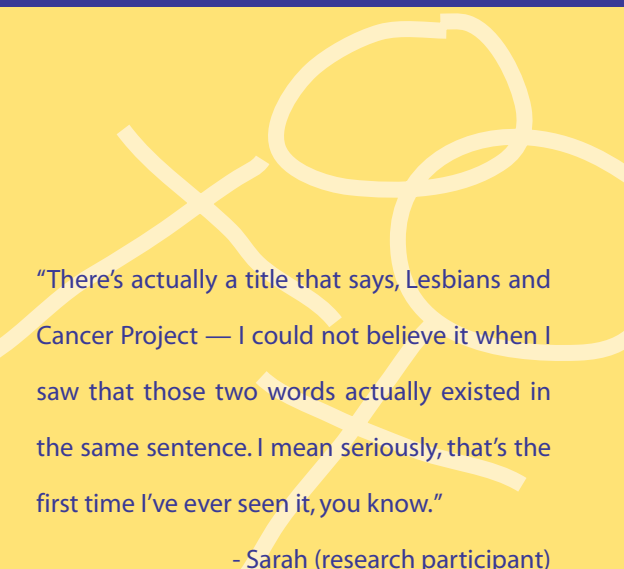


Coming Out

Coming Out

About Lesbians and Cancer



"There's actually a title that says, Lesbians and Cancer Project — I could not believe it when I saw that those two words actually existed in the same sentence. I mean seriously, that's the first time I've ever seen it, you know."

- Sarah (research participant)

Summary Research Report

The Lesbians and Breast Cancer Project

April 2004

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About Lesbians and Cancer

The Lesbians and Breast Cancer Project was a community-based participatory study conducted in Ontario, Canada, in 2003. We interviewed twenty-six lesbians diagnosed with a 'woman's cancer' (twenty-two with breast cancer, three with gynecological cancer, one with both) about their experiences of treatment, cancer care, and support, and their feelings and ideas about changes in identity, body, sexuality and relationships. Demographic information about the women can be found beginning on page 39 of this report.

This document is a summary of our research. See the back cover for details about how to obtain a copy of the full research report.

Lesbians and Cancer: Coming Out Again

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. [Lillian]

For lesbians, being public about cancer has parallels with coming out as a lesbian. Cancer and lesbian identity have historically evoked shame, and we share a long tradition of hiding both. Often neither identity is immediately obvious to others, and so lesbians, and all women with cancer, face ongoing choices about 'coming out.' Being public about having cancer, and about being a lesbian, is still a risk. People may — and sometimes do — back away (and worse); certain aspects of our security (like our jobs) may be jeopardized.

You get that look on some people's faces that, you know 'oh, she's got cancer.' 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. [Laura]

It's very lonely. I had a very good doctor at that time, very lesbian positive. She was all that I had. Even my family — there was the thought that I'm lesbian but then the other thing about cancer. People just have their own reactions about cancer. Some fly away, some stay beside you. I was very clear about

what my needs were, and it just, oh, it was one of the saddest, loneliest times of my life. [Glenda]

These quotes point to the ways homophobia links up with society's fear of cancer to take a particular kind of toll on lesbians with this diagnosis, to require a special kind of courage from them, as Laura says. In what both Laura and Glenda say, we can see and feel how the social consequences of a cancer diagnosis may echo the sense of separation and aloneness that sometimes accompanies living as a lesbian.

Marie talked about this as well. She continues to sense fear in new people who come into her life and learn she has had cancer. Their fear makes her feel 'other' — a feeling that is already familiar:

As dykes... from a very young age feeling 'other', you know, like there's something different about me, even before you know you're queer. So it wasn't an unfamiliar, that's not an unfamiliar thing for me to feel, other. And I sort of learned to celebrate otherness and that's okay for me. [Marie]

Because of its echoes with coming out as a lesbian, having friends 'fly away' when they learn about cancer may be an especially complicated and painful experience for lesbians with cancer. At the same time, as Marie points out, lesbians have had to develop strategies for dealing with the feeling of being 'other,' and we can see how this might be, at times, a source of strength for lesbians with cancer.

Support

After Lillian spoke of the difficult parts about ‘coming out again’, she noted a flip side:

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, I didn’t tell anybody...’ [Lillian]

As Lillian suggests, coming out about cancer does hold possibilities for connection. Many of the women who took part in this research felt immensely well supported by their partners, friends and communities, and some found community with heterosexual women with cancer.

In fact, some participants argued that lesbians may be ‘better off’ than heterosexual women, when it comes to support. Several of the women we interviewed spoke of feeling really well understood by lesbian partners and friends. Part of this capacity for understanding is, as Rosalie says, the shared experience of having a woman’s body:

My partner has ovaries. My partner has a uterus. 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 that it can be difficult to talk about in general society. My partner knows what a check-up means, and submitting to all that poking. [Rosalie]

A few research participants felt their partners, because they are women, were particularly able to be present and to connect emotionally. And some of the women we interviewed experienced other lesbians as offering especially well-organized and competent care. In speaking about these qualities, research participants made reference to traditions of lesbian community organizing; they also explained that caring for gay male friends and colleagues with AIDS has provided lesbians with a store of knowledge about care teams and networks. It was clear from this research that support for lesbians with cancer in lesbian community can be emotionally engaged, competent, well organized and immensely meaningful to the woman with cancer.

