

Coming Out About Lesbians and Cancer

“There’s actually a title that says, Lesbians and Cancer – 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)

Research Report
The Lesbians and Breast Cancer Project
June 2004

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Introduction

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Many people and agencies created the Lesbians and Breast Cancer Project.

~ The project began
because lesbians and community agencies believed in it & wanted it to happen.

~ The project became possible
when the Canadian Breast Cancer Foundation – Ontario Chapter funded it.

~ The project gathered momentum
when people in the queer, women's health and cancer communities started spreading the word.

~ The project became meaningful
when lesbians with breast and gynecological cancer spoke with us
about their experiences with cancer and cancer care.

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The evolution, focus and values of this report

When we first set out create this project, we had some ideas about why it was important. We know, of course, that homophobia and heterosexism exist in health care. We know, too, that lesbians have come together in strong ways to respond to suffering and fight injustice. We wanted to know about how oppression, and the strengths in lesbian communities, affected lesbians' experiences with breast and gynecological cancer. We also wondered if lesbians' particular feelings about our bodies, or the fact that we partner with women, shape what it is like to have a 'women's cancer.'

It wasn't until we were almost at the end of the project that we really understood why it was so important.

In an early interview for this research, we asked Maureen what she thought might be unique or particular about being a lesbian who has had breast cancer. This was part of her answer:

In my case I don't have other lesbians who are survivors around, or I don't know other lesbians who've had breast cancer. And so I haven't really had a chance to explore other issues that could come up that I haven't thought of, or have gone, 'oh, that's happened to me too but I didn't realize it was because I was a lesbian.' It might be quite revealing to discuss this issue with other women who identify as lesbian.

Because lesbians with cancer in Ontario have not yet had a chance to come together to talk, ideas and language for saying 'what's lesbian' about one's own cancer experiences are not yet easily available.

We learned in this research about the unnecessary isolation and struggle this can create for lesbians with cancer. It also creates a challenge for researchers.

A few of the research participants who read an early version of this report felt that 'the lesbian part' was not strong enough. They felt that the report did not make really obvious how being a lesbian mattered to a woman's cancer experience.

As we talked about this as a group, we reflected on the fact that the research interview was the first time many women had spoken in a full way about their experiences as a lesbian with cancer – and that this affected what they were able to say:

I think that for a lot of us that interview was perhaps the first time we'd ever been asked really to think of how it did affect us as a lesbian and when I read the transcript of my own interview I felt that I sort of ducked some of the issues. I missed a bit of the point, not because the interview wasn't conducted beautifully, satisfactorily, sympathetically, but the more I think about this whole

issue, the more I realize yes I am a lesbian and that was never addressed at the time. And I could probably talk more about that now than I did when I was interviewed... [Liz]

[The interview] was the first time I got lesbian and breast cancer in the first sentence. So that was just an emotional interview. And as I sit back and look at this process and what the project means to lesbians, I'd like to be interviewed again, because I got the emotion out and I got my story out, and now what I need to talk about is being a lesbian with breast cancer. [Sarah]

Another woman, Teagan, said that reading other women's quotes, and having some time to reflect, changed how she understood her experience and what she wanted from the Research Report. Now she sees more aspects of her cancer experience being connected to being a lesbian. **"The lesbian voice [in the Research Report] needs to be louder"**, she said.

So we made the lesbian voice louder. And we did this not just because we understand better why the interviews unfolded as they did, but also because what happened in the interviews, and what didn't happen, is part of a bigger picture where lesbians' experiences with cancer are rarely named, welcomed, or given space. In the bigger picture, systems and individuals, working with a heterosexual 'default setting' (assuming everyone is heterosexual) render lesbians invisible, or create a situation where lesbians have to do the work of coming out, explaining their needs (again), and, sometimes, asserting their right to equal care. As became very clear in our research, this kind of work, demanding at the best of times, can be especially taxing when you have cancer.

So in this report, we affirm the value of doing all we can to make 'the lesbian part' of lesbians' experiences with cancer visible.

And yet... One of the consequences of focusing intently on 'what's lesbian' about lesbians' cancer experiences is that lesbians for whom 'lesbian' is not a particular focus in terms of identity and social life tend to be less well represented.

As well, highlighting aspects of the cancer experience linked to lesbian identity means that certain other aspects of having cancer – things that might in fact be very important to an individual lesbian's experience – receive less attention. So, for instance, one woman we interviewed said that many people focus on hair loss as the most difficult thing about chemotherapy:

They just don't know about all the other stuff, mouth sores, you know ... all the other stuff that comes with it.

Interviewer: Hm. Like they're missing out on the main part of the story there.

Right, and all the suffering that goes on. [Theresa]

In this report, we do overlook some of the suffering that goes on, and we miss some of the joys that women have found after cancer, the positive life changes they have made. Yet we trust it is clear from what we have just said, why we have made the choices we have to bring ‘what’s lesbian’ about lesbians’ cancer experiences to the foreground.

While the central focus of this study was lesbians’ experiences with breast cancer, the Project Team decided early on that lesbians with gynecological cancers probably faced similar issues. Both for this reason and to increase the number of potential study participants, we promoted the study to lesbians with ‘women’s cancers’ – lesbians with either breast or gynecological cancers.

Report Summary

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.

In this report we focus directly on ‘what’s lesbian’ about lesbians having breast and gynecological cancer. The reason for this is simple: we haven’t found this knowledge anywhere else. We read about ‘the experience of breast cancer’ in books, watch it in videos, hear about it in support groups... yet lesbian cancer realities have, with rare exceptions, gone unnamed.

COMING OUT AGAIN

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.

Because of its echoes with coming out as a lesbian, the social consequences of ‘coming out about cancer’ may be especially complicated and painful for lesbians with cancer. At the same time, lesbians have some familiarity with the feeling of being ‘other’, and as communities we have developed strategies for responding to marginalization and loss. We can see from this research how these strategies can support lesbians with cancer.

As well, it seems that the AIDS movement serves as a kind of touchstone for lesbians with cancer, an example of what’s possible in terms of support, awareness and activism. That example is one we draw from in a positive way, and at the same time it shows us how much more we could have for lesbians with cancer.

SUPPORT AND ISOLATION

Participants in the Lesbians and Breast Cancer Project frequently spoke of receiving strong support from partners and friends. Support in lesbian community can be emotionally engaged, competent and well organized – immensely sustaining for individual lesbians and a kind of community achievement.

Feeling strongly supported was connected with participants’ sense that women, and particularly lesbians, felt like ‘it could be me.’ The fact that participant’s partners are women and could be diagnosed with a woman’s cancer was a source of understanding and connection. The ‘could be me’ feeling also seemed to draw lesbians into support teams for women they did not know especially well.

Yet ‘could be me’ worked against lesbians as well. As some research participants’ experiences revealed, ideals of support in lesbian community do not always unfold in real life. Participants said that lesbians, witnessing another lesbian diagnosed with breast or gynecological cancer, sometimes identify with her in ways that make support awkward or impossible.

In a more general way, 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 – perhaps especially strong in relation to women’s cancers – affects the support lesbian communities can offer.

Lesbians with breast cancer may be further isolated if they live in areas where homophobia goes relatively unchallenged, or where lesbian community is scarce or lacks diversity to begin with. Not having enough money – for instance, to pay for self-care resources – can isolate lesbians who are poor from lesbians with more resources. Experiences that are ‘out of synch’ (because of age, for instance) are also linked with isolation.

FALLOUT FROM TREATMENT: HAIR LOSS, LOSS OF PHYSICAL STRENGTH, BREAST LOSS, SEXUALITY

It became clear from this research that ideas society has about lesbians – ideas about our appearance, bodies, sexuality – and ideas lesbians have about ourselves, affect how lesbians experience the fallout from cancer treatment.

Queer culture and community lends hair loss a wider range of meanings for women than does the dominant culture, and this can be a source of strength for some lesbians with cancer. Yet while lesbian identity might allow some women to buffer the difficult impact of hair loss, or even to find power in it, hair loss can also disrupt identity and be traumatic and disempowering for lesbians.

Risking a stereotype, we can suggest that women’s physical strength and competence are especially valued in lesbian culture (in contrast with norms of femininity valued in the dominant culture). Especially outside urban centres, sports teams are a rare safe public space for lesbians. A cancer diagnosis and the effects of treatment can challenge a lesbian’s valued identity around physical strength and fitness; it can also disrupt her connection with lesbian community.

The beliefs we hold in lesbian community about breasts are contradictory, and linked with our relationship to societal ideas about what woman should look like. We heard the belief that lesbians with cancer are less affected by breast loss than heterosexual women; we also heard that breast loss is especially difficult to lesbians because breasts matter more to us than they do to heterosexual women. Our beliefs about breasts sometimes suggest there is one ‘right way’ for every lesbian with cancer to deal with breast loss.

Woman’s cancers can have unique affects on lesbian sexuality. In very basic ways, women’s bodies mirror one another; when two women are being sexual after one has had a woman’s

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.

PARTNERSHIPS AND DATING

Cancer affected lesbians' partnerships in a whole range of ways, and tended to make lesbians without partners very aware of being alone. Some of the experiences the women we interviewed had with cancer revolved around the idea that, with the diagnosis, they became undesirable as partners: sexually undesirable, and 'bad investments' for a partner.

Lesbians' worries about being undesirable occur in a context where dating, and sustaining relationships, have particular challenges. Heterosexism means there are very few supports to facilitate lesbian relationships; it also means that 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. A cancer diagnosis thus complicates and disrupts relationships that have fewer supports in the first place. At the same time, lesbians we interviewed spoke about the ways facing cancer together had strengthened their relationships.

We also learned from this research how lesbians with cancer can become (additionally) vulnerable in their relationships. Circumstances of lesser power – like disability, or less secure housing situations for instance – can combine with cancer to create or exacerbate inequality in relationships. This research raises 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.

The understandings of desirability, partnership, interdependence and equality developed by lesbians with disabilities have much to offer lesbians diagnosed with cancer.

FAMILIES AND FINANCES

Several women we interviewed talked about how hard cancer was for their partners and children. A few felt that their partners' experiences were in some way worse than their own. A central feature of the worry lesbians with cancer felt about their families was the lack of support available for them. Formal support services – support groups, for instance – were inaccessible. It was clear in this research that the isolation some lesbians with cancer experience is made all the more acute, with the recognition that their partners and children are also alone.

In lesbian communities we understand that our relationships with families of origin can be strained, sometimes entirely hostile. A cancer diagnosis sometimes makes the tension even greater. Yet it was also evident that many of the women we interviewed received a great deal of support from their families of origin. In a few cases, the situation of illness shifted lesbians' relationships with their families in positive directions.

Many heterosexual women diagnosed with cancer face financial struggles and worries similar to those described by participants in this research. However, lesbians as a group may be less able than heterosexual women to rely on their families of origin for financial support. A few women also drew attention to their relatively less stable financial position compared to heterosexual couples.

CANCER CARE

Most of the women we interviewed for this study said they had not encountered homophobia in cancer care. 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.

Yet at the same time, the comments women made about their good experiences with cancer care sometimes tell us as much about the ongoing reality of heterosexism as they do about lesbian-positive care. Lesbians' gratitude for equal care, and how prepared they are to fight for it, are legacies of heterosexism – and so is the amount of energy lesbians devote to getting good care and avoiding bad care: screening for homophobia, being out or being closeted, looking for lesbian health professionals, taking partners and friends along.

