

Aiming for Better than “Nobody Flinched”

Notes on Heterosexism in Cancer Care

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Dans cet article nous réfléchissons sur ce que nous avons appris sur le “Projet du cancer du sein chez les lesbiennes,” comment l’oppression s’installe, surtout comment elle fonctionne avec ses déguisements surnois. Nous discutons d’abord des façons subtiles qui révèlent l’oppression dans la vie des lesbiennes et de leurs histoires. On examine ensuite les routines des pratiques apparemment inoffensives qui excluent ces femmes socialement marginalisées des services et des soins qui sont réservés à certaines privilégiées. Nous demandons, pour conclure, à toutes les aidantes de se rendre compte que les pratiques quotidiennes peuvent perpétuer ou favoriser l’exclusion.

The Lesbians and Breast Cancer Project explored lesbians’ experiences of cancer and cancer care and fostered positive change for lesbians with cancer in Ontario communities and in health and social services. Twenty-six lesbians who had experienced a cancer diagnosis participated in the study, offering stories and insights about health care and social support and about how their identities, bodies, sexualities and relationships were affected. The full research report and a summary report are hosted at the DisAbleD Women’s Network Ontario website at (see also Barnoff, Sinding, and Grassau; Lesbians and Breast Cancer Project Team; Sinding, Barnoff, and Grassau).

In this article we reflect on what we learned from the Lesbians and Breast Cancer Project about how heterosexist oppression works—especially its disguised and how covertly it operates. We focus initially on the subtle ways oppression revealed itself in lesbians’ lives and stories. We then examine one of the routine, apparently innocuous ways that cancer support services perpetuate oppression, and resist progressive change.

When our project team traveled to cancer centres or cancer support agencies to present study findings we were often asked to tell the ‘horror stories,’ to recount the most blatant examples of homophobia we had heard. We never felt fully comfortable with this request as the pivotal presentation focus, but we have often met it—so, let us tell you just two of these sorts of stories.

Paddy had a heart 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 and he told me that I was a dyke, therefore I should be able to tolerate pain.

Theresa was in hospital due to complications of her treatment, and only ‘family members’ were allowed

into her room. And at a hospital in downtown Toronto, not all that many years ago at all, the attending nurse’s definition of family excluded Theresa’s partner.

And so [my partner] would stand out in the parking lot and wave. So she was ... pretty heartbroken.

The horror stories often evoked gasps from audience members (physicians, nurses, community service providers)—and we were glad they did. But also, and perhaps more importantly, the horror stories sometimes contributed to a sense that oppression was ‘over there,’ done by ‘those people’ and easily identifiable. When it’s a really bad story, it seems we can easily think: I would never do that, that would never happen here, at our cancer centre, in our support group. And we can let it go—distancing ourselves from the problem, and failing to acknowledge the persistent (but less obvious) harms, the subtler ways that access to care and support are compromised.

So we want to come at this from the flip side: we want to tell you the ‘good stories.’

Most of the lesbians we interviewed said they had not encountered homophobia in health care and support services they sought during their cancer treatment and its aftermath. This is something to celebrate—Ontario’s

impressive history of activism by lesbians, gay men, bisexual people, transgender people—along with women's health activism, feminist activism—have made a difference in health and social services.

And yet, and yet... As the 'good stories' accumulated and we started hearing echoes between them, the spaces in-between, we realized that the situation was more complex

When I came out of surgery the surgeon went right to my partner... So I was pleased with that, that she wasn't sort of because they could have gone to my mother or my father or whatever. It made such a difference to me that she went to [my partner] first. Just that, in legitimization of who we are... because she would have for sure gone to my

decriminalize, to pronounce lawful, to sanction, to authorize. We often think of sanctioning and authorizing as what courts or judges do, or what religious care providers do. We realize in Paula K's quote how everyday interactions can also carry this sort of meaning. The health provider here confirmed that Paula K's relationship with her partner was legitimate, real, genuine.

This level of gratitude for such ordinary instances of care—how they are felt as gifts, rather than being so expected that they are not even noticed—gives us important information about what lesbians have come to expect in health and social services.

than it seemed. Here are a series of quotes—the 'good stories.'