At the same time, several of the lesbians we interviewed had experiences that ran counter to the idea that women partners and lesbian friends are especially emotionally available, or good communicators; one woman, for instance, regretted that she and her partner **“didn’t talk about the cancer hardly at all.”** And it was in part comparing her own experience to what she saw happen for men with AIDS that Marcia found lesbian community organizing in relation to cancer lacking. She said, **“I think we did a terrific job in terms of the HIV/AIDS epidemic, but ... How do we care for each other, rather than how do we care for the boys?”**

Marcia went on to describe many ways that lesbians could (and haven’t, as yet) create support for lesbians with cancer using existing services. Along with other participants, she raised the need for formal lesbian-positive cancer services where informal networks are not strong and in situations where care is needed over long periods of time.

Women who did not always get the support they expected from other lesbians talked about some of the possible reasons. The main one was the ‘could be me’ factor. Theresa identified a

number of different aspects of ‘could be me’ that may have made it hard for her friends — and may more generally cause struggle for lesbians who do not have cancer trying to support lesbians who do:

It becomes like ‘wow, what if I lost [my breasts] ... how horrible would that be, you know? Who’d want to touch me?’ Like all those issues when you lose body parts, right? [Theresa]

Fear can also operate at a community level. Marcia, for instance, said she **“did feel invisible as a cancer survivor, in the lesbian community... [I] felt like I represented the fear of all lesbians, of getting breast cancer.”**

And Theresa observed, other lesbians **“know the resistance they’ve had in the hospitals.”** Other lesbians know what it’s like to experience and worry about homophobia in the health care system. Theresa suggests that this point of connection can lead to lesbians focusing on how hard it would be for them, and how they would handle the situation, rather than being present with the lesbian who has cancer.

It seems from this research that as lesbians we hold certain ideals about support in lesbian community. Sometimes our ideals match reality really well, and support for lesbians with cancer can be immensely sustaining for individuals, as well as a kind of community achievement — something to really appreciate and celebrate. At other times, the notions we have about how well we support each other do not come true, making times of isolation especially painful.

It was also clear from this study that the ‘could be me’ theme worked both positively and negatively. It was a source of understanding and connection — the fact that Rosalie’s partner

“**could be in my position**” helped Rosalie feel understood, for instance. The ‘could be me’ factor also seemed to draw some lesbians into support teams for women they did not know especially well. On the other hand, the feeling that it ‘could be me’ may lead some lesbians to distance themselves from lesbians with cancer.

In a more general way, the fear generated by cancer and the lack of dialogue about the illness in lesbian communities contribute to the isolation of lesbians with cancer. Our ‘phobia’ about cancer — perhaps especially strong in relation to women’s cancers — affects the support lesbian communities can offer.

Fallout from Treatment

HAIR LOSS

Here's a stereotype: lesbians like hair in places heterosexual women don't (legs, armpits); lesbians don't like hair in places heterosexual women do (heads!). Like all stereotypes, it's wildly oversimplified, yet it links in with ideas that society has about lesbians, and ideas that lesbians have about ourselves, in ways that are relevant to lesbians with cancer.

Often chemotherapy causes hair loss all over a woman's body. Many women cut their hair short before chemotherapy. For the lesbians we interviewed, having very short hair, a shaved head or being bald was sometimes linked with a positive lesbian identity:

I always struggled with, 'OK, 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...[and] sort of in tune with, we're queer, we're here, and we're not going away! [Marcia]

For Marcia, as for Mary Lou and Paddy, having very short hair was a way of affirming a lesbian or a butch identity and a way of maintaining or connecting to power. Constance also noted that in queer community, a bald woman is not necessarily seen as a woman with cancer. She said this meant that she was treated **"like a normal human being."** Queer culture and community lend hair loss a wider range of meanings for women

than does the dominant culture, a fact that may be a source of strength for some lesbians with cancer.

Yet for some of the women we interviewed, there was nothing good or normal or powerful at all about hair loss. Rosalie, for instance, loved her long hair, and found it **“so hard to go bald.”** For Teagan, losing hair during chemotherapy was part of **“not feeling human.”** And Laura spoke about hair loss as **“dreadful.”**

While lesbian identity might allow some women to buffer or even find power in the impact of hair loss, it was also clear from our research that hair loss can disrupt identity and be traumatic and disempowering for lesbians.

LOSS OF PHYSICAL STRENGTH

Many of the women we spoke with talked about how physically active they had been before their diagnosis. A few had regained their fitness levels and were feeling strong again after treatment. Other women told of how cancer treatment had stopped them — in some cases over long periods of time — from being active and strong in the ways they had enjoyed. A few of the women specifically said that being athletic was, for them, part of being a lesbian.

We can understand the connection between being athletic and lesbian identity in at least two ways. Again risking a stereotype, we can say that women’s physical strength and competence are especially valued in lesbian culture (in contrast with norms of femininity valued in the wider society). It is also the case that, especially outside urban centres, sports teams are a rare safe public space for lesbians. A cancer diagnosis and the effects of treatment, then, can challenge a lesbian’s valued identity around physical strength and fitness and disrupt her connection with community.

Paddy, for example, was once an athlete, and, in her own words, a person who would **“never back away from a fight.”** The effects of cancer treatment along with severe arthritis and heart problems mean she can no longer walk, run or dance; she takes a three-wheeled scooter when she goes out. As she said, **“I am this butch dyke who’s falling all over the place like a lost lamb.”** Paddy spoke about the ways cancer may be an acute challenge for butch lesbians whose identities are especially linked to physical strength. The challenge may be even more severe and complex for lesbians for whom cancer is part of a series of physical changes, changes that are experienced by some women as ongoing losses.