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

We learned in this research how heterosexism can link up with health professional-patient dynamics, and with the effects of cancer treatment, to compromise lesbians' capacities to advocate for themselves as cancer patients. Silence about lesbian identity can be associated with silence about treatment decisions; in a parallel way, lesbian identity, and asking lots of questions, can be perceived as piled-up demands on health professionals. Heterosexism means that lesbians with cancer do not get care and services to which they are entitled. The ongoing encounter with heterosexism as a cancer patient can push lesbians to feel less entitled to care, and can make self-advocacy especially difficult.

In contexts where lesbians can be denied standard care, wind up feel grateful or ready to fight for what other women take for granted, and cannot find space to talk about how cancer and treatment affects their lives, it is difficult to imagine or articulate what actively lesbian-positive cancer care and support looks like. Yet the lesbians who took part in this research had ideas... see the section called Ideas for Change, towards the end of this report.

[As this report](#) is being completed, individuals and agencies continue to [explore 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](#).

[For details](#) on this work, for a summary of this report, or for a resource list for lesbians with cancer, [contact Willow](#) Breast Cancer Support & Resource Services: [Toll-free: 1-888-778-3100; in Toronto: 416 778-5000; TTY: 416 778-4082; Email: \[info@willow.org\]\(mailto:info@willow.org\)](#)

The lesbians who shared their stories

Each woman who participated in this research was asked if she wished to write a brief profile to introduce herself to readers of the report, and to speak directly to other lesbians diagnosed with breast or gynecological cancer. Here are the profiles we received, with appreciation to the women who wrote them, and, again, to each woman who participated in this research.

I am a lesbian living in a large urban centre. At the time of my initial diagnosis, I was newly 'out' and in my first relationship with a woman. I was afraid my life was at an end. Instead, I found that through my first surgery and subsequent metastatic diagnosis, I was surrounded by a host of friends both gay and straight who are a sustaining strength.

My partner is a wellspring of support as I continue to battle this disease.

~ PAULINE

Who is a lesbian with breast cancer?

She is a warrior named Glenda. She is originally from Halifax, Nova Scotia, is a silvered hair lesbian, mother of four adult children, gushing granny and living with the struggles of poverty and cancer.

On a rainy day in November 11, 1998. Just before leaving my home I took one last look at my breasts and said to myself in a whisper, “the old gals aren’t as pretty and firm as they used to be but they are healthy.” So I headed off for my mammogram. After the mammogram was finished I was told not to get dressed, there was something suspicious showing. I was being told I had to have an ultrasound. So I had the ultrasound. I was told by my doctor to come directly to her office. She already had the news by the time I got there. I was given a piece of news that would change my life completely. I was given a new road on this journey that I have been taking and I did not know where it was going to take me. This route was one no woman wants to walk.

The voice said, “you have cancer!” My doctor put her arms around me as I started to cry. My heart broke on that day of the news. I am mature enough to know each choice I make has a consequence. This was not a choice I was making for myself. I DID NOT INVITE CANCER INTO MY BODY AND I DID NOT WANT IT THERE.

So what do you do when it is not your choice? I did the very best I could with what I had available to me. When what I needed was not available I used my gift of being creative. So the journey of the unknown began. To be honest it was a very lonely and fearful road. I had very little support almost no lesbian support. This journey has turned into one of many different directions. Now at my five year celebration of life, I can look back and validate myself for being the warrior I am.

I have great respect and gratitude to the team of the Lesbians and Breast Cancer Project for not giving up on this project and pushing through. Thanks to the team for giving me the space to tell my story, the story of a lesbian with breast cancer. You witnessed my truth and you sat with me in my pain. For the first time I was acknowledged for whom I was a poor lesbian who suffered tremendously not only because I was poor but also I was lesbian with breast cancer. Thank you for giving the space to find my voice as a very proud lesbian.

Just to add a little bit more on my herstory. Today is International Women's Day. I always seem to be waiting for news. Today the news is different. Healthy news I have been waiting five years for this news, I am having mixed feelings excitement, fear and guilt. I am being discharged from Princess Margaret Hospital. My journey at PMH is over. It is time to celebrate my five-year celebration of life. As Gilda Radner said, "it is always something". What to do and where to go. Life after cancer. ~ GLENDA

I am "gay women who dances with cancer."

An intruder that was not invited to the party but picked me half way through the dance. We got down and boogied right away in a frenzy of surgery, losing a part of my soul, my breast, chemo and now we are slow dancing.

I am fierce women who jumped out of planes for fun, and at the same time looked to the world in childlike wonder. Who rode horses in Jamaica and jumped over fallen trees in the warm sun. A woman who loves nature, animals and people and sometimes in that precise order.

The intruder has ravished my body and my mind, when I was just ready to enjoy the fruits of my labour. On one hand I appear to all who worry about me, as the brave one, who knocked down the intruder and on the other -only stepping gingerly through life with a keen heightened sacred awareness that the intruder may want to dance with me again.

It is harder than you know.

~ LAURA

Diagnosed at age 44. Too young. Cat lover. A person who walks in the rain while others just get wet. Residing in an ultra conservative city. Hand drummer whose soul beats to the sound of a drum. Fatigued. Sports enthusiast. Go Sens go. Desperately trying to keep my breasts, while surgeons stand on the sidelines with scalpels at the ready. Passionate lover of womyn. Enthusiastic golfer and wannabe gardener. Fighter of those days when nausea rears its ugly head and "kermit" becomes my middle name. Small 'c' Christian, struggling with the fairness of it all. Survivor. Lover of life.

~ SARAH

Kate is a 50 year old Irish Canadian lesbian, who grew up in a working class home in Woodstock Ontario. She had advanced cervical cancer at 44, which was treated with chemo and radiation.

Kate works and lives in Toronto with her partner, step-children, friends and family. She works as a social worker in the hospital system in which she was treated. Much of her work has been in the area of violence and trauma – this has helped her get through some hard times with the cancer – at the same time she suspects to some degree this work has worn her.

She currently does volunteer work with women with cancer, draws and writes a lot.

My name is Theresa. I am a 40 year old lesbian. My journey began 10 years ago with my first diagnosis of ovarian cancer. After completing four surgeries, a complete

radical hysterectomy, chemotherapy and radiation over three years, I was in remission by age 35. After genetic testing was done, I was found to carry the BRCA 2 gene for breast cancer due to my cross European background; my grandmother being a French Jew. During a routine mammogram, the doctor found four lumps; two in each breast. An ultrasound and biopsy was done that day showing a lumpectomy should be completed within two days. After the lumpectomy it was confirmed that I had four cancerous tumours. A double mastectomy was performed with a follow-up of radiation and chemotherapy. The cancer has metastasized to my colon. I am currently undergoing treatment for this.

However, I would like to emphasize that the cancer does not define who I am. Who I am is defined by my partner of ten years, my family, my friends and my life's journey. This is what happened to me! It strengthened me, taught me valuable life experiences and with each day I learned and grew both emotionally and spiritually. What a test of the human spirit!!!

I hope that my journey will help other women never lose hope.

Liz - who is she? She is 72 years old. At times she bewails her great age, but by and large she is happy with it...

Having lived so long, she, of course, has had and still has many lives. She has been and still is a teacher. She has been and still is in love with drama and the theatre. She has seen as much theatre as she can afford, she has acted, she has directed and she has been lucky enough to teach drama. She has always loved water, travelling on it and swimming in it. She has always loved reading. For years she has practised yoga, and now teaches several yoga classes.

Liz is a lesbian, but did not understand and acknowledge this even to herself for a very long time. Back in the late 1940s she fell in love with a girl. It ended very nastily. They were found out. They were reviled, ostracised by their peers, spoken to in anger and horror by those who had authority over them, separated and forbidden see each other. Liz was told that she was not really wicked – that she would one day meet a young man, fall in love, get married and have children. She did all those things. Liz stayed married a very long time - had four children - took on the new role of Mother, which she can never, never regret.

And then I met this woman. WoW. I remember the morning after thinking, "At last I know who I am! I can speak with my own voice. At last I am "I". I am a lesbian - I will always be a lesbian - I love being a lesbian." I left my husband and lived with my lover. We were happy, but she was dying of breast cancer and all too soon she did. Then I too got breast cancer. Sad, bad times.

When I was invited to join this project I was overwhelmed - so proud. I believe this project to be so important. Meeting with the other women, feeling involved, has given me such a feeling of strength, such solidarity, such support.

Warrior Lesbian who has a whole new outlook and grip on enjoying life. Live every day to your fullest. Enjoy every sunrise and sunset. Stop to feel the warmth of the sun on your face and inhale a gentle breeze and the fragrances that surround you. Look at life the way you would if you snuggled a kitten close to your face and looked it in the eyes when it cried. Don't wait for a challenge, go after one. You still have lots of time to try one more adventure. Never give up on what you believe in; never back down

from what you don't. Always have faith and trust in life and cures. Never give up on life, especially yours. Now kiss the kitten and remember how good it feels. ~ JACQUIE

Two years left (2001). You have metastatic breast cancer. The worst kind. Oh shit! What do I do now?

"Jump into the chemo river!" the medical system shouted.

"No thanks," I replied

Every day I went to the forest with my dog to my prayer rock. (It looks like an upside down shoe - the sole/soul rock). It's here that I asked the goddess for guidance. She sent me many wonderful people and products and other guides to help on my new journey.

Two angels she sent, told me about a product called HMS 90 which has saved my life. Now she has allowed me to be part of a Lesbian Breast Cancer Project which could lead to further initiatives to help others. Who knows where the journey goes now. I feel so blessed. ~ LOU

I am a 51 year-old lipstick lesbian and have been an LGBTTTQ community activist and organizer for over 30 years. I was diagnosed with cervical cancer in 1979 when I was 27 years old. I had cryosurgery, as the laser technique was not in common use in those days. The experience was a nightmare! I went to the hospital to get my biopsy results never for a moment thinking I had cancer. Within minutes, I was on the table in stirrups having my cervix eroded. Then the doctor packed me with gauze and told me to get dressed and come back in three weeks. I, literally, staggered out to the hallway, and while trying to make my way down a flight of stairs, passed out! Thank God I didn't crack my head open!

Looking back on this experience today, I have trouble believing that I, the 'tough, outspoken, political dyke' could have let myself agree to this procedure without demanding information and discussion that would have let me make an informed decision. Years later as an HIV/AIDS counsellor in the 80's and 90's, I made it my business to ensure that none of my clients got treated disrespectfully. And having had 'the big C' myself, I could empathize with their experience of being diagnosed with 'the big A'. I feel that I was able to turn around a very scary and horrible experience and, in fact, be a very effective counsellor and advocate as a result of it.

The impact of cervical cancer on my relationships was HUGE. For years, my cervix became a 'temple' that no one could touch. I felt diseased and dirty and, of course, also believed that the cancer would come back, spread throughout my body and kill me. For a number of years, I continued to have 'bad' pap smears and be thrown right back into a fear place. It was only through time and with the support of friends and lovers that I was able to move through these experiences and reclaim the upbeat and optimistic gal that I always was underneath. ~ MARIE

I was finally and properly diagnosed when I moved to a large city. Although a stressful period, due to my break-up, relocation, unemployment, and diagnosis, I credit this move with saving my life. I was also angry for some time at the misdiagnosis, and the subsequent stage three diagnosis I was given (eventually reduced to a stage two). It found its way into only one lymph node out of ten removed (none would be better, but in this situation, you take what you can get). I also escaped lymphedema by

constant workouts on the universal gym. For six months, through the surgery, chemo and radiation, I cut out white sugar, white flour, alcohol, and caffeine, and watched my diet like a hawk. People said I looked great, but I felt like hell on some days, and literally dragged my butt through the door at night after work. I worked through everything but the surgery, and chemo days.