I remember this one young woman who was the receptionist where we went for chemo.... She was so bubbly, we'd walk in and she'd go, 'hi, how are you girls? She recognized our relationship, she asked [my partner] how she was doing, and that was lovely. (Maureen)

When [the doctor] came in, I introduced [my partner] as my partner.... I'm sure they wrote it down in the chart ... they were actually really really good. (Bonnie)

We just tell people that she's my partner and you know, they have adjusted, nobody has flinched. One of the nurses said, 'oh that's so cool, that's so great,' and then she went on complaining about her husband [laughter]. (Paula K.)

The staff [at the hospital] was wonderful, they let [my partner] stay with me in the hospital room. She slept in the bed next to me on the left hand side and they let her.... (Constance)

husband if I were married, right? It just, normalizes it, and you've got so much to deal with emotionally.... (Paula K.)

What do these experiences tell us? They tell us that things are likely better than they have been for lesbians within the health care system (for historical context, see Coalition for Lesbian and Gay Rights in Ontario, 1997). And they also tell us that we have a long way to go. Because in these quotes perfectly ordinary care, care that most women in heterosexual partnerships would not think twice about, is praised, deemed in some way exceptional, unexpected. There is nothing wrong with appreciating good care, of course. But this level of gratitude for such ordinary instances of care—how they are felt as gifts, rather than being so expected that they are not even noticed—gives us important information about what lesbians have come to expect in health and social services.

Take the last quote for instance. We can read here how much it mattered to Paula K that the physician went to her partner first—that the professional providing the health service recognized her partnership. She said that physician legitimized their relationship. Legitimization means to

Of course the physician here acted just as she should have. Yet as Paula K says, if she were married (to a man) she believes it would have been so matter of fact, so natural for her—this action on the part of the doctor, addressing her husband—that no thought would have been given to it. That a physician will 'naturally' address a woman's husband is, of course, not something all heterosexual women can assume: for example, mixed race heterosexual couples are sometimes not recognized as couples (Steinbugler, 2005) and in a paternalistic cultural context the woman as patient may be ignored and the male partner seen as primary contact. So this dynamic is more complex than it might at first seem. However, what is clear is that in an institutional context that constitutes women with breast cancer in particular ways—as heterosexual, white, able, middle class—Paula K experiences the care she and her partner received as "a gift," something to be thankful for, or relieved about, an anticipated harm that has been dodged rather than something expected. In this study, we see it throughout the quotes: what's assumed, what's rendered 'normal' and expectable by the hegemonies of the cancer care context, is something that is 'remarkable' for lesbians.

Stories of exclusion, horror stories,

obviously matter, and definitely require action. But often too the ‘good stories’, the moments when service providers are praised for the care they provide, signal that genuine equity has yet to be achieved. In the contexts where we live and receive care, we see there is still disempowerment, which is in part reflected in this high level of gratitude for the care and courtesies that should be routinely offered to all patients.

Disempowerment—this subtle, hidden (even from lesbians) expectation of sub-standard care—works in another way too: it means lesbians go into health care encounters ready to fight.

If anybody had ever said anything about, you know, men only partners or something, then they would have had a fight on their hands, that’s for sure. (Constance)

That hospital accepted my lesbian partnership, right from the volunteer auxiliary who said, ‘of course your friend can wait for you,’ before the surgery to nurses who basically gave [my partner] the open door, to.... That wasn’t an issue—but I wouldn’t allow it to be an issue. (Marcia)

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. (Rosalie)

Again, these are all positive comments, ‘good stories’. And at the same time, they reflect something else, something far less positive—they reflect a persistent alertness to the possibility of exclusion and potential harm; they reflect lesbians’ knowledge that respect—as women and as lesbians, and for our partnerships—might well need fighting for; they reflect the persistent possibility that the stress of the cancer journey will be exacerbated by the “care” pro-

cess. In its subtler workings, then, a history of lived experiences of oppression generates relieved praise and readiness to fight, for good care.