BREAST LOSS

One thing that became clear over the course of this research is that lesbians have very different understandings of what breasts mean and how to deal with breast loss. Some of the women we interviewed believe that lesbians rely less than heterosexual women on the social symbols of womanhood, including breasts, and are thus less affected by breast loss. Several said they think that heterosexual women struggle more with breast loss because men value breasts.

Parallel themes emerge here — that lesbians with cancer are less affected by breast loss than heterosexual women and that lesbian partners (and potential partners) care less about breast loss than male partners do.

How did these themes play out in our research? Several of the lesbians we interviewed told us that they knew their partners were still attracted to them; breast loss had not diminished that attraction. One woman said she knew women around her continued to find her sexy. Another told us about the tattoo she has on her chest and how it inspires other lesbians.

Yet some women did say that breast loss affected partners and potential partners in negative ways. One woman talked about the strength she initially drew from ‘the lesbian belief’ that changes to her appearance would not affect her desirability or lovability. It was especially hard, then, to find out that sexual partners sometimes did not want to touch her breast.

And most of the lesbians who spoke about these issues described some level of personal struggle about what had happened to their breasts. Contrary to the idea that breasts matter less to lesbians than to heterosexual women, some women we interviewed felt strongly that breasts, and breast loss, matter *more* to lesbians:

I think lesbians really identify with their breasts, you know, as a sexual thing... [Theresa]

As a woman who loves women and loves women's bodies, it's hard for me to imagine that another person could love me completely without having all of my body there. [Jessica]

It is not especially a problem, of course, that some lesbians think breasts matter more to us, and some think they matter less, than they do to heterosexual women. What becomes a problem is when these messages turn into prescriptions and judgments for lesbians with cancer. For instance, lesbians in our research heard ‘shoulds’ about breast loss — that as lesbians, they should wear prostheses or have reconstructive surgery, or conversely, that they should not.

Theresa talked about how for a lot of her lesbian friends, Pride Day (and lesbian community more broadly) is **“all about their bodies.”** Her friends label the women around them as dykes or femmes. In this context, her friends encourage her to wear a

prosthesis. **“A lesbian femme, that’s what they call me,”** she says, **“with ... no breasts! So where do you fit?”**

Lillian heard an opposite message. She talked of reading accounts 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.”**

Here, Theresa gets the message that she can’t be a proper lesbian (at least not a proper femme) without breasts, while Lillian hears that she can’t be a proper lesbian if she chooses to have breast reconstruction.

Perhaps the central lesson here is that the beliefs we hold in lesbian community about breasts and breast loss are contradictory and linked with our relationship to societal ideas about what women should look like. Certainly as lesbians we have been oppressed by these ideas, and we have good reason to be wary of them. Yet this research shows that our beliefs about breasts sometimes suggest there is one ‘right way’ for every lesbian with cancer.

SEXUALITY

With breast and gynecological cancer, sexual parts of a woman’s body have disease; they are screened, monitored and repeatedly examined. Cancer treatment is in many ways violent, albeit unintentionally. The procedures and feelings of being violated can become entwined with sexuality. In our interview, Marie said that for years after her diagnosis of cervical cancer, she could not separate the fear and sadness cancer had generated from sexual practice:

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. [Marie]

Several women we interviewed spoke about missing (or anticipating missing) their breasts and nipples in their sexual lives — and also about how infrequently this particular issue is talked about.

Some of the participants spoke about the specific ways that a woman's cancer affects lesbian sexuality. Kate explained that when two women are being sexual, and one has had a 'woman's cancer,' it is hard to avoid awareness of the cancer. As she says, **"the fact that my body and her body are different in that way is always present in that relationship."** In very basic ways, women's bodies mirror one another; with cancer, the mirror shows a change, an absence, a loss. As well, of course, lesbians know what it is like to touch another woman's body sexually. When a lesbian loses a breast, she knows what her sexual partner misses in a very personal, physical way.

The loss or changes in a breast, or the changes to the function, appearance and feel of sexual organs that can come with gynecological cancer, are a kind of double loss, then, to lesbians with cancer. The sameness of bodies in a lesbian relationship may make the effects of treatment for a 'woman's cancer' especially complicated and difficult.

Partnerships and dating

FEELING 'LESS THAN A WANTED PERSON'

Several of the women we interviewed spoke about the feeling that, with a cancer diagnosis, they became undesirable. Worries about being undesirable were especially present for women who were dating or thinking about dating:

You feel like you're never going to be in a relationship again. You go through that mentally in your head, 'OK, who's going to want to deal with this?' you know. And then you feel less than... oh, less than a wanted person, I guess. [Laura]

Sarah kept her cancer diagnosis hidden because of her worry about how it would affect her possibilities for a relationship, a worry especially acute because she lives in a small community. Yet as she moved to protect the possibility of a relationship for herself, she also lost a key source of support. Heterosexism and 'cancer phobia' can combine to put lesbians in impossible positions.

Lesbians' worries about finding partners 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. Heterosexism means there are very few supports to facilitate lesbian relationships.