When it felt at times like the heart-breaking series of events would never end, like many other people, I had the common thought that death might be less painful than life. But when faced with my own potential death, my overwhelming response was: "Not yet! I'm not finished with you yet!" It became crystal clear then that there were too many things I had left to do, and see, and live for. This realization was important, because it has helped me to live every day with a renewed sense of purpose, discovery, and gratitude.

Having breast cancer has forever and unalterably changed my life. The good news is, in most respects, it has changed for the better (many people cannot get their heads around this concept, but I understand it implicitly). My spirituality, which has always been there but never fully expressed, made a strong emergence. It has led me to many good places, and has been a constant companion since. Maintaining a feeling of gratefulness as part of an overall "good attitude"-- including as much compassion and empathy for others as I can muster on any given day--has done me (and others, I suspect) nothing but good. Frustration and anger is now, for the most part, a waste of a good moment, but I still let myself feel it when it happens. I have learned more to "go with the flow" and to be grateful for small things.

I consider breast cancer to be a modern-day plague on women, and very much believe that there are serious environmental carcinogens which are major factors in the development of breast cancer.

A strong believer in naturopathy and alternative therapies, I've gone from not being a pill-popper, to maintaining a shoebox full of vitamins. I now try not to eat like I'm being monitored by some scientist--you can start to go a little "bananas" (pardon the pun), eating fruit till you think you'll gag, and counting servings of vegetables in your sleep.

I mourn the loss of all the women who were not as fortunate as I am, including my mother. I send healing energy and support to all those newly diagnosed, in the midst of their treatment, or in the post-treatment period. And to the Lesbians and Breast Cancer Project personnel, thanks for all your work, and for letting me be part of this great project.

~ JANN

I chose to use the name Jessica. Jessica is the name of my Groovy Girl. She came to me with her body torn open and in need of repair. I carefully stitched her up, dressed her and placed her beside my bed where she has lived for the past several years. Jessica is special to me because like me, she needed mending. Also like me, that "mending" was done with love and care and now she is all the better for it.

My first breast cancer diagnosis came at age 31. I was diagnosed at Stage 4 and told I had a 10% chance of surviving for five years. Through spiritual guidance from books by Bernie Siegel and Edgar Cayce, traditional and complementary therapies, I gathered and utilized all my resources and won my battle against this dreaded disease. I was again diagnosed with a different breast cancer seven years later. Although much less invasive, I still had to gather all my strength, all my available

therapies and again wage war on what was attacking my body. I was again successful. Unfortunately my mother was not. She died of breast cancer this year.

Hopefully the fruits of this project will help bring us together so that as women, as lesbians we can share our knowledge and our strength to help each other deal with this disease.

Quotes from research participants are in this type. Participants chose the names associated with their quotes.

Demographic information about the women we interviewed

Twenty-six lesbians diagnosed with cancer were interviewed for this study.

DIAGNOSIS: Twenty-two of the women we interviewed had breast cancer, 3 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-one women were born in Canada, two were born in the US, 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 EuroCanadian; 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.”

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 – 3 women
20-29,000 – 2 women
less than 20,000 – 1 woman [actual income under \$8000]

EDUCATION: Nineteen of the women we interviewed had a university degree, 6 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 problem other than cancer. One woman has a hearing impairment, one has heart problems and arthritis and is a psychiatric survivor; one has experienced depression and has fibromyalgia; one has endometriosis.

URBAN/RURAL: Judging by the size of the population of the town where they lived when they were having treatment, twenty women lived in urban areas, two in semi-urban areas, and four in rural areas.

PARTNERSHIP STATUS + CHILDREN: Sixteen of the women had a partner at the time of diagnosis, and seven 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.

SEXUAL IDENTITY: In the promotional material for the interviews, we had this line: “Labels – we can’t live with them, can’t live without them. By ‘lesbian’ we mean women whose primary emotional and sexual relationships are with women.” Women were drawn to this study, then, who identified in a few different ways: as lesbians, gay, dyke and bisexual.

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 2, the family physician did not know; and one woman was not sure if her doctor knew.

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 some familiarity with the feeling of being 'other.' As communities we have developed strategies for responding to loss and marginalization. We can see from this research how these strategies can be, for some lesbians with cancer and at some times, a source of considerable strength.

Support

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

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, 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 this section, we explore ‘the lesbian parts’ about the support research participants received, and the isolation they experienced.

Lesbians with cancer – ‘better off’ in terms of support?

The women we interviewed talked about what it was like to expect and to receive support from women, and in lesbian community. A theme in several interviews was the idea 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 speaks here of so many shared realities – a shared vulnerability to this kind of cancer; a shared knowledge about a woman’s social experience, including the taboos of speaking about sexual parts of women’s bodies; a shared experience of Pap smears and the feelings that come with having intimate parts of our bodies subjected to clinical scrutiny and intervention. The experiences she and her partner had in common helped her feel understood during cancer.

The understanding that comes with the shared experience of a woman’s body may also have implications for partners’ experiences of meetings with health professionals. Mary Lou described a meeting she and her partner had with a surgeon, about her options for breast surgery:

Through the course of the conversation he just kind of very glibly said, “well we could just lop the whole thing off.” When we left the room my partner said, “I bet he would never say that to a man if he was talking about his testicles”, you know... I didn’t realize that it had upset my partner as much as it did.

It may be that lesbian partners feel the casual cruelties of health professionals especially acutely.

Rosalie also referred to the possibility that her partner’s gender may be a factor in how present and connected emotionally she was:

My partner has a woman’s point of view, a woman’s experience that ... you can just be quiet together and not have to fix anything. My partner doesn’t make me feel there’s something wrong with me because I cry. And ... I don’t know if it’s because she’s a woman or not, but my partner is very able to talk about her feelings and my feelings. [Rosalie]

I think that [my partner] understood how I felt about certain things because she’s a woman. Understood how I felt when I didn’t have any pubic hair, like I don’t know, because I think that’s gorgeous and I love it and I didn’t have any and it was a big thing to me, and she was really supportive and helpful... I just think that women are softer and more caring, oh that’s a bad thing to say, but I do believe it! [Gerrie]

Marcia believes that lesbians in particular have these strengths:

I think lesbians have much more of a capacity to dialogue around emotions and feelings and ... so I think we do a better job in terms of talking through the stuff ...

Interviewer: More than straight women?

Yeah.

Lillian noted that other lesbians understand ‘the lesbian part’ about having cancer:

Another dyke... will understand as a fellow female what it would feel like to lose your breast but she would also understand as a dyke how important it might be to you to be out about your cancer or not.

Other lesbians know what it is like to weigh the pros and cons of coming out, and have a sense of both the value and risks of being visible; this knowledge can translate, as Lillian suggests, into an understand of cancer-related ‘coming out’ decisions.

And Gerrie said that she thinks lesbians have especially strong friendships:

There's something about being a lesbian and being friends together, it's like a family. I don't know how to explain it but... I think it's an advantage for me to be a lesbian and to have so many gay friends, gay women and men too actually, the gay guys are really good too...

A few of the women we interviewed experienced other lesbians as especially competent, and as offering especially well-organized care. Sherry, for instance, said:

I could have asked for anything but I didn't have to, I mean, they said, "we're here, what do you need?" You know, they're dykes...Do you need food, do you need a drive... you need a phone call? They just like, started taking care of stuff, you know what I mean?

In Sherry's assessment, 'taking care of things' and 'being a dyke' go hand in hand. Along the same lines, Lillian spoke about how, in her view, being a lesbian puts women 'outside the box' in ways that enable creativity and effectiveness. She also referred to a tradition of community organizing that serves lesbians well, when a lesbian is ill.

Several women we spoke with said that the process of figuring out how to provide care for gay male friends and colleagues has meant that lesbians have a store of knowledge about how to make care teams and networks successful. Mary Lou, for instance, described **"this incredible support network that worked liked a charm,"** that allowed her to **"just be sick and not worry about things."** As Mary Lou saw it, it was the skills one particular woman brought, along with a community experience of caring for men with AIDS that lent the support network such a high degree of organization and effectiveness.

As Lillian continued to talk about support in lesbian community, she suggested that connections among lesbians can bring resources where they're needed:

And the other thing is that the 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 sort of concentric circles or what I like to refer to as the great lesbian chart.

The 'great lesbian chart' worked well for several of the women we interviewed. Paula K., for instance, spoke about how lesbians she didn't know well at all before her diagnosis started bringing her meals when she became ill. Where lesbians are connected to community, one lesbian's diagnosis with cancer can generate a community response, drawing lesbians beyond her immediate circle into a network of support.

Yet as Lillian pointed out, the ‘great lesbian chart’ may not work as well – or at all – beyond urban centres; Lillian felt that the support she received was very much related to living where she does in Toronto. Other women agreed, and pointed out that even in urban centres, many lesbians are disconnected from lesbian community. We discuss this further below.

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 women at the centre of it.

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:

[My partner and I] didn’t hardly communicate, or we didn’t talk about the cancer hardly at all ... so it was really hard. [Theresa]

[The woman I was with at the time] was wonderful in dealing with the logistics, she really was. I mean she’s a nurse, she had me well looked after. But she couldn’t cope with my emotional reactions. She didn’t know what to do. [Liz]

Even in the lesbian community, lesbians have a difficult time with [cancer], you know, I had a couple of friends that I don’t talk to anymore – ‘you can come with us, you can do whatever but don’t talk about the cancer.’ [Glenda]

And it was in part comparing her own experience to what she saw happen for men with AIDS that another woman found lesbian community organization in relation to cancer lacking:

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 ... you know, how do we care for each other, rather than how do we care for the boys. I think we did a terrific job in terms of the HIV/AIDS epidemic, but ... [Marcia]

Marcia went on to describe many ways that lesbians could 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.

It seems from this research that as lesbians we hold certain ideals about care and support among women and in lesbian community. Sometimes, as was apparent in this research, our ideals match reality really well, and support for lesbians with cancer can be immensely sustaining for individual lesbians, 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 fail to come true and may make times of isolation especially painful.

As well, it seems that the AIDS movement serves as a kind of touchstone for lesbians with cancer, an example of what's possible in terms of support. That example is one we draw from in a positive way, and at the same time it shows us how much more we could have for lesbians with cancer.

Support in lesbian community: the challenge of fear

In our interview with her, Glenda talked specifically about wanting and needing support from lesbians and lesbian community, and not receiving it – this was part of the loneliness of cancer for her.

Even women who were generally well supported by lesbians said there were things that surprised them. For instance, Lillian said:

Telling other lesbians that you have cancer is a very brave act. It's funny, you could probably tell them that you are HIV positive, and you'd get more ... like people wouldn't be as creepy, because there's been enough in the community about being supportive, and it's not so bad and everything. But 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.

Over the course of interviews, women who did not always get the support they expected from other lesbians talked about some of the reasons this might be the case.

The woman quoted above, Lillian, suggests that as communities, lesbians do not yet have the resources to respond to cancer. As difficult as it is to hear about an HIV diagnosis, she says, as we at least have some familiarity with that, some sense of community competence about providing support. This is not the case with cancer.

A few of the women we interviewed felt that lesbian communities seem to have avoided addressing subjects related to illness, aging and frailty in a general way.

The main reason that the women we interviewed gave for why other lesbians were sometimes unable to support them was the 'could be me' factor, especially the fear that comes with the knowledge that 'it could be me.'