We also learned in this study about some of the covert practices that sustain the operation of oppressions in cancer care services. Over many interviews, and reflecting on our own experiences as service providers and activists in the cancer community, we came to understand how cancer care services often set boundaries around their role and responsibilities, boundaries that function to recognize and affirm only certain identities.

Theresa told us about joining a support group. She described telling the women in the group that she had ovarian as well as breast cancer, and how the room went silent. She then mentioned her partner.

The woman beside me goes, so your partner is [name]? Is that a guy’s name? And the room is like, hushed, eh? ‘No, actually, I said, it’s a woman’s name, I’m a lesbian.’ ‘No! You couldn’t be a lesbian’—like this, right? And I go, ‘well, yeah, last time I checked, I am a lesbian.’ ... Then I was even more isolated from the group, because I confirmed it for them.

After this uncomfortable meeting, Theresa asked the facilitator to talk with the women in the group about different kinds of relationships and how important relationships and partnerships can be, for coping with really difficult life situations:

[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, right?’

This was the first instance of the phrase ‘not my mandate’ that came forward in our study. The phrase became an important thread through our study findings. A story Glenda told helped us understand it more deeply. Glenda was on social assistance at the time of her cancer di-

agnosis. When she had the opportunity to meet with a counsellor at a support service, one of the issues she wanted to talk about was how the counsellor could help her access much needed resources, such as a local food bank. The counsellor was insistent that she focus only on her cancer:

The [worker] 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.

For these service providers, supporting lesbians and poor women (and in this specific instance a lesbian whose experience of cancer was very much shaped by poverty) was deemed ‘above and beyond.’ Not what we do here. Not what we are concerned about. In an instant, in phrases that might at first appear to be benign, they define who they serve, and by extension, who they do not. This process rests on the assumption that there is an ‘experience of cancer’ that is lived as somehow outside of other aspects of one’s identity or supersedes any identity concerns

These processes of inclusion and exclusion are much more subtle and hard to identify than outright discrimination. Service providers can easily claim that all women are welcome, and point out that in some cases, diverse groups of women do participate in their services. But when the focus of cancer agencies is limited to ‘only you and your cancer’, as Glenda was told, or when taking steps to address barriers and actively include lesbians is said to be ‘beyond our mandate,’ as Theresa was told, some groups of women do experience being *excluded* from the service (even if—and while—they participate in that service). The exclusion might not be at the level of being refused entry to the group, but is there nonetheless, informing and circumscribing involvement and the privilege of belonging to and in the group.

The trouble is this: hegemonic constructions of ‘cancer experience’ and ‘cancer support needs’ are quite narrow. They mean, really, the experience and needs of white, middle class, non-disabled, straight women with cancer. These women’s identities, experiences and circumstances are enabling of care—they fit the mandate. ‘Other’ women, who bring ‘other’ issues into the mix, are understood to be asking for something outside of ‘cancer support’ when they ask for exactly the same thing: “I and my cancer”—for their own experiences and needs to be recognized. Service providers (including those who identify as lesbian) committed to these narrow definitions of cancer experience and cancer support needs can make ‘other’ women feel wrong for having multiple needs, or greedy for asking that they be met.

As we continued to come across ‘not our mandate’ messages, we realized we had encountered them before. Chris (one of the authors of this article) worked in the cancer support and advocacy community for several years, organizing workshops for women starting and sustaining cancer support groups. She and the agency director were travelling together to a workshop one day, and Chris said she was thinking about coming out during the introductions, and speaking briefly about diversity among women, how identity and social location can affect support needs and options and so on. The director said: “this is a workshop about support for women with breast cancer. It doesn’t make sense to complicate it with other issues.” The director, it seems, was speaking a kind of code—the ‘not our mandate’ code, we came to call it.

‘This is a workshop about support for women with breast cancer. It doesn’t make sense to complicate it with other issues.’ What was she saying, really? She was saying: this is a workshop about support for *heterosexual middle class non-disabled white* women with breast cancer. It doesn’t make sense to complicate it with other *women*. So, it seems that

oppressions move through cancer care wearing masks. One of the masks is the ‘not our mandate’ code.