Women who were in relationships at the time of diagnosis sometimes faced the possibility that their partners might

leave. Even women in very established relationships felt a niggling worry. These worries are heightened in a context in which lesbian relationships lack institutional frameworks (like nation-wide legal recognition of same-sex marriage) and often lack the sustaining social support of families of origin, for example. As Marcia said, lesbians **“don’t have the supports in terms of relationship stability to handle [the added] pressure [of cancer].”**

VULNERABILITY AND INEQUALITY IN PARTNERSHIPS

Our research uncovered many ways that cancer made lesbians vulnerable in their relationships. Liz spoke about how cancer created a situation where her (now ex-) partner emphasized her ‘failings.’ Liz felt she wound up in this diminished position **“partly because I was aware of the fact that I was no longer perfect. You know, half a breast gone, and always the fear.”** She went on to talk about the other factors involved in this changed dynamic, including an accident in which her feet were permanently injured. As she says, her mobility limitations were not related to her cancer diagnosis. Yet it was clear in Liz’s story that circumstances of lesser power, like disability, can combine with cancer to create inequality and vulnerability in relationships.

It was in fact two women with multiple health problems and disabilities who spoke about their ‘second class’ status in the bluntest language. Liz told a potential partner, **“you don’t want to take this on.”** Paddy, who lives with heart problems and severe arthritis, said, **“I’m afraid to try and find another mate... Who in the world is going to take on somebody like me?”**

These words link with the general worries that lesbians with cancer have about their desirability as partners. Yet the strong language here alerts us to the ways women with disabilities

and multiple health problems may already be viewed, and come to internalize a negative view of themselves, as 'burdens.' A cancer diagnosis, for lesbians living with disabilities, may go beyond anxiety about desirability; it may exacerbate existing power imbalances between them and lesbians who do not deal with the same issues.

Theresa talked about the ways cancer and cancer treatment meant she could not live up to her ideas of what it means to be in a relationship. In a relationship, she said, there is growth — and her growth stopped. She and her partner could do very little together because she was so ill. Similarly, Pauline had a hard time thinking about herself as a 'partner':

What does partnership mean when it's unequal? What does equality mean ... in a partnership in which one can barely manage to tie up her shoes? Can't, in fact ... can't bend over to reach them. [Pauline]

Like Liz, Pauline talked about the personal cost of dependency, the personal struggle. She also pointed to the ways that broader social factors — her inability to work and her financial situation — affected her capacity to "give back" in the ways she had before her diagnosis.

Pauline, Liz and Theresa raise important questions about how lesbians define relationships when one partner becomes ill or acquires a disability. Both independence and relational equality tend to be valued in lesbian communities; it is possible that cancer, and especially metastatic cancer, challenges these values in ways that are particularly difficult for lesbians. Yet we must remember that we draw our ideas about equality and independence from a society that focuses on 'ability' as a measure of desirability and that values certain kinds of independence

over others (physical and financial independence are especially valued, for instance). The understandings of desirability, partnership, interdependence and equality developed by lesbians with disabilities have much to offer lesbians diagnosed with cancer.

Families and finances

LESBIAN FAMILIES

Several women we interviewed talked about how hard cancer was for their partners and children. A central feature of the worry lesbians with cancer felt about their families was the lack of support available for them. The women we interviewed did describe friends attempting to offer support to their partners and children. Yet formal support services — support groups, for instance — were inaccessible.

As several research participants noted, any support group for children that would be genuinely useful would enable children to speak freely about their mothers. This would mean that they would have to ‘come out’ about their lesbian mothers, and deal with all the reactions this usually generates, and provide all the explanations it usually requires. Children of lesbian parents are in this situation frequently. As Kate said, when a parent has cancer, **“do they really want to deal with their sadness and grief and have to explain all that? ... no, they don’t. And neither did my partner.”**

That support was so unavailable for partners and children meant that lesbians with cancer often ended up putting a lot of their own energy into offering support, or trying to arrange support from friends for their families. It was clear in this research that the isolation lesbians with cancer experience is made all the more acute with the recognition that their partners and children are also alone.

FAMILIES OF ORIGIN

In lesbian communities it is well understood that our relationships with families of origin can be strained, sometimes entirely hostile. Breast cancer forced Sarah into very difficult conversations with family members who had told her she would go to hell for being a lesbian and had disowned her. She makes the point that instructions from health professionals that might seem relatively straightforward — for example, for a woman with breast cancer to gather her family’s cancer history — can be immensely complicated and painful for some lesbians.

A few of the women we interviewed were coming out around the same time they learned they had cancer, so their families learned about both at once. Teagan’s mother had been **“in denial”** about Teagan’s sexuality. The cancer diagnosis, and the requirements of treatment, led Teagan to be much more explicit about her relationship than she had in the past. In one sense, cancer and treatment forced Teagan out of the closet. And while she’s glad she came out, she certainly would have preferred it to have happened in circumstances **“of our own choosing, rather than in the midst of a full-blown crazy time, with a life-threatening diagnosis.”**

Cancer and its consequences sometimes brought to the fore how a woman’s family of origin felt about her lesbian identity and relationships. For Theresa, lesbian identity and the consequences of cancer became joined together as a series of painful losses in her mother’s mind. Her mother cannot, as Theresa says, get her head around the fact that her daughter is a lesbian, has lost her breast, and will not have children. **“She can’t even really look at me anymore because she just feels inside so much pain for me. And I think pain for herself.”**

Yet for some research participants, cancer shifted the feelings of families of origins about lesbian relationships in a positive direction. Jessica, for instance, spoke about how her mother needed to trust that Jessica was being cared for, and has come to **“appreciate [my partner] differently, seeing how completely there she is.”** Other participants described similar experiences.

