, it's all about their bodies. The way they dress and stuff like that, they say "she's a dyke, she's a femme," you know.... But now you're a lesbian femme (that's what they call me) [laughs] with no breasts! So where do you fit? A lot of my lesbian friends would say stuff like, "you know, you should try wearing prosthetic breasts, because your clothes will fall better."

R1: I read stuff by lesbians about the patriarchy forcing implants upon you and lesbian survivors saying "I was proud to not have boobs." ...It was like that, sort of strange, judgmental bit about, you know, somebody wants to be femmy, "oh, well, they're just passing."

NR: *The women we interviewed talked about community cancer services. Some felt pretty well supported by these services. Others never tried to access services because they felt they wouldn't be welcome. A few had very difficult experiences.*

R1: Like 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 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. Right? 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 and 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.

R2: The woman beside me goes, "so your partner is Lesley—is that a guy's name?" And the room is hushed. "No, actually," I said, "it's a woman's name, and I'm a lesbian." "No! You couldn't be a lesbian," she said. And I go, "well, last time I checked, I am a lesbian." And I was even more isolated from the group because I confirmed it for them.

R1: I asked the facilitator to talk with the group about different kinds of relationships and how important partnerships are for coping 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?"

R2: 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.

NR: *The "not our mandate" comment was heard by more than one of the lesbians with cancer we interviewed. This comment implies that providing support that includes lesbians is "above and beyond" what the service does. Yet unless the service has been created and designed with the intent of only serving heterosexual women which none of the services claimed to be, then obviously it should work to integrate and reflect*

lesbians and lesbian realities. It was also clear that the isolation lesbians with cancer experience is made all the more difficult with the recognition that there are no services for their partners or children.

R1: Where does my partner go? I mean, there's not a lot of support for heterosexual partners, but there's none for lesbian partners.

R2: If you have kids you have to worry about whose looking after the kids, who's helping with the kids. Are the kids in an environment that's safe for a child of lesbian and gay parents?

R1: To get support, my children have to talk about me, right? Which means coming out as the kids of a lesbian mom, and dealing with all the reactions about that. My kids are in this situation a lot. And do they really want to deal with their sadness and grief and have to explain all that? No, they don't.

NR: *When they spoke about the formal health care system, a few women told difficult stories of encountering homophobia.*

R1: I have to say, it would've been much better if I had been heterosexual. I think people would have touched me more ... you know, just from what I've observed in the hospital.

R2: They put me in quarantine, because they were afraid I had AIDS, because I was gay they put me in quarantine....

R1: They had to do the lumpectomy under local anesthetic because of my heart problems. I told him that he was beneath the level of the freezing and he told me that I was a dyke, therefore I should be able to tolerate pain.

R2: The doctor was supposed to do a breast examination and she stood about as far away as a person could, you know, like she was moving a computer mouse from across the room.

NR: *Heterosexism was relatively common.*

R1: I don't know how many times I got asked that question, "could you be pregnant?" It's like, no, I'm a lesbian and I've been in a committed relationship for the last nine years, there's no possible way that I could be pregnant. "We don't believe you, pee in the cup." What I found more difficult than anything was fighting the system on stupid little issues like that. I want to walk away sometimes when I have those battles.

R2: The boob dude—the surgeon who did my reconstruction—just looked at me funny when I asked when I could play softball and hockey ... same thing with the little exercises you're supposed to do. The little drawings that go with your rehabilitation exercises are all these lovely women with scars looking ever so serene, lifting their little hands up with their three-inch fingernails, lifting their hands up and looking just lovely, waving their little wrists. And I'm thinking, when can I play hockey?

NR: *It's important to note that most of the lesbians we interviewed said they did not encounter homophobia in cancer care. But when they talked about this, we learned*

something surprising. Listen to this quote:

R2: It made such a difference to me that the surgeon spoke to my partner first, instead of my parents. Just that 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.

NR: *The physician clearly acted in lesbian-positive ways, and the participant's appreciation is real. Yet, as she herself says, a heterosexual woman usually doesn't even have to think about the possibility that a physician might "overlook" her*

"The doctor was supposed to do a breast examination and she stood about as far away as a person could, like she was moving a computer mouse from across the room."

spouse. What is normal for heterosexual women is something that lesbians in this study remarked on, even praised. A long history of homophobia in health care leaves lesbians in a position of gratitude for things that heterosexual people take for granted. It was pretty clear in our research that cancer care and support is not organized to be accessible and welcoming to lesbians. Care and support was inaccessible along class lines as well, as lesbians living on social assistance soon discovered.

R2: I needed a nurse after my surgery, and welfare wouldn't pay for it. Welfare said Community Care Access should send me somebody. All they did was argue. So nobody got to me. Later in my treatment I called a cancer agency to get a ride to treatment and they told me that welfare should pay for the cab. The welfare worker said the cancer agency provided the service free to other people so they refused to pay. I ended up walking, every day, for 28 radiation treatments.