Theresa, for instance, was surprised to find that she was in some ways better supported by her gay male friends than her lesbian friends. The gay men in her life wanted to know the details about what it was like for her on a daily basis to live with cancer. If she got bad news, they would be right there. Talking about her lesbian friends, Theresa said,

I mean they all came, they were all very good, they come in shifts to the hospital and stuff, right? But ... I think it was very hard on them.

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.

I think lesbians really identify with their breasts, you know, as a sexual thing... And then it becomes like ‘wow, what if I lost mine ... how horrible would that be, you know? Who’d want to touch me?’ Like all those issues when you lose body parts, right?

As we discuss in the section on Fallout from Treatment, some of the women we interviewed felt that breasts are especially important to lesbians, and that breast cancer is thus something especially feared by lesbians. In Theresa’s description here, breast loss implies aloneness, living without touch. Theresa felt her friends’ struggles to be present with her, and she wondered if these kinds of fears played a part.

As well, as Teresa went on to say, other lesbians **“know the resistance they’ve had in the hospitals, and ... would they be that strong, you know.”** Other lesbians know what it is like to experience and worry about homophobia in the health care system. Teresa 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.

And of course, when we hear of a lesbian being diagnosed with cancer, we sometimes think right away about other lesbians we know who have had cancer, some of whom have died. Sarah spoke about how some of her friends shied away from her when they learned she was diagnosed **“because I think they see [name] and her journey and it was horrendous.”**

The women we interviewed pointed out many ways that lesbians who have not had cancer can feel especially threatened by a lesbians’ diagnosis with breast or gynecological cancer. Fear, then, operates as a barrier to individual lesbians who do not have cancer providing support to lesbians who do. Yet fear also operates at a community level, as Sarah pointed out.

There’s five of us [lesbians] in [city] with breast cancer and two have died in the last 12 months, so people are scared. Yeah, what makes it more scary is the fact that the women who died were the leaders of the community, they were the ones who coordinated the dances, coffee houses and everything like that so they were very visible so it scares women.

Like many other marginalized groups of women, lesbians live in relatively small communities, and communities that sometimes feel under siege. In this context, it seems that each lesbian with cancer is a symbol for all lesbians, of the threat of the disease. This can also be a barrier to support. As Marcia said:

I did feel invisible as a cancer survivor, in the lesbian community... I think I felt like a hero. I'm not sure whether that was because ... I was a [professional] and I'm a leader and whatever, but... I think it also felt like I represented the fear of all lesbians, of getting breast cancer.

Feeling 'like a hero' may not seem like such a bad feeling. Yet of course, a hero has to be strong, and cannot make her own fears and sadness visible. Just like someone who is stigmatized because of cancer, someone who is made a hero is made 'outside' community.

Isolation during cancer

The sense of isolation experienced by several of the women we interviewed was shaped by social identities and social locations in addition to lesbian. Support was affected by where in the province they live, and by age.

Laura pointed out that homophobia in small and rural communities **"leads you not to have friends as much, it leads you not to have support."** When Laura was diagnosed, people at work knew that she was single, and lived alone. Some of them tried to reach out to her:

But again, I couldn't broach that subject and I couldn't be totally honest with them. And that hurts because I'm a very honest person. And I like to be open about everything. [pause] You just can't.

I: Because of the worry of how they would respond to it and ...

Oh yes. The ridicule ... [discrimination is] banned and it's outlawed, but it's never enforced... No, when you hear co-workers talking about gay people and ... ridiculing and, oh, the comments ... you just don't want to go there.

It is clear that homophobia prevented Laura from receiving the support that a heterosexual woman might have received. As Laura said, no one should ever have to deal with homophobia; but especially in the situation of a life threatening illness, when a woman really needs support and help, we want to believe that homophobia will be erased. But in her situation, it was not:

It just doesn't make any difference. They're still going to view it as, 'oh, she's gay,' you know. It's just ... you just don't even want to deal with that.

Laura noted that homophobia can occur everywhere, not only in small towns. Yet she feels that in urban centres, complaints about homophobia are more likely to be taken seriously.

As well, support from other lesbians may be especially scarce in rural areas and smaller towns, as Jacquie and Marcia pointed out.

I was really isolated up there... I wasn't in the community, I was out in the middle of nowhere. So I had to find different things for my own wellbeing and mental health to try and get me through. [Jacquie]

Now I'm in [names county] and ... all gays and lesbians are mostly invisible up here. There are no gay and lesbian resources up here. And so ... well, that simply makes me sad in terms of, you know, good grief, it's 2003 and there are still parts of Ontario that are completely in the closet.

Interviewer: So there's no even small community near where you live ...

No. No, no, no, no.

Interviewer: [laughs] No no no no, you say

[laughs] No no no no! No no no!

Interviewer: Just you and your partner and ...

Oh, well, and ... hidden people who ... you know, we're at the stage of, 'oh, are they or are they not,' or how do you have the conversation or ... you know, all that kind of stuff.

For Marcia the scarcity of lesbian contact has meant that both her sources of support and her identity have shifted. It is very difficult, as she says, to cherish lesbian identity without community support and without having lesbian reality reflected back to you. Because she does have contact with the breast cancer community, she feels that her identity as a breast cancer survivor is more central to her just now.

When I was in [small city] and connected with the church and with gay and lesbian people constantly, I would say I was very much ... a lesbian ... with this little disorder called breast cancer... Whereas now it's/ yeah, it's no longer in my context. And I feel sad about that. But that's, you know, that's the reality. [Marcia]

Like Marcia, Maureen lives in a rural community. Yet the reason that most of her support was from heterosexual women was quite unique. The lesbian community in her area was actually very strong until a workshop was held about abuse in lesbian relationships. The workshop **"blew the community apart,"** and women who, like Maureen, had been active in raising the issue were viewed as ending the community camaraderie. Most of Maureen's support, then, was from heterosexual friends. It is possible that in a larger centre, the workshop might not have disrupted the entire lesbian network, and Maureen may have had more support from lesbians. Yet as Maureen pointed out, lesbians in her community **"were together because**

we were lesbians... Now it's more important to me to have somebody who has the same political belief system."

Liz also had more support during breast cancer from her heterosexual friends than from lesbians. As much as she appreciates their support, she describes a "little lack" in their understanding of her and her situation. Liz came out as a lesbian in her 60s and she knows no other lesbians her age in her community.

I have to say it, I have to say this fact that I ... I have this sense of isolation. And part of it ... and a good part of it is because I do not find that I have the support that I'm needing from lesbians.

Among participants in this research were also women who felt alone as young women with cancer. Talking about media images of breast cancer, Teagan said she never saw anyone who looked her age.

I really for a long time felt like a freak, you know. I was the youngest one on my [dragon boat] team ... And had a really hard time relating... it took until this year for me to be able to look out there and say, oh, OK [laughs] ... you're cute, you're gay, you've also had breast cancer, cool, I can identify with you.

Here, Teagan points to the ways that, until recently, she felt 'out of place' in the breast cancer community. Theresa spoke about the other side of being young – being 'out of place' with lesbian peers who have not had cancer.

I think it's very hard for people to understand, at thirty you're supposed to be going to the bars, drinking, having fun, and ... you know, and that wasn't how my life was going to be.

Marie echoed Theresa's comments, pointing out that for many young women, a peer's cancer diagnosis is a pretty foreign experience. This can mean that, despite their friends' best intentions and efforts, young women face cancer alone.

[My friends] were not unwilling to give me room to talk about it... I think they 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.

It was clear from this research that there are many dimensions to the isolation that lesbians with cancer face. Coming out about cancer, and feeling 'other' because of how people react, may remind women of difficult experiences and strong feelings of isolation from when they came out as a lesbian. As well, lesbians with breast cancer may be further isolated if they live in areas where homophobia goes relatively unchallenged, or where lesbian community is scarce or lacks diversity to begin with. Experiences that are 'out of synch' (because of age, for instance) are also linked with isolation.

Several woman we interviewed spoke about what it would mean to them, to meet and get support from other lesbians with cancer. We include some quotes about this in the final section of this report, Ideas for Change

Fallout from Treatment

Hair loss

Here's a stereotype: lesbians like hair in places heterosexual women don't (legs, armpits); and lesbians don't like hair in places heterosexual women do (heads!). Like all stereotypes, it's wildly oversimplified, yet it links 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 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, '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]

Mary Lou spoke of a similar experience; after her hair grew back, she continued to shave her head. **"It's given me the freedom just to go - it's given me the excuse to be able to look, well, to look butch!"**

And Paddy said, **"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.

In these women's stories, having very short hair was a way of affirming a lesbian or a butch identity and a way of maintaining or connecting to power.

Hair loss can also make a woman 'less lesbian.' Gerrie thinks hair under the arms is really beautiful. The last time she shaved was as a present to her daughter (it was the only wedding gift her daughter wanted). With chemotherapy Gerrie lost the hair under her arms. **"I had bald armpits," she says. "My kids were thrilled."**

Constance spoke about yet another connection between hair loss and being a lesbian with cancer.

On Church Street [in Toronto] they're like, "yeah, you go girl..." I still have one waiter at [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.

In queer community, Constance suggests, a bald woman is not necessarily seen as a woman with cancer. This meant that Constance was treated **"like a normal human being."** Queer culture and community lends 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 said this:

You feel like in a way you've died and been reborn. Your hair goes right down below the skin line, it takes month for it to even come back, I'd never seen my bare 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 naturally would say, 'when I was on chemo.'

While a lesbian identity might allow some women to buffer the difficult impact of hair loss, or even to find power in it, 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 women had regained their fitness levels and were feeling strong again after treatment. Others talked about how cancer treatment stopped them – in some cases over long periods of time – from being active and strong in the ways they had enjoyed. Jacquie, for instance, said this:

One of the hardest things getting through, other than the modified radical (mastectomy), was the fact that my body just fell apart because I wasn't getting the exercise that I normally did.

A few of the women said that for them, being athletic was part of being a lesbian.

When I asked [the surgeon] about [when I could play] hockey, it was a perfectly valid question... There must be straight women that play sports that would be concerned but probably there's going to be more dykes that are and that's a realistic thing. It's a huge part of my mental health to play sports. [Lillian]

We can understand this 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 dominant culture). 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; it can also disrupt her connection with lesbian community.

The women we interviewed often spoke about physical activity and being outdoors – hiking, bike riding, playing sports and so on – as markers of health and a return to normalcy after cancer. This is also true for heterosexual women, of course, but may be even more often the case for lesbians.

Some of the women we interviewed had jobs that require considerable physical strength. Rosalie, for instance, managed a building complex, which involved a great deal of physical work, and shift work. **“I can't even do a portion of what I used to [before cancer treatment],” she said. “I really do feel diminished physically.”**

One woman we interviewed, Paddy, was once an athlete, and 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.

I am this butch dyke who's falling all over the place like lost lamb [Paddy]

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 which are experienced by some women, like Paddy, as ongoing losses.

Breast loss

It became clear over the course of this research 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:

I think definitely, for lesbians - at least this is the way I feel - that it is not a priority for them to go out and get reconstructive surgery... I think heterosexual women have more pressures about the fact that they have to have breasts to be a woman. Whereas I didn't feel that way at all. I didn't feel any less of a woman, in any way, losing my right breast. [Jacquie]

Several women felt that heterosexual women struggle more with breast loss because men value breasts. Laura told a story about a young woman whose male partner left her when she had a mastectomy:

I think a woman has more empathy towards that if it was her partner, I mean she wouldn't drop her partner because a woman doesn't have breasts... it's more of an emotional love than a physical fixation... If I had 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. [Laura]

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 it 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 continue to find her sexy. Jacquie told us about the tattoo she designed for her chest, and how other lesbians **“really admired me getting the tattoo, and the strength behind it.”**

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 loveability:

[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.[Glenda]

It was especially hard, then, to find out that changes to her breast sometimes did matter:

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. [Glenda]

In terms of how breast loss affected their own sense of their bodies and selves, a few of the women we interviewed said the affect was not negative.