FINANCES

Several of the women we interviewed said that cancer and cancer treatment had been difficult financially. Women in early stages of treatment worried about the toll that a period of not working would take and were already thinking about ways to make up for the financial losses. Women without benefits spoke about the strain of having to work during treatment, and the cost of drugs affected women who had no benefits plan. Some of the women found alternative therapies important to their recovery, and a few really struggled to pay for them. Single women were finding things especially difficult. Lou said, **“I have nobody else to help me out financially. Like, even though I have friends ... you know, they have their own struggles.”** Laura also made the point that financial strain sometimes extends well beyond the time of treatment; some women are unable to return to their previous jobs and must live on considerably reduced income.

Many heterosexual women diagnosed with cancer face similar issues. However, lesbians as a group may be less able than heterosexual women to rely on their families of origin for financial support. As well, men as a group have higher incomes than women, and lesbian couples in general thus have less access than heterosexual couples to financial resources.

One of the heartening things about doing this study was hearing most of the women we interviewed say that they had not encountered homophobia in cancer care:

My partner went with me right... as far as just before the operating room, as far as she could. And she was there to meet me. So there was no, no doubt about that... I didn't encounter anything... I think part of that is because I don't expect to encounter anything. [Paula]

I made no bones about identifying [my partner] as my partner... never once was there a single indication that she was not an appropriate person to have around, for all the consultations. So I didn't encounter anything that I could point my finger at and say, 'that was homophobic.' And I was in a sense looking for it, because we were so out. [Pauline]

While the lesbians we interviewed cannot be said to be representative of all lesbians with cancer, this study seems to indicate that, at least in certain settings and for some women, homophobia may be less pronounced than it has been in the past. This is clearly something to celebrate; Ontario's impressive history of queer and women's health activism seems to have made a difference in cancer services.

At the same time, the comments women made about their positive experiences with cancer care sometimes tell us as much

about the ongoing reality of heterosexism as they do about lesbian-positive care. Several women spoke about how they appreciated the ways health care workers and support staff related to their partners. Paula B, for instance, told us about a surgeon who could have spoken first with her mother or father about how the surgery had gone, but who instead spoke first to Paula B's 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? Um, it just normalizes it, and you've got so much to deal with emotionally. [Paula B.]

The physician here is clearly acting in lesbian-positive ways, and Paula B's appreciation is very real. Yet as Paula B. herself points out, a heterosexual woman would not even have to think about the possibility that a physician would not address her spouse first. What's 'normal' for heterosexual women is something that lesbians remark on. It is clear that a legacy of heterosexism leaves lesbians in a position of being grateful for things that heterosexual people take for granted.

If gratitude for equal treatment is one of the consequences of heterosexism, so too is an anticipation of problems, and a readiness to fight for care. Rosalie said she felt her partner was always given respect as her partner; yet **"I think she would've clobbered anyone that didn't [respect her]."**

We learn at least two things from these comments: that we cannot underestimate the value of lesbians and lesbian relationships receiving respect equal to that given heterosexuals, and that much needs to change if lesbians still do not assume or expect to encounter equal treatment in cancer care.

Heterosexism in Cancer Care

While most of the women we interviewed said they had not encountered homophobia in cancer care, several did describe clear instances in which they were denied standard care or targeted as lesbians. As well, research participants described many situations in which lesbian realities were ignored or dismissed.

Several women spoke of being treated differently — not as well as other patients — by health professionals. Theresa, for instance, spoke about how the nurses around her in hospital didn't quite believe she was a lesbian, and showed both their disbelief and disgust:

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. [Theresa]

A few women described blatant examples of heterosexism. In some instances, health professionals' discomfort with lesbians affected the quality of medical care women received. Paddy has heart problems, so she could not have a general anesthetic; her lumpectomy was performed with only a local anesthetic. She described looking away as the physician started to cut. Yet as he proceeded, Paddy could feel it. **"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."** 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."**

Kate described her interaction with the physician with whom she discussed her unusual vaginal bleeding. The physician pulled herself back in her chair in the middle of the 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 prior. 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, because 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. [Kate]

In these stories, health professionals demonstrate anxiety and lack of competence in relation to lesbian health. Heterosexism unfolds in these situations in at least two ways. Firstly, lesbians trying to get care are treated as if they are somehow contagious or so outside a framework of 'normal' that physicians are unable to proceed in a professional way. Secondly, the medical knowledge required to take an adequate history from a lesbian with cervical changes is unavailable to the physician. In the encounter she describes, Kate was essentially denied care. The

Pap test — which might have offered Kate more information about what was happening with her body — could not reasonably proceed; the physician's discomfort and lack of knowledge were so apparent that continuing would have only made things worse.

Among the many lessons from these stories is the critical role that lesbian-positive family physicians play in securing quality care for lesbians. In two of the situations described here, the women were being seen by someone other than their regular family physicians. Both felt confident that things would have happened quite differently if their regular doctors — whom they had 'screened' and knew to be lesbian positive — had been available.

In recounting her experiences with the health care system, Sarah described an incident in which an aspect of her lesbian identity was casually dismissed. As she says, **"I'm a lesbian woman and my breasts are my core sensuality piece of my body."** She had to draw on her courage to raise the question of breast removal 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 and *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. [Sarah]

Clearly this physician, in his failure to recognize Sarah personally and as a lesbian, jeopardized her cancer care. In the

small city where Sarah lives, this physician is her only option. Yet Sarah cancelled her next scheduled appointment and seriously considered not going back at all as a result of this interaction. As she put it, **“if I have to battle this one emotionally, I’d rather die physically.”**

The poor care that lesbians received was sometimes linked to their economic class as well as their identity as lesbians. Glenda told us about situations in which she was denied services from cancer and health care agencies. At home with a drain after her surgery, she needed nursing care, but **“Welfare wouldn’t pay for it; welfare said Community Care Access should send me somebody.”**

Interviewer: And Community Care Access said welfare should send you somebody, so nobody got to you?