NR: *Obviously the discrimination and exclusion lesbians experience in cancer care is related not only to their identities as lesbians. Other kinds of discrimination also deny lesbians access to care.*

R1: When we're vulnerable, we're very unlikely to be advocating about race, disability, sexual orientation on top of everything else. But to assume that these things don't affect our experience or aren't things we wish to talk about if someone dared to ask is totally different.

R2: Being a lesbian, and having cancer, are both part of who we are.

ALL: If you don't know who we are, how can you support us?

Conclusion

What is clear from this research is that lesbian identity and community matter—sometimes very significantly—

in lesbians' experiences of breast and gynecological cancer. It is also apparent from this project that heterosexism shapes cancer care and support (see Sinding *et al.*; Barnoff *et al.*). Resoundingly clear across all of the participants' interviews was the need for lesbians to be recognized and supported throughout the cancer care system and beyond. For the women we interviewed, having health care providers (from doctors to nurses to home care support) acknowledge who they are as lesbians, and who their loved one's are, was critical in being able to support and care for them throughout their cancer experience. Since the spring of 2004, the *Coming Out about Lesbians and Cancer* script has been presented within a variety of community, health care and cancer centres across Ontario. Central to the project's original mission is to ensure that the project findings return to cancer care and support settings, and to lesbian communities. Other studies have confirmed the effectiveness for health professionals of research-based dramas (Gray *et al.*); the script presented here has also won warm praise—as one health centre counsellor said, “I learned, I celebrated, I connected and I was inspired. Not the usual outcome of a report presentation for me....” Our goal remains the same as we embark on taking the *Coming Out about Lesbians and Cancer* script to a wider audience: that is to begin and continue a dialogue between cancer and LGBT communities about the strengths, needs, and barriers facing lesbians diagnosed with cancer.

We want to express our sincere appreciation to the women who agreed to be interviewed for this project, and to members of the Lesbians and Breast Cancer Project Team. Coming Out About Lesbians and Cancer is the research report from the Project. The report [in summary form, and as a 100+ page document] is available on the DAWN Ontario website, <http://dawn.thot.net/lbcp>.

The Lesbians and Breast Cancer Project was undertaken by a coalition of agencies and individuals active in the cancer community, as well as the lesbian and women's health communities. Lesbians directly affected by cancer were involved along with agency staff and volunteers, and researchers. This research was made possible with funding from the Canadian Breast Cancer Foundation, Ontario Chapter.

Members of the Lesbians and Breast Cancer Project Team: Maureen Aslin, Jennifer Alexander, Lisa Barnoff, Pauline Bradbrook, Michèle Clarke, Teri Henderson, Pam Grassau, Patti McGillicuddy, Fran Odette, Samantha Sarra, Chris Sinding, Anna Travers, and Danielle Vandezande. Lesbians and Breast Cancer Project Partner Agencies: The 519 Church Street Community Centre; DAWN Ontario: DisAbled Women's Network Ontario; The Coalition for Lesbian and Gay Rights in Ontario; Gilda's Club; The Metropolitan Community Church of Toronto; The Ontario Breast Cancer Community Research Initiative; The Rainbow Health Network; Sherbourne Health Centre; Sunnybrook and Women's Col-

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References

- Barnoff, L., C. Sinding and P. Grassau. “Lesbians Diagnosed with Cancer: Experiences of Cancer Support Services and Recommendations for Change.” Unpublished paper, 2004.
- Denzin, N. *Interpretive Ethnography*. Thousand Oaks, CA: Sage, 1997.
- Ellis, C. and M. G. Flaherty. “An Agenda for the Interpretation of Lived Experience. *Investigating Subjectivity: Research on Lived Experience*. Eds. C. Ellis and M. G. Flaherty. Newbury Park, CA: Sage, 1992. 1-13.
- Gray, R., M. I. Fitch, M. Labrecque and M. Greenberg. “Reactions of Health Professionals to a Research-Based Theatre Production.” *Journal of Cancer Education* 18 (2003): 223-229.
- Gray, R. and C. Sinding. *Standing Ovation: Performing Social Science Research About Cancer*. Walnut Creek, CA: AltaMira Press, 2002.
- Lesbian and Breast Cancer Project. *Coming Out About Lesbians and Cancer*. Toronto: Ontario Breast Cancer Community Research Initiative, 2004.
- Sinding, C., L. Barnoff, and P. Grassau. “Homophobia and Heterosexism in Cancer Care: Lesbians' Experiences.” *Canadian Journal of Nursing Research* 36 (4) (2004): 170-188.

The Ontario Breast Cancer Community Research Initiative (OBC CRI) envisions a future where there is understanding of, and responsiveness to, women's experiences with breast cancer.

This research unit is a partnership of Sunnybrook and Women's College Health Sciences Centre, the Centre for Research in Women's Health and is funded by the Canadian Breast Cancer Foundation, Ontario Chapter. Using participatory approaches and mainly qualitative methods this research unit engages in psychosocial research about the experience of breast cancer for marginalized communities of women; actively shares research findings; and, increases research capacity to address the needs of women living with breast cancer.

If you'd like more information about OBC CRI please contact Angela.Sardelis@sw.ca or call 416-351-3811.