However, most of the lesbians who spoke about these issues described some level of personal struggle about what had happened to their breasts (or, for women who had not yet had surgery, about what might happen).

You do feel mutilated, I mean, you know, someone's lopped you up... so you have to deal with your body image issues around that. And you may or may not have a great body image to start off with... I still don't feel totally comfortable with it. [Lillian]

And 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:

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]

I can even picture myself having the surgery and getting through the medical component of that, but I can't picture myself being a lesbian without my breasts. Because when I try to picture myself making love after my breasts have been cut off I can't see it, I can't visualize it because for me, my breasts are an intrinsic part of making love to another woman. [Sarah]

Lillian, as well, feels that in coming out as a lesbian **"you have to claim a certain amount of sexuality that heterosexual women don't ever have to."** She suggests that sexual parts of a woman's body are integral components of lesbian identity; losing sexual body parts is, then, a challenge to lesbian identity. (We speak more about the struggles around breast loss and its effects on sexuality below).

It's not especially a problem, of course, that some lesbians think breast 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. So, for instance, lesbians in our research heard 'shoulds' about breast loss – that as lesbians, they should wear prostheses or have reconstruction, or conversely, that they should not.

One woman said this:

A lot of [my lesbian friends] would say stuff like, 'you know, you should try wearing [prosthetic breasts], because your clothes will fall better.' Like Pride Day and stuff like that, it's all about their bodies, a lot of them. The way they dress and stuff like that, they identify, '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? [Theresa]

Another woman heard an opposite message:

I read some stuff, little bits and pieces about lesbian breast cancer survivors... There's a lot of it about the patriarchy forcing implants upon you and you know these horrible chemical things and how awful it was. And [lesbians 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'...

Interviewer: So, how did that make you feel?

Oh, the usual, you know, you're not part of the group, you're being culled from the herd. [Lillian]

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.

The message Lillian hears is very much connected to the idea that the only reason that a woman would have reconstruction is to affirm that she really is a woman. The other part of this judgment is that reconstruction is about *hiding* breast loss. Hiding, of course, holds special meanings for lesbians: for the most part we value, wherever possible, 'being out'; hiding, unless there is danger, tends to be judged negatively. It seems this kind of negative judgment about hiding lesbian identity may be transferred over to the decision to have reconstruction after cancer.

Perhaps the central lesson here is that the beliefs we hold in lesbian community about breasts are contradictory and linked with our relationship to societal ideas about what woman 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

It became clear in this research that diagnosis and treatment for breast or gynecological cancer can pose particular challenges for lesbian sexuality. Our interviews also confirmed that a profound silence surrounds lesbian sexuality generally, and sexuality after cancer in particular.

Several of the women we interviewed talked about how the changes to their bodies left them feeling disconnected or distanced from their bodies. Possibilities for intimacy felt very limited in this context:

I don't really want to be in my body anymore... Since the last time I got diagnosed, I think I've put on about 45 pounds and it acts like a barrier. To me it's a barrier against intimacy, so, like, so that less people will ask me out or something like that, you know what I mean, and it's a direct result of the changes that have happened to my body and just not feeling connected to my body anymore, like not wanting to feel connected... I have not even wanted to be in a relationship because I just can't understand how... another woman would be able to relate to my body because it looks sort of like a patchwork quilt, after having so many scars and things, so... So I'm not sure how much different that is to heterosexual women. I mean, I don't know, but it's a woman to woman thing for me. [Jessica]

I find [my breast] very ugly. I find that if I started dating or whatever, maybe that's what keeps me from intimacy or dating is that, 'oh, my gosh'... And I gained so much weight with the [drug]... [Glenda]

As is apparent, weight gain from treatment was linked to a reluctance to seek out intimacy for some women. The feelings research participants share here link up with a cultural context that tells us that large bodies are undesirable; in a similar way, especially for women who grew up in more punishing cultural contexts, lesbian bodies have been marked as shameful. One of the women who took part in this research, for instance, recalled falling in love as a teenager. **“We were found out. We were reviled... spoken to in anger and horror, told to give up our disgusting practices immediately...”** Many lesbians (still) hear these messages, in our heads and around us – and they may echo especially loudly for lesbians whose bodies have been touched with a disease that is associated with fear and shame.

One of the especially difficult things about being diagnosed with a ‘woman’s cancer’ is the way sexuality and cancer can become directly linked. One woman, Kate, spoke of how **“sexuality and disease all come in the same package”** now.

I mean I can rationalize it and I can say it doesn't come in the same package but it does because it's my body and it's about the way I relate to my body.

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. Rosalie spoke about how very hard it was to have so many internal exams.

Submitting to all that poking... It made me feel more naked than I wanted to be... And I guess too because I'm so busy trying to hold myself and heal myself, and it's just the opposite of that.

The procedures and feelings of being violated can become entwined with sexuality for lesbians with breast and gynecological cancers.

In our interview, Marie said that for years she could not separate out 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 was thinking, 'it's going to activate the cancer', that's where the crazy place was.

Marie spoke about partners who did not understand or could not respond in ways she needed to her emotional reactions, or to her need to control the pace and pressure of sex. She also talked

about anticipating her lovers' fears about being sexual with someone who had cervical cancer. Similarly, Sherry referred to a moment when she and her partner were having sex where she could tell that her partner's decisions about which breast to touch, and how, were shaped by her awareness of cancer in one of them.

In the section on Support we talk about the fear and awkwardness cancer generates, even in people who want to be loving and helpful. It was clear from our research that this fear and awkwardness unfolds in sexuality as well.

In talking more about sexuality after cancer, Marie said that her strong emotional reactions only eased after she worked on the anger she felt towards one particular doctor. Marie's comments remind us that it is not only the diagnosis and treatment that affect sexuality – how health professionals act also matters. This is one of the ways that heterosexism in cancer care, and poor care generally, can affect lesbians in their most intimate experiences and relationships.

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:

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?' There are women like myself who can't have an orgasm without involvement of their nipples. You lose you boobs, what do you do now? You get really frustrated. It's very frustrating. There's things like that, that people don't, like who do you talk to about that, you know? [Lillian]

Some of the women we spoke with talked 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:

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. Yeah, it has become my enemy, when it comes to that piece of my sexuality. [Sarah]

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 fallout from treatment for a 'woman's cancer' especially complicated and difficult.

A few women also spoke about treatment-induced menopause, and the ways it has changed their desire to be sexual.

It's been very tough for both of us, especially for [my partner] because of course she's still in the prime of her life, you know, and so that's been hard, because it's not that I don't love her, but, you know, somebody's just not paying attention down there. [Constance]

As well, a few women we interviewed said that sex hadn't been a big part of their relationships before cancer:

So it really hasn't changed that part for us because we weren't, we haven't had a lot of sex, to be putting it really bluntly... this is an issue I would like to discuss with other lesbians. [Maureen]

We've been together for thirteen years and have two kids and I don't know too many lesbians that are still having too much sex. And I don't know if I going to have much to say [about sexuality after cancer] but I wouldn't have had much to say a year ago either. [Paula K.]

The women we interviewed identified particular issues around sexuality for lesbians with cancer, and – quite consistently – the ways those issues are not talked about. How lesbians are and are not sexual after cancer appears to be an area of vast silence; there appear to be virtually no places where this kind of conversation is made possible.

A few of the women we interviewed discussed what was helpful to them, to ease the ways cancer negatively affected their sense of sexuality. As mentioned above, Marie spoke of the benefit to her of trying to work through the anger she felt about how a physician had treated her. Sarah talked about deliberately trying to stay connected to her breasts:

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. [Sarah]

Several women talked about how lovers and partners had been helpful. Most referred to partners who had continued to make them feel desired even when they felt unsure they were desirable.

It's very helpful that I have a partner now who is deeply attached to my wounded boob, that's very helpful. [Marcia]

Even when I was having chemo we still made love and loved each other. I was just worried when I was bald but then, she didn't mind my bald head, so, I felt good about myself [Gerrie]

Marie explained how a casual lover had helped her reclaim herself as a lesbian and a sexual woman:

She 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.

Sherry spoke of the value of talking with a partner, and trying to be comfortable in herself about the changes in her body. And, as Lillian said, there's always practice...

Like I said, I was one of those people for whom the nipple was a denouement, 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. We've had to train really hard and practice a lot. Now you've got to get the tone on that for the transcript, you know, think of it as a gentle bit of sarcasm about how awful it's been to have to practice and work on it so hard just to get it right, you know.

Partnerships and dating

A cancer diagnosis did all manner of things to partnerships – from ending them to making new relationships very close, very fast; damaging them and making them stronger (and sometimes both at once). A cancer diagnosis also made some women who did not have partners acutely aware of being alone.

Feeling ‘less than a wanted person’

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

Teagan, for instance, talked about the difference between how she wanted to feel about her changed breast, while she was dating, and how she actually felt.

You want to be confident, and you want to be sure of yourself and say, ‘well quite frankly, if those are things that bother you, you are not worthy of me... 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 thirty-six... 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?’ [Teagan]

Women talked about feelings of being undesirable in at least two ways: in terms of feeling sexually undesirable (feeling that their bodies were undesirable), and in terms of the cancer making them ‘bad investments’ for a partner.

I said, OK, now, who’s going to want me now, now that I have cancer, you know ... I’d have to tell somebody if I was planning to become involved with them that, hey, this is the situation, I’m honest... But you feel like you’re never going to be in a relationship again.... You go through that mentally in your head, you’re going to say, ‘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, (is) what I’m trying to say. [Laura]

When I was thinking about getting back into dating... oh my God, who’s going to ... who’s going to want someone who has this kind of scar, and is someone going to consider me sexy?... Or are they going to be frightened that I might have a reoccurrence ... and they / so they won’t want to invest in me for fear of something happening. [Teagan]

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 might have cancer, you know, 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.' You know. [Lillian]

Worry about how a sexual partner will react is something both lesbians and heterosexual women with cancer experience. Yet lesbians who have had a 'woman's cancer' do face particular challenges. Because women's bodies mirror one another, differences between bodies – including the difference of a scar, or a lost breast – become acute when two women 'end up naked' together, and cancer can become especially present in sexuality (we talk about this more in the section on Fallout from Treatment).

Lesbians' worries about finding partners also occur in a context where dating can be a serious challenge. Heterosexism limits lesbians' capacities to be out and visible, and it's pretty hard to date when you can't find or identify potential partners. Heterosexism means there are very few supports to facilitate lesbian relationships.

In small cities the situation is especially difficult and complex.

I didn't bring my diagnosis to the group... because my lesbian partnership was breaking up, of 9 years, and I remembering 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 labelled. [Sarah]

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 relationship for herself, she also lost for a period of time a key source of support. Heterosexism and 'cancerphobia' combine to put lesbians in impossible positions.

Even in a city as huge as Toronto, the lesbian community can feel small. One of our research participants, Lillian referred to 'the great lesbian chart' which plots, among other things, who has slept with whom (Lillian was amazed and delighted to find a partner with whom she had no previous connections – by which she meant, actually, that they had no exes in common).