Glenda: No, no, 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. At community-based cancer services, Glenda’s request for tokens to cover the cost of transportation was not met.

These incidents make it very clear that lesbians’ experiences of cancer care are related not only to their identity as lesbians; other systems of privilege operate in concert with heterosexism to diminish lesbians and deny them access to services.

LESBIAN PARTNERS: OUTSIDE THE CANCER CARE BOX

As noted above, several of the women interviewed in this research felt that their partners had been granted a status equal to that of male partners in consultations with health professionals and in hospital settings. This was not true, however, for all of the women we interviewed.

Gerrie said that her physician had asked ‘who is this?’ when her partner arrived with her for an appointment (a question unlikely to have been asked if she had shown up with a man). **“At first he didn’t look at her...”** Yet after the second visit the physician was, as Gerrie says, **“fine.”** Her story reflects the capacity of health professionals to change — later, this physician began to ask Gerrie about her partner.

Lesbians who spoke with us also described not having certain ‘privileges’ that heterosexual couples and traditional families had, like extended visiting hours. A series of conflicts that Theresa experienced with health professionals draws several issues to the surface. Because she was in isolation, health professionals would only let Theresa’s ‘family members’ come into her room. **“And so [my partner] would stand out in the parking lot and wave. So she was pretty heartbroken.”**

Theresa attempted to convince the nurse to let her partner in, saying, **“this wouldn’t happen if I was a straight person, right?”** The nurse refused, making reference to the hospital regulations.

Here, the heterosexist definition of family excludes Theresa’s partner from the room. Then the nurse declines any personal responsibility for the decision by referring to ‘rules,’ denying her role in reinforcing and supporting heterosexism in health

care. Finally, the hospital ombudsperson, the person designated to protect patients' human rights in the broader system, failed to return calls.

It is telling that Theresa speaks about feeling like **"they suck away your power — the little bit that you have!"** Certainly the power of heterosexism — the systemic power, and the ways individuals use their own power to maintain it — is evident in her story. The effect of this power, in terms of Theresa's own feelings of being diminished and worn down, was also clear.

CANCER SUPPORT SERVICES: NO PLACE FOR LESBIANS?

In the face of obvious homophobia and heterosexism in cancer care, it may seem that the lack of lesbian-specific support services, or explicitly lesbian-positive services, is a less serious issue. Yet it was clear from our interviews that the absence of services reflecting lesbian realities sometimes ends up in the same place: as an exclusion of lesbians, a denial of standard care.

Jessica described a situation where a social worker told her about a support group at the hospital and asked if she would like to come. The social worker asked it casually, as if it were an easy decision. But it was not: Jessica was pretty sure she would be the youngest woman in the group, as well as the only lesbian; she wasn't at all sure that she wanted to go. (Being younger than most women with cancer was an experience a few of the other women we interviewed shared; age very much mattered, along with lesbian identity, in their experiences of care and support.)

Jessica 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. 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? 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]

Taking the first step to become part of a cancer support group can be difficult for any woman. But Jessica's comments point to the need for cancer care professionals to recognize what it takes for a lesbian to join a support group or service. Lesbians, as well as other marginalized women, face particular risks, and the decision to join may be more complicated than many health professionals expect.

Paddy and Theresa reported experiences that exactly confirmed Jessica's worries about coming out and experiencing very difficult reactions from other women in a support group. Even when responses were not obviously negative, the feeling of being 'not quite part of it,' not quite 'there' in the group, was common among the women who took part in this research. Anticipating a similar experience, some of the women we interviewed never even attempted to access existing services.

In a few instances, research participants had made deliberate efforts to get their needs as lesbians met. After a session in which members of the group Theresa was part of had reacted negatively to her coming out, Theresa 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,’ right? And I go, ‘so, what you’re saying is, you’re not willing to help me integrate into the group, right?’ [Theresa]

The ‘not our mandate’ comment was heard by more than one of the lesbians with cancer we interviewed. With this comment, efforts to provide care and support that include lesbians are made out to be ‘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 have been, of course — then obviously the service should work to integrate and reflect lesbians and lesbian realities.

The ‘not our mandate’ line was heard in relation to other dimensions of lesbians’ lives and social realities, as Glenda noted:

[The health professional] said to me, ‘I can only work with you and your cancer, you’ve got too many things going on.’

Interviewer: So they couldn’t help you because you had other things.

I was too poor, I was too busy figuring out what I was going to eat.

The notion that lesbians and poor women are ‘not our mandate’ clarifies the position of many agencies; they do not intentionally exclude anyone, but lacking a critical perspective on their own services, they wind up excluding lesbians and other marginalized women. This process of exclusion is much more subtle and hard to identify than outright homophobia.

Service providers can easily claim that lesbians are welcome, and some can even point out that lesbians participate in their services. Yet it is often the case that heterosexual, middle class, white, able-bodied women are at the centre of what they do; it is this reality that defines the scope and landscape of many cancer care and support programs.