The power of the ‘not our mandate’ code is partly its capacity to exclude many women’s identities and circumstances (while hiding that this is occurring). The power also lies in its capacity to include, make central, certain identities and life circumstances. When service delivery systems promote the idea that ‘other’ issues (issues related to heterosexism, or poverty, or racialization, or disability, and so on) are irrelevant to women’s experiences of cancer, they create spaces in which only certain conversations and claims are invited and welcome. And this process works to deny or constrain space for some women, and to unfairly and invisibly preserve space for and benefit other women (for discussion of a parallel process at the policy level, see Daley).

Patti encountered yet another version of the ‘not our mandate’ code when she and a management colleague at a large urban hospital with a cancer centre approached the vice president of public relations to request a simple Happy Pride message be included in the staff newsletter in which many diverse cultural and social greetings often appear. After a review of the request, Patti and her lesbian colleague were repeatedly told that this was a “downtown” issue, not an issue at this mid-city hospital. Downtown—not here. ‘Not our mandate’: and they were saying this even in the context of knowing there were lesbians right there.

When the ‘not our mandate’ code is operating, so too are exclusionary and inequitable practices. We contend that it is this fact that cancer care and support services need to grapple with, in their efforts to build equitable workplaces for staff and service delivery models for patients. The operation of oppressions is masked by the idea that only the stories of obvious, explicit discrimination really matter, and therefore, that only these stories form a legitimate basis for attention and

change. In fact, these stories presented out of context can marginalize and minimize integrated change.

There is another important message in the responses Chris and Patti received from cancer agency senior management, a message directed not at women with cancer but at lesbians working in cancer care. The message is this: do not complicate patients’ complex cancer journeys with your extraneous identity issues. As a result, the support that might be offered to lesbians with cancer from lesbian service providers is thus often coded, muted or invisible. Equity in service delivery for lesbians with cancer can hardly be a goal embraced by organizations in which lesbian care providers themselves are discouraged or disallowed from any degree of visibility.

Everyone who provides cancer care and support has a responsibility to reflect critically on how everyday, seemingly ‘ordinary’ practices can inadvertently perpetuate processes of exclusion, so that we can begin to take steps toward change. It is not enough to ‘acknowledge’ lesbians (by, for example, recognizing and including partners) nor should service providers be content with the knowledge that some lesbians (whether they be white or racialized, affluent or living in poverty, non-disabled or living with a disability, older or younger) might in fact already use their services. In order to actively confront oppressions and to offer services that embrace equity, service providers have to do so much more. Lesbians working within the cancer care system and those living with cancer can work together. One way to begin is to consider how the sorts of subtle processes of exclusion we discuss in this article might be operating. We can reflect, for example, on whether and how the ‘not our mandate’ code appears and gets used, and consider its various consequences for women—and for our collective ideas about who women with cancer really are. Once this sort of reflection begins and we build allies in the work, transformative change can follow.

This article is written in memory and celebration of Glenda Adshade.

The stories, commitment, and passion of many people and agencies made the Lesbians and Breast Cancer Project possible. Chris, Lisa, Patti, Pam and Fran were members of the Project Team. The names of all of the team members and of the women who participated in the study, along with a list of partner agencies and funders and the project report, are hosted at the DisAble Women's Network Ontario website <<http://dawn.thot.net/lbcp>> (thanks to DAWN Ontario, and Barbara Anello, for this).

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MALCA LITOVITZ

Cheap Top

Cheap top — twenty-five bucks—
made me feel great for a summer.

Now even expensive clothes
leave me the same —
I can't play with what I wear.

My hands are clasped,
feet flat on the floor
like some grade school student
in Gradgrind's college.

Where did my daring go?

Jarred, rattled, shot down —
a tube up my nose,
a bag on my waist,
an uncertain future.
Chemicals through my body —
hair lost —
no eyebrows, no eyelashes —
no trace of hair any where.

Music I can't listen to,
books I can't read,
files I can't sort.

"Accent the positive," dad used to say.

Dad's gone.
November is almost gone.

Malca Litovitz's poetry appears earlier in this volume.