For women who were dating, it was easy to think that they were 'less than wanted' and that other women would not risk a relationship with them. And women who were in relationships at the time of diagnosis faced the possibility that their partners might leave:

You're thinking, am I going to lose my partner because of this ...? Who wants to be around someone that's, you know, potentially terminally ill, right? [Theresa]

Theresa and her partner had been together for about year when she was diagnosed. That their relationship was in its fairly early stages meant that the threat of her partner leaving was especially acute. In a similar way, when Sarah told a woman she was dating about her diagnosis:

We cried, we swore, we were angry together and at the end of the conversation I basically said, 'if you need to walk away I will understand', I said, 'it will hurt, but I will understand.'

Pauline and a woman she'd been friends with for years just come to the realization that they were in love when Pauline was diagnosed. She spoke about how surprised – and delighted – they had been, to discover love together. Cancer threatened to all this before it had really begun.

Our relationship was so new, and the thought that I was going to die before we had had a relationship at all, that was what devastated me, terrified me, had me in tears. It's like, I'm going to die... it's only been three months ... four months, what is that, you know [Pauline]

Women coming out later in life, who have faced such a struggled to recognize and acknowledge a lesbian identity, sometimes have a sense of many years of 'lost time' living as a heterosexual woman. In these situations a cancer diagnosis can seem especially unfair.

Again, these worries and sadness unfold in a context where 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. As Marcia put it,

[Lesbians] don't have the supports in terms of relationship stability to handle this kind of pressure.

Yet while cancer was clearly a strain on relationships, some of the women we interviewed said that over the course of facing cancer together, their partnerships grew stronger:

My relationship has matured tremendously. There isn't a day that goes by that my partner and I aren't able to look at each other and say, 'we are just two of the luckiest people on earth.' [Mary Lou]

It almost has brought us closer, it just made us more aware... we were innocent and now we're not innocent anymore. When we were innocent we were going along thinking that everything was going to stay the same and we were going to

be healthy and we didn't really think about either one of us getting sick. So now we know that can happen. [Gerri]

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':

[The diagnosis] gave her more justification for, you know, making sure that I'd got my scarf on straight – that my inadequacies or incapacibilities were only to be expected. So I became / I was shifted into ... [pause]

Interviewer: That diminished kind of position in relation to her...?

Yeah... And again, that might have been partly because I was aware of the fact that I was no longer perfect. You know, half a breast gone, and always the fear.

Liz went on to talk about the other factors involved in this changed dynamic:

And then of course, though this has nothing to do with the cancer, my feet never came back to normal [after an accident]. So the relationship that we had, which was an outdoor, hiking, totally equal relationship ... I think was shifted. I became the dependent one, or potentially dependent one. I also didn't have any rights, any ownership in where I was living, but that was nothing to do with it, but it all together ... I think I became ... a bit of a second-class citizen. [pause] Yeah. I think I did.

Liz points to the ways cancer can factor in the balance of power in a relationship. As she says, her mobility limitations and lack of ownership in where she was living were not directly related to her cancer diagnosis. Yet it is clear how circumstances of lesser power – like disability, and less secure housing situations – can combine with cancer to create or exacerbate inequality and vulnerability in relationships.

It was in fact two lesbians with multiple health problems and disabilities who spoke about their 'second class' status as partners in the bluntest language. Liz said to 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.

For Pauline, metastatic breast cancer meant that she became dependent on her partner, and fearful of her leaving, even for short periods of time:

I hate ... being at a loss this way. I want to be able to say, go and enjoy, get as much as you can out of the ten days [away], you know. And all I want to do is cry because she’s going, you know. I don’t want to be like that! Don’t want to be like that. Gosh, I even hate for her to be gone an hour at a time. It’s fear, it’s fear that I could lose her. Not fear that she’ll lose me, because she will lose me. [laughs] She’s going to lose me, and I should care about that, but I care more that I could lose her.

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’.

Interdependency is partnership, in which one can manage on one’s own ... and I can care for her. How can I care for her? Barely managing myself...

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.

I don’t know that I’ll be able ever even to work again... Losing [my partner] would be catastrophic. Apart from the personal ... all apart from the personal, that would be catastrophic... I mean) I’m sustained by her financially [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

Cancer is typically life threatening... so there are all sort of issues that are going to include all of the people around you. Lillian]

Several women we interviewed talked about how hard cancer was for their partners and children. A few felt that their partners' experiences were in some way worse than their own. Gerrie explained it this way:

I know what's happening to me, I know where I am, where she doesn't know and sometimes she's afraid to ask me certain things, you know. So I know where I am and she has to just sort of suffer through it sometimes. So I think it was harder for her than it was for me.

Along similar lines, Sherry talked about the affect on her partner, of her decision not to have chemotherapy or radiation:

Having done the research and reading that I had done and started making my choices and building my own response, you know, I felt in control. And I knew that I could never transfer that over to [my partner], right?

Bonnie said that her partner's anxiety about the possibility of cancer returning is sometimes higher than her own. This makes sense to her: **"If the cancer comes back for me, and God forbid it's bad and I die, she's alone. And if the roles were reversed, I would probably be more freaked out."**

A central feature of the worry lesbians with cancer felt about their families was the lack of support available for them. Constance said that her partner really did feel that she was going through it alone. The friends supporting Constance often thought first about Constance herself, which, as she says, is **"fair... but not helpful because she really did need more support than I did."** Gerrie spoke about her partner in a similar way. Friends would ask how Gerrie was doing, and send gifts, and Gerrie felt, **"like, send her [my partner] the flowers and nightgowns because she's here everyday and I don't know, I always felt so bad for her. She never complained or anything, but I just thought she needed more than I did."**

The women we interviewed did describe friends offering important support to their partners and children. Yet formal support services – support groups, for instance – were inaccessible.

For the children in my life, for my partner, they weren't things that were very useful. They weren't things that were open, it didn't feel like an open door was there. [Kate]

Kate went on to say that any support group that would be genuinely useful for her children would enable them to speak freely about her. This would mean that they would have to 'come out' as the children of a lesbian mom, and deal with all the reactions this usually generates, and provide all the explanations it often 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."**

Speaking about her own partner's experience, Constance confirms Kate's assessment:

We did check into support groups and they were always for men, for male partners of, and [my partner] said, "there's no way, I'm not going to those, they won't understand what I'm going through, I don't want them looking at me". She was having a hard enough time... she just couldn't, she just said, no.

That support was so unavailable for partners 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. Sherry explained that she very much wanted to be there for her partner, and was; and yet when friends rallied around her partner, it was helpful for both of them: it eased her worry and her sense of having to be present for her partner when she was trying to keep herself strong.

It was clear in this research that the isolation some lesbians with cancer experience is made all the more acute, with the recognition that their partners and children are also alone.

The women we interviewed also spoke about what it was like for their partners and children in cancer treatment settings. We discuss this in the section on Cancer Care.

Families of Origin

In lesbian communities it is well understood that our relationships with families of origin can be strained, sometimes entirely hostile. It was clear from our interviews that a cancer diagnosis sometimes makes the tension even greater. Yet it was also evident that many of the women we interviewed received a great deal of support from their families of origin. In a few cases, the situation of illness shifted lesbians' relationships with their families in positive directions.

For Sarah, breast cancer forced her into very difficult conversations with her family, when she was just beginning to speak with them again:

I come from a very Roman Catholic family and um, my father told me I was going to hell for being who I was, for being a lesbian. And so I was disowned by my Roman Catholic family for quite awhile, and I was just creeping back in to my biological family when this diagnosis came around. The hospital, my family doctor and my cancer specialist all needed to know if breast cancer was in my family. I had no idea, it had never been talked about. And, so I had to go back to the matriarchs of my biological family and ask those questions and it was hard because I had to first of all get invited back in to my family of origin after being kicked out because I was lesbian. And then I am forced to have this even harder conversation about breast cancer...

I didn't know my oldest sister had had a lumpectomy. I didn't know my grandmother had breast cancer until just the last year. So it's just made it harder, it's just made it harder... my family is full of homophobia, you know, and so now I have to deal with that and breast cancer.

Sarah makes the point that instructions from health professionals that might seem relatively straightforward to them – 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.

Like just months before, I was telling people I was with a woman ... And then I was telling people I had cancer, so it was ... a very good lesson to me ... [laughs] that it's a lot easier to tell people up front. [Rosalie]

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.

When we sat down to talk about my treatment, I also told her, 'you need to be aware that my support will come from you, but it will also come from [my partner]. I'm in love with her, she's my partner, and that's who I'm choosing to spend my time with...' So, that in itself ... you know, boom, your daughter has breast cancer, boom, she's also having a relationship with a woman [Teagan]

When Constance was diagnosed, her partner "had to tell her mother not only that she had a girlfriend but that [her girlfriend] was going through [cancer]... and she had to go through her mother saying, 'you're going to burn.'

Cancer and treatment can push lesbians out of the closet. And while Teagan, for instance, says she's glad she came out, she certainly would have preferred it to have happened under more

relaxed circumstances – **“of our own choosing, rather than coming out 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 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 breasts, and will not have children.

She just ... she won’t even really ... 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.

Jessica, who felt a great deal of support from her parents around the time of her cancer, nevertheless wondered if she was perceived to be less well or less fully taken care of because she was in a relationship with a woman. There were times when Jessica felt that her parents saw her as ‘on her own’, even though she and her partner have been together for 13 years.

Yet for some research participants, cancer shifted the feelings of families of origin about lesbian relationships in a positive direction. Bonnie, for instance, said this:

Not that they didn’t get along, but [my mother and my partner] ended up spending a lot of time alone [when I was sick] and I think my mom could get a very good appreciation of how much [my partner] cared for me.

Maureen’s mother had never totally accepted her relationship with her partner. Her attitude shifted when she saw how well Maureen’s partner took care of her:

It was like there was some kind of repairing of our relationship or of an understanding, you know, even though I still don’t think she’s totally joyous about it. It was helpful in our relationship, to bring us closer and for her to accept [my partner] more.

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.

I’m trying to not think about it, because I can get pretty stressed out and freaked out about it... We were just sort of barely making ends meet and when I got sick,

so, I need to be more creative [to find ways to make more money]... You know, with two little kids, and it's a long haul ahead of us. [Paula K.]

Women without benefits spoke about the strain of having to work during treatment.

I had no coverage and I was getting an hourly wage, not a salary... When I had the radiation, I'd have three or four hours off for the appointment, I'd come back to work and finish the day or, I shifted my schedule around so I made up my hours because I couldn't afford to take the time off because if I didn't work, I didn't get paid. [Constance]

I had some sick days left. But if I had a choice I would have taken more days off because of the radiation [Anette]

The cost of drugs affected women who had no benefits plan. Constance spoke about the shock of learning just how much anti-nausea drugs cost.

They don't tell you that because they assume everybody has benefits... [the pharmacy] filled it and said, "okay, that's one hundred and forty-five dollars" and I went, 'ha, ha, ha'. Fortunately my girlfriend had just been paid so she paid for it for me. But I thought, 'well, a little warning would have been nice'. [Constance]

Single women were finding things especially difficult. Sarah spoke about being a sole bread winner running her own business, **"so I gotta work three hundred and sixty-five days a year."** Lou said this:

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, like her, 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. A few women also drew attention to their relatively less stable financial position compared to heterosexual couples.

When I was off work and I didn't know when I was going to go back to work, I didn't know if I would have enough finances to last me and my partner wasn't even working at the time so this was a scary... a scary thing. But if it was a man that I was with who had a stable job and I'm sure they would go with stable jobs,

that would be the big difference for me, for any lesbian who has cancer. [Anette]

Not all heterosexual couples are comfortable financially, of course, and not all men have access to good jobs and high incomes. But Anette points to the overall reality that men as a group have higher incomes than women, and lesbian couples in general thus have less access than heterosexual couples to financial resources.