Getting good care, avoiding bad care

SCREENING FOR HOMOPHOBIA

Screening is a big part of cancer care. There's lots of talk about mammography screening for breast cancer, for instance, and Pap smears to detect cervical cancer. In this study, a whole other kind of screening came into play — the screening lesbians do to detect heterosexism. Maureen, for instance, described going for her first appointment with the primary nurse assigned to her care, and deliberately asking about the nurse's beliefs and values about lesbians:

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. [Maureen]

As Maureen and others pointed out, a screening strategy that involves coming out usually assumes that lesbians have other options for care. Of course, this was not always the case for the women we interviewed; for instance, women in rural areas of Ontario often do not have a choice of care providers.

Mary Lou also described how her family doctor took a role in ensuring that specialists to whom she referred Mary Lou were lesbian positive. Mary Lou appreciated her family physician's efforts. This kind of commitment by health professionals represents real progress. Yet the fact that health professionals have

to make a deliberate effort to protect their patients from the heterosexism of some of their colleagues reveals the ongoing nature of oppression in health care.

BEING OUT, AND NOT BEING OUT

The lesbians who took part in this research help us see how coming out, and remaining closeted, can both be strategies to affect care in a positive way. Sarah, for example, came out to a nurse and explained what her breasts meant to her as a lesbian — and, thus, explained just how difficult it was for her to think about losing her breasts. She felt it would not be possible for the nurse to adequately support her without understanding this. Mary Lou spoke about the commitment she and her partner have to be out as much as possible in their lives, to allow others, including health professionals, to learn.

Some research participants' statements reveal the importance of cancer care professionals recognizing coming out for what it is — often quite a deliberate effort on the part of lesbians with cancer to help professionals understand what 'good care' looks like for them.

On the other hand, several of the women deliberately remained closeted in an effort to avoid homophobia in cancer care. Laura, for instance, kept her sexuality to herself over the course of her treatment for cancer. She is out to her family physician, but the physician is based in a city. **"Had I come out here in my town, I don't think it would have gone over so well,"** she said.

Both Glenda and Kate make the point that to be safe in the cancer care system, women may work to 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.”** Similarly, Kate spoke about masking her working class background when she spoke with health professionals, working to **“talk the talk ... act in a certain way to get what you need, which is stressful, due to the situation.”**

A few of the women explained that the cancer care system was one of the very few places in which they were not out as lesbians. Like Laura and Glenda, they worried that their care might be compromised. They also reminded us about just how energy draining it is 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. And because dealing with cancer is itself incredibly depleting, lesbians with cancer may not feel able or willing to expend extra energy battling heterosexism.

TAKING PARTNERS AND FRIENDS ALONG

Several of the women we interviewed spoke of the benefits of having partners and friends around when meeting with cancer professionals, or spending time in hospital. As Lillian put it, **“the positive part about being a lesbian is, I had chosen family. I had a nice gang of female friends, fearless dyke female friends who would take shit off no one and who looked after me.”**

And Kate said that having supporters **“countered some of the lesbiphobia around.”** Sarah has told her friends that it’s their job to **“fight those heterosexual verbal battles”** — to respond to health professionals who want her to pee in a cup to ensure she’s not pregnant, for instance — and to **“answer all those stupid questions”** about her ‘husband.’

Participants in this research had different levels of support around them, from those with virtually none to others with well-organized and well-resourced networks. Where some women went to all of their health care consultations alone and struggled to figure out the system, others had health professionals as part of their family and friendship networks or were health professionals themselves; the latter seemed able to get what they needed more easily and quickly. Some women, as well, made a point of assigning their partner power of attorney for health care, and doing what they could to establish their relationship as legitimate in the eyes of health professionals. In a practical way, when a lesbian could not be sure that her partner would be welcome, lying was not an uncommon strategy: partners became friends, sisters, roommates — whatever seemed likely to work at the time.

The efforts lesbians with cancer made to get good care and avoid bad care were often strategic, creative and defiant. The fact that lesbians feel the necessity of this work calls attention once again to the need for change in cancer care.

Ideas for Change

We look to leadership from cancer care agencies (starting with Boards of Directors) to identify access for lesbians as a priority and to engage in the task of improving accessibility. In a parallel way, we look to the leadership of agencies in the lesbian community to identify health issues (and cancer in particular) as a priority and to develop programs, services, and advocacy initiatives.

INCREASE ATTENTION TO CANCER IN LESBIAN COMMUNITIES

- ◆ Increase the visibility of lesbians with cancer and lesbian cancer advocates; bring voice to the experience of lesbians with cancer
- ◆ Educate lesbians about their risks for cancer, about primary prevention and early detection, and about the experiences and needs of lesbians who have had cancer

CREATE OPPORTUNITIES FOR CONNECTION AMONG LESBIANS WITH CANCER

- ◆ Support networks or groups
- ◆ Connections between lesbians with cancer not focused specifically on cancer (for instance, wellness activities)
- ◆ Connections between lesbians who share experiences beyond the initial diagnosis (for instance, lesbians with cancer who are a similar age; lesbians with metastatic cancer)
- ◆ Opportunities for partners and children of lesbians with cancer to meet

CREATE SERVICES FOR LESBIANS WITH CANCER, THROUGH EXISTING CANCER AGENCIES

- ◆ Service where lesbians meet (face to face) with a lesbian cancer survivor early in the process; a 'buddy' through cancer
- ◆ Service that link lesbians by phone
- ◆ Support groups for lesbians and their partners
- ◆ Assistance with setting up care teams for lesbians with cancer
- ◆ Resource libraries with lesbian sections

Services must be sustainable over time; accessibility must be carefully considered; promoting the service widely and consistently as a lesbian-positive service is critical.

Missing from existing cancer services, and urgently needed, is practical support:

- ◆ Financial support [financial planning, and funds for band-aids, drugs, self-care...]
- ◆ Practical support [including meals, travel to treatment, places to stay in the gay community when lesbians are traveling into cities for treatment, etc.]

CREATE RESOURCE MATERIAL FOCUSED ON LESBIANS AND CANCER

Resource material reflecting lesbian realities (including issues like sexuality, spousal rights and benefits, sports rehabilitation...) is scarce, and needed. Making lesbian-focused resources available in waiting rooms and cancer information centres would also serve an important role in creating visibility for lesbians in the cancer care system.

ADDRESSING HETEROSEXISM IN CANCER CARE; CREATING WELCOMING SPACE FOR LESBIANS WITH CANCER IN CANCER CARE

The urgent need to address homophobia and heterosexism in cancer care — to create training and care protocols that value effective care for lesbians as a matter of cultural competency — is clear from this research. We look to cancer care professionals to actively create welcoming space for all of our identities, and to develop processes that do not depend on lesbians with cancer ‘coming out’ to access lesbian-specific services or resources.

For example:

- ◆ Intake forms that allow for self-identification as a lesbian. When a woman identifies as a lesbian, she may wish to discuss the meaning of her identity in relation to cancer and cancer care, and make choices about how and with whom the information is shared.
- ◆ Intake procedures that include something like the following: ‘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 a series of questions: ‘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... etc.’
- ◆ ‘Positive space’ campaigns
- ◆ Lesbian and gay cancer care professionals coming out — recognizing that this requires workplace support

Demographic information about research participants

Twenty-six lesbians were interviewed for this study.

DIAGNOSIS: Twenty-two of the women we interviewed had breast cancer, three had gynecological cancer (two cervical, one ovarian), and one had both breast and ovarian cancer. For three of the women, cancer had come back after their initial treatment. Two of the women are living with metastatic (advanced) cancer.

TIME SINCE DIAGNOSIS: Thirteen women were three years or more past diagnosis, and 13 were less than three years away from their diagnosis. Three were in treatment at the time of the interview.

AGE: The youngest woman we interviewed was 36; the oldest was 72. No women in their 60s took part. The average age was 50 years old.

PLACE OF BIRTH: Twenty women were born in Canada; two were born in the United States, one in England, one in the Philippines, one in Jamaica, and one in Hong Kong.

FIRST LANGUAGE: Twenty-four women spoke English as their first language, one spoke Cree, and one Dutch.

RACE/ETHNICITY: Seven women identified as Caucasian/White (one noted multi-ethnic ancestry), six as British; two as Canadian; two as Jewish; one as Indigenous and one as Native; one as mixed Metis-Ukrainian; one as Euro Canadian; one as Polish Canadian; one as Italian; one as Asian. One woman said the question was impossible to answer as her ethnicity was "too mixed." One did not respond to the question.

INCOME: Total annual household incomes were as follows:

Over 100,000	-	6 women
~ 90-99,000	-	1 woman
~ 80-89,000	-	1 woman
~ 70-79,000	-	2 women
~ 60-69,000	-	3 women
~ 50-59,000	-	4 women
~ 40-49,000	-	1 woman
~ 30-39,000	-	4 women
~ 20-29,000	-	2 women
~ less than 20,000	-	1 woman [actual income under \$8000];

one woman did not answer.

EDUCATION: Nineteen of the women we interviewed had a university degree, six had a college diploma, and one had a secondary school diploma.

DISABILITY/HEALTH PROBLEMS: At the time of their diagnosis, four of the women were living with a disability or serious health problems other than cancer. One woman is hearing impaired; one has heart problems and arthritis and is a psychiatric survivor; one has experienced depression and has fibromyalgia; one has endometriosis.

URBAN/RURAL: At the time of their treatment, twenty women were living in urban areas, two in semi-urban areas, and two in rural areas.

PARTNERSHIP STATUS + CHILDREN: Seventeen of the women had a partner at the time of diagnosis, and nine were single. Five of the women had adult children at the time they were diagnosed and one had young children. Two were trying to have children at the time of their diagnosis.

IDENTITY: Twenty-two of the women identified as lesbians at the time of their diagnosis, two identified as gay, one as a dyke, and one as bisexual. For 23 of the women, their family doctor knew their sexual identity; for two, the family physician did not know; and one woman was not sure if her doctor knew.

Coming Out About Lesbians and Cancer, the summary research report of the Lesbians and Breast Cancer Project, is available as an html file and for download in PDF on the DAWN Ontario website, <http://dawn.thot.net/lbcp>

Paper copies are available free of charge from Willow Breast Cancer Support & Resource Services.
Toll-free: 1-888-778-3100; in Toronto: 416 778-5000;
TTY: 416 778-4082; Email: info@willow.org

The full research report will be available as an html file on the DAWN website in June 2004.

Partner agencies (listed at the front of this report) have links on their websites to the reports.

As this report goes to press, members of the Lesbians and Breast Cancer Project Team and their agencies are exploring ways to create (and encourage others to create) support services and resources for lesbians with cancer, to improve access to cancer services for lesbians, and to make lesbians' cancer experiences visible. We have also created a list of existing resources for lesbians with cancer. For details, contact Willow (see contact information above).

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