Even women with benefits and who were in relationships struggled with money. Gerrie said that money was issue for her because **“I felt I wanted to contribute something other than my bills to the relationship, you know.”**

Kate felt lucky that she had a good benefits plan. And yet for the entire period she was off, she never did receive money on time; and a mistake by her employer meant that, as she was returning to work, she had to pay part of the money back.

She points out that people often want to take vitamins, or pursue treatments or self-care not covered by OHIP, and these things are expensive. Taking a taxi home from radiation is expensive.

And generally speaking, you're on some form of disability if you're lucky, and if you're not, then ... you really need the money. But one way or another, there's quite a financial cost to it, that's what I found. [Kate]

An awareness of what it's like to have to borrow money and depend on friends during cancer treatment led Kate to offer this advice for people who want to support someone with cancer: **'give them money.'**

Some of the women we interviewed found alternative therapies important to their recovery, and a few really struggled to pay for them. Jacquie, for instance, worked many extra hours to try to cover the costs of supplements; Lou is deeply in debt for the costs of alternative therapies and may have to sell her house.

The costs of care meant that women who had been in difficult financial situations before diagnosis had to work very hard to try to support their health during cancer.

You need the money to get the food and all this stuff, vitamins and whatever to make you healthy, so what do you do? Do you just give up?... I'm a very resourceful person. I shop at Goodwill, I check the discount things at Dominion and all them, I make very good meals, I go to some of the places, I go to the Native Women's Centre for dinner some nights, it's free. I do different things like that and that can weigh you down.

As Glenda said, having to work this hard to take care of yourself when you have cancer can **“weigh you down.”** Yet it is not only the work that is difficult; it is also other women with cancer taking their resources for granted:

These women are talking about juicers and I’m sitting there thinking, ‘juicers, like juice, I don’t have juice...’

In this section we have talked about the financial toll that cancer can take, which is significant. For women who are poor at the time they are diagnosed, a whole other set of issues can come into play. A few of the women we interviewed found access to community and health services difficult or impossible because basic resources – like tokens to get to support group meetings – were not made available. As well, class privilege and class oppression factored in interactions with other women with cancer, as is apparent in Glenda’s comments above, and with service providers. We discuss this further in the section on Cancer Care.

Cancer care

We start this section with a very important finding in this study – most of the women we interviewed said they had not encountered homophobia in cancer care. 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. Yet at the same time, as we discuss, the comments women made about their good experiences with cancer care sometimes tell us as much about the ongoing reality of heterosexism as they do about actively lesbian-positive care.

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

We describe what we learned from the women we interviewed about the various forms heterosexism can take in cancer care and community-based cancer services. We follow this with quotes and analysis about what heterosexism and homophobia can do to lesbians with cancer.

It became obvious in this study that lesbians actively work to get good care and avoid bad care. This work – determined and creative – reflects the strength of individual lesbians and lesbian communities. Yet the fact that lesbians continue to have to do this work marks the ongoing nature of heterosexism in cancer care, the ongoing need for change.

Lesbian-positive care ... ?

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... [In terms of home care] I mean the house is full of rainbows... I didn't encounter anything... Nothing... 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]

Paula suggests that she did not encounter homophobia because she was not looking for it; Pauline says she was in fact looking for it, but didn't find it.

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 certain women, homophobia may be less pronounced than it has been in the past.

Yet while we celebrate this change, it is also important to note that some of the comments women made about their good experiences tell us as much about a legacy of heterosexism, and about how things are in the health system these days, as they do about lesbian-positive care.

Several women we interviewed spoke about how they appreciated the ways health care workers and support staff related to their partners. They described instances where health professionals had encouraged them to bring partners to consultations, enabled partners to be with them for procedures and during hospital stays, left information with partners over the phone, and asked after the wellbeing of partners. A few examples:

My partner was always with me... No questions were asked [Anette]

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 she went on complaining about her husband [laughter]. [Paula K.]

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]

I really admired the fact that everyone respected my partner... Everyone was totally cool, I never got any negative energy from anyone. Absolutely none. [Jacquie]

[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... They were great, you know, they left us totally alone which I was very impressed with because I thought for sure, you know, we could have had some problems there. [Constance]

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. [Paula K.]

Paula K. went on to talk about how much it meant to her, that the physician had addressed her partner:

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

The physician here is clearly acting in lesbian positive ways, and Paula K.'s appreciation is very real. Yet as Paula K. herself points out, a heterosexual women 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.

Mary Lou confirms this:

We upfront say, '[my partner] has power of attorney, if there's any questions, you talk to her.'

I: And people have respected that?

Absolutely, absolutely, it's been really quite remarkable. It's been gratifying, I mean, for heaven's sakes, we grew up in a time when these words were not spoken. [Mary Lou]

Like all lesbians, participants in this research have many identities. Heterosexism was not the only form of oppression the women we interviewed faced. Oppression based on class, for instance, worked in a way similar to heterosexism: that is, classism left poor lesbians grateful to health professionals for things that middle and upper class lesbians take for granted.

Glenda describes an art therapist who responded to her difficult financial situation by getting the hospital to provide tokens for the transit system. This gesture is an important one; as Glenda says, the therapist 'went out on a limb for me.' At the same time, covering the transportation costs for women who are poor, especially for a well-resourced service, is a basic issue of accessibility, and not something for which women should have to feel grateful.

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:

I need to say that 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 ... Yeah.

**Yeah. It wasn't/ 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]

**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]**

Both the gratitude expressed above, and the readiness to fight, occur in a context: a historical and political context in which lesbian relationships have gone unnamed, unrecognized and stigmatized. That health professionals have historically (and currently, as we describe below) failed to grant legitimacy to lesbian relationships means that lesbians often do not expect that our partners will be treated as heterosexual partners will.

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 equal treatment in cancer care.

Heterosexism in Cancer Care

'Pink and blue coloured glasses'

This is an awkward title for this section, but we wanted to get away from the term 'lesbian invisibility,' which seems to imply that if lesbians decided to become more visible in health care, all would be well. Instead, we want to draw attention to the ways heterosexism means that health professionals (like the rest of us, until we work on our 'glasses') perceive that women are always and naturally seek (or are in) relationships with men, and vice versa. Sometimes these 'glasses' result in health professionals failing to consider the possibility that a woman is lesbian, and/ or failing to take lesbian identity seriously, once it's known. In other instances, the glasses prevent health professionals from taking lesbian identity, lesbian 'culture' or the social context of heterosexism into account in health care.

The possibility she's a lesbian not considered

Theresa and her partner had been together for about a year when she was diagnosed, and they were both in the process of coming out. She describes the awkwardness of trying to organize her care needs, and specifically to involve her partner in her care:

That was a heavy factor, the fact that I wasn't identified in the hospital as a lesbian. Like they would always refer to wanting to speak to my mom and dad ... it took months before I could even say / you know, [my partner] was my roommate [laughs] ... my roommate! She's waiting for me after surgery. And then saying to [the surgeon], 'I would really like you to address my roommate before my parents,' and ... and he was just sort of like, 'what?'

As is the case in society generally, this surgeon seems to be operating from the presumption of heterosexuality – he presumes his patients are heterosexual. It is possible, of course, that if Theresa had been more explicit about her lesbian relationship, the surgeon might have recognized it. But this should not have to be her job: if the physician operated with the assumption that a woman might be lesbian, or bisexual, or heterosexual (if he rid himself of his pink and blue coloured glasses), he might have been able to meet her half way, to pick up on her coded language. More generally, of course, a patient should expect to have her requests respected – if she wants her roommate to get the information first, that should happen, without questions or awkwardness.

The failure to consider the possibility that a woman might be a lesbian is also reflected in standard ways of addressing patients, and standard intake questions. **"It's so annoying!" says Lou. "People just assume if you're an older woman, you're a 'Mrs.'"** A question about 'your husband', which on the surface may seem benign, reflects the power and pervasiveness of heterosexism. Sarah describes this:

The first person I encountered at the oncology clinic asked me where my husband was. I recall him taking down my health card number, you know, and I

just thought, wow, not only am I babbling incoherently because of the fear I was feeling from coming into this place for the first time, but I was also taken aback because I was confronted with the heterosexuality of the environment.

As Sarah says, heterosexist assumptions can have a significant effect, especially when the power of heterosexism links up with the power of a medical institution.

Lesbian identity, needs, culture and social context not taken into account

There are various ways that being a lesbian ‘matters’ in relation to a cancer diagnosis, as we discuss in other sections of this report. Yet in cancer care, lesbian identity tended not to be taken into account in even the most basic of ways. The ‘pee in a cup’ scenario – health professionals asking lesbians for urine samples to determine whether or not they are pregnant – became famous in this research; we thought about calling this report, Refusing to Pee in the Cup: Lesbians and Cancer Care.

Of course, lesbians can get pregnant. For women who partner exclusively with women, however, becoming pregnant is not something that happens without our knowledge. And yet:

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’ [Sarah]

It may be difficult for heterosexual people to imagine how wearing it is, to have to explain time and time again that you could not possibly be pregnant, and, worse, not to be believed, even when you come out as a lesbian. Sarah described “**fighting the system on stupid little issues like, ‘could you be pregnant?’**” as “**more difficult than anything.**”

I often want to walk away sometimes when I have those battles... it takes energy to have to explain time and time again that I am a lesbian. And it’s energy that I don’t have to spare. [Sarah]

Similar ‘battles’ unfold when lesbians are asked about issues that are only relevant for women who partner with men – asked, for instance, if they have concerns about not being able to get pregnant, with the assumption that the ‘getting pregnant’ happens with a male partner. Of course, the flip side of this is that health professionals, learning a woman is a lesbian, sometimes assume she is not interested in being pregnant; in fact, in this research, two of the lesbians we interviewed discovered their cancers as they were trying to become pregnant.

The examples above show us how health care professionals fail to take lesbian identity into account in a very basic way: they fail to accommodate the fact that women who identify as lesbian often do not have sex with men, and rarely have husbands.

The lesbians we interviewed had to deal with heterosexism assumptions – and assumptions about issues beyond sexuality. Certain kinds of disabilities, for instance, went unaddressed. Lillian has a hearing impairment which **‘nobody noticed... They didn’t give me my hearing aid, they had my hearing aid in a bag somewhere’**.

Lillian also described her conversation with ‘the boobdude’, the surgeon who did her breast reconstruction. For Lillian, sports are “a huge part” of mental health. Yet when she asked how soon after her surgery she could play softball and hockey,

the boobdude just looked at me funny... 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?

The images of women in rehabilitation pamphlets, and the failure to anticipate the range of ways women will want to be physically active after surgery, show us how lesbian realities can be missing from cancer care.

The *Look Good, Feel Better* Program drew critical commentary from several of the women who took part in this research. LGFB was created from the concept that if a woman with cancer can be helped to look good, her improved self-esteem will help her to approach her disease and treatment with greater confidence. The program was founded and developed by the Cosmetic, Toiletry, and Fragrance Association (CTFA) Foundation, a charitable organization established by CTFA, the trade association that represents the cosmetics industry.

Several research participants suggested that LGFB is a program organized around particular ideas about what it means to ‘look good’ as a woman, and particular ideas about who women ‘look good’ for – ideas that do not fit well for many heterosexual women, and fit especially poorly for lesbians. Here are just a few of the comments women made about the program:

They provide these lovely little kits and apparently you get a nice scarf and you get makeup and they come and visit and they probably bring chicken soup and I’m sure it’s lovely but what I discovered was, a lot of it was about your physical appearance to others in a heterosexual framework. You know, makeup, haircut, looking nice in clothes, like, what do you do about swimsuits, how to make sure your man is accommodated, you know, looking good for men in a very specifically sort of heterosexual way. [Lillian]

My oncologist and I looked at this advertisement, and I said, ‘oh, for God’s sake, I’ve never worn makeup in my life, I’m not about to start now!’ [laughter]. She said, I don’t know what to say to that. I said, ‘well, it’s just not part of my

culture, part of my orientation...’ I think it’s a great program. But it reinforces to a high degree lesbian invisibility. [Marcia]

Both Lillian and Marcia note that the LGFB program has value. And yet, as Marcia says, it is not a program in which lesbians or lesbian ‘culture’ are visible or taken into account. Lillian developed a list of all the things that she would imagine being in a “lesbian cancer kit” – a lesbian alternative to *Look Good, Feel Better*. Her ideas are included in the Ideas for Change section in this report.

The encounters with health professionals, cancer systems and cancer programs described here reveal how cancer care and support is organized around the assumption of heterosexuality and a certain image of heterosexual femininity. Cancer care is not organized to be welcoming and comfortable for lesbians.

Our research also showed that care and support is not organized to be welcoming and comfortable to poor women. Glenda describes what it was like to walk into a community cancer agency that is quite luxuriously furnished and decorated:

For someone who lives on welfare in housing, it’s like, **‘oh, my God’ and I know it’s all donations but... I was really uncomfortable, really, really uncomfortable.**

Health professionals’ words and action also revealed certain kinds of middle-class assumptions – assumptions about income, work, and access to resources. So, for instance, Glenda describes this conversation with her physician:

He said to me, “how you doing, you been travelling around a lot, you been travelling and seeing the world, I hope?” and I thought ‘what’s that got to do with my appointment here’ and, you know, “I guess you’re back to work” and all this...

At the time that she had this conversation, Glenda was living on \$314 a month. Just as health professionals fail to take lesbian identity into account, so too do they fail to take class differences between themselves and their patients into account – ‘middle class glasses’ operate in the same way as ‘pink and blue coloured glasses’.

These stories alert us to differences between lesbians in their experiences of cancer care and support. Lesbians who have the privilege of good incomes and professional jobs may find cancer care and support to be less alienating than do lesbians who are poor.

We learned a great deal in this research from women’s comments about what made them uncomfortable, and what made them want to walk away. Cancer care and support is welcoming and comfortable, it seems, for middle class and heterosexual women. This does not mean that all middle class or heterosexual women necessarily feel well supported by services

when they have cancer. It means though, that lesbians and poor women (and, especially, lesbians who are poor) are very rarely ‘met’ in their identities, cultures and particular needs by cancer care professionals or cancer community service providers.

Lesbian identity and social context ignored and dismissed

In the section above we describe the ways that cancer care and support is organized around heterosexuality and class privilege, and how this leads lesbians to feel (and be) alone and invisible. The ways cancer care is organized around heterosexuality can also compromise health care, as we discuss here.

In recounting her experiences with the health care system, Sarah described an incident in which an aspect of her lesbian identity – the profound ways her breasts matter to her – was completely, and painfully, dismissed. Sarah had gone into a meeting with her physician with a great deal of apprehension, but very clear about what she wanted:

What I really wanted to have was a conversation about, okay, I’m a lesbian woman and my breasts are my core sensuality piece of my body... and I’m a health care person so I like stats, I like information, so talk to that part of my brain too, but you have to talk to my soul and my spirit as well, as a woman and as a lesbian woman in particular.

She prepared carefully. When they met the physician was late and rushed which, as Sarah says **“didn’t help the atmosphere.”** Drawing on her courage, she raised the question of having both of her breasts removed:

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.

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.”**

Other research shows us that lesbians sometimes delay *seeking* care for health problems, because of worries about homophobia and heterosexism. Here we see that heterosexism can profoundly affect a woman’s capacity to *continue* with care. When the care is care for cancer, heterosexism can become a matter of life and death.

Prior to this meeting with the doctor, Sarah had been well supported by a ‘nurse navigator’, a nurse with a role of assisting women to figure out and get what they need from the cancer care system. Yet as a result of the physician’s actions, Sarah’s connection with this important support person has been lost:

I said, ‘I will call you when I’m ready’, I haven’t called her, I couldn’t call her. I know she has left messages on my phone, but I can’t call her, because I’m so angry, and I’m so lost.

In another instance, a genetic counsellor wanted permission to contact Sarah’s older sister for testing, to see if she had the genetic mutation associated with hereditary breast cancer.

I said, ‘you can’t, because there’s too much other stuff in the way’ and, I said, ‘I’m leaving it there’ and she wouldn’t hold back. She kept pressing the point about the need to test my sister and I finally broke down and said, ‘I’m lesbian and my RC [Roman Catholic] family makes it difficult for me to be that person’ you know... She didn’t get it, she fought me on that one for a half hour and I finally stood up and said, ‘I’m leaving’ and I walked out. [Sarah]

Here the counsellor essentially forces Sarah to come out, and then entirely fails to appreciate (or even accept Sarah’s account of) how being a lesbian facing a homophobic family matters in this situation. Even further, she continues to pressure Sarah despite her clearly stated decision. The reality of the social context in which lesbians live was central to a cancer care situation, and yet this reality was dismissed. Clearly, the care – and the woman – suffered for it.

Lesbians targeted, and denied standard care

Women who took part in this research recounted instances where they were targeted as lesbians by health professionals and community workers, and others instances in which health professionals’ discomfort meant that they did not receive standard care.

Several women spoke of being treated differently – not as well as other patients – by health professionals. Paddy, for instance, described one nurse being very rough with her, despite the nurse’s knowledge of Paddy’s back pain. Paddy was sure that homophobia played a role, **“because I could watch her with other patients and she was very gentle with them.”**

Paddy said that this experience **“makes me aware again that there’s a price for being gay. And sometimes you have to pay it.”**

More generally, Theresa said,

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.

Theresa also 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 saying, 'you're a nice looking girl, you can find someone ...' So, it was ... it was very hard, and they would pull faces, and all different kinds of stuff.

Here, nurses both resist and reject lesbian identity, their actions contradicting any notion of patient-centred care. Laura had a parallel experience in a support group when the study that formed the basis of this research was being advertised. When the study was announced in the group,

One of the members said to me, **'hey, maybe we should join this group,' and it was your project... And then she started laughing ... well I almost turned around to her and said, 'yeah, maybe I should, because I'm the only lesbian in this group.'**

Interviewer: She was really joking about it.

Yes.

A few women who participated in this study described blatant examples of homophobia. 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 anaesthetic; her lumpectomy was performed with only a local anaesthetic. 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 and he told me that ... I was a dyke, therefore I should be able to tolerate pain.

When Theresa came out, health professionals assumed she either had, or was at high risk for, AIDS.

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

[The doctors] would say, so, do you have AIDS, have you been tested for AIDS? And I go, 'why would I be, like...'

Interviewer: More so than any other person ...

Yeah. But that was like ... for me it was like a standard question. Or he would come in and see the next patient beside me. And I would just, you know, I would shout at him... 'You forgot to ask all your questions,' right? [Theresa]

Both Lillian and Kate described experiences where they attempted to get medical attention for the physical changes that were eventually diagnosed as cancer.

First of all [the physician] paused at my chart where the word lesbian was written and you could see her eyes, read, read, read, eek, sort of stopping, contemplating it... So then she 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.

Eventually this physician did refer Lillian for a mammogram. What stands out for Lillian, however, was how this physician “fixated” on the word lesbian, **“and she was all like, oh what do I do, what do I do?”**

Kate described her interaction with the physician she saw to talk about unusual vaginal bleeding. The physician pulled herself back in her chair in the middle of the Pap test, and asked 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.

And she said, 'well, I think there's something wrong. I can either finish this test, or I can refer you to an obs and gynie person and you can see them.' So, 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 was ... 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 asked them about their relationships with men. She didn't know where to go from there. I was very uncomfortable with her proceeding because she seemed like she didn't quite know what she was doing.

In these stories, health professionals demonstrate anxiety and lack of competence in relation to lesbian health. Heterosexism unfolds in this situation in at least two ways. Firstly, lesbians trying to get care are treated as if they are somehow contagious, and so outside a framework of ‘normal’ that physicians are unable to proceed in a professional way (in fact, both physicians seemed to be trying to leave the room – either standing far away, or ‘disappearing’ into anxiety). 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.

In thinking about what is unique about being a lesbian with cancer, Mary Lou spoke about the fear that cancer generates, and how important it was for her to have a medical team that was not going to be unsettled by fear – of cancer, or of her. **“If my lesbianism is going to provoke fear on their part, that’s at my expense,” she said.**

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 seen by someone other than their regular family physicians; both felt confident that things would have unfolded quite differently if their regular doctors – whom they had ‘screened’ and knew to be lesbian positive – had been available.

The poor care that lesbians received was sometimes linked to their economic class as well as their identity as lesbians. Glenda, for instance, spoke about the fact that her physician knew she was on welfare.

That’s probably why I get a little bit of... like this is my feeling, ‘you’re not so important.’ I still get that from him.

Paddy said almost the same thing: “if you don’t have money, lots of money that you can throw around, they pretty much look at you like you’re a bug.”

Glenda also told us about situations in which she was denied services from cancer and health care agencies. At home with a drain after her surgery, Glenda needed nursing care.

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?

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.

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 families and partnerships: outside the cancer care box?

Some of the women who took part in this study described instances in which their families were treated as less real and less legitimate than nuclear families.

Kate's partner and two friends went with her when she had to meet with a physician to decide on treatment. She describes getting the feeling that health professionals **"didn't know what to do with me... they didn't know how to welcome this group of people to the room that didn't fit into a traditional kind of family."**

Kate's two children were nine and twelve when she was diagnosed. The fact that she's not their biological parent seemed to make health professionals uncomfortable; Kate felt they did not understand her need to talk about her children and what they were going through.

Kate describes feeling that health professionals reacted to her family with **"a fair bit of, 'why do we need these people here?'"** Sarah spoke about a similar feeling when lesbian friends accompanied her to consultations: **"There's always a barrier there in terms of explaining who I am and that this is the support that I have and this is my way of dealing things."**

As noted above, several of the women interviewed in this research perceived 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.

Some women spoke about feeling that health professionals revealed a lack of empathy with lesbian partnerships and partners. Liz's partner had died of breast cancer a few years before she herself was diagnosed. At her first appointment at the cancer clinic, she was overcome with grief for her partner. Health professionals assumed that she was anticipating her own death, and were quick to assure her that her situation was different than her partner's had been. While she appreciated their efforts to support her, Liz said they entirely misunderstood her tears, and that their misunderstanding was related in part to heterosexism.

If I had been bringing my husband up for the best part of two years and had then come back a couple of years later ... I just have the feeling that they would have had a different understanding.

Kate, reflecting on how health professionals had related to her and her partner, described having felt that her partner's feelings, needs and experience were given "no consideration whatsoever." She notes that she has nothing to compare that to – she cannot be certain that a male spouse would have been treated differently. Yet as she says,

I suspect that generally there's more deference given to somebody's husband or male spouse in these situations, especially with a cancer that quite clearly has sexual implications.

A few of the women we interviewed also described actions on the part of health professionals that they felt pretty sure that heterosexual people or couples do not experience.

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 in her care, this physician began to ask Gerrie about her partner.

Theresa described health professionals' failures to include her partner:

If I was sitting in the waiting room they wouldn't say, 'both of you come in.' They would say, Theresa, I'm ready for you. Or 'she can just wait there.' So ... it made it very hard.

One of Theresa's doctors refused to have her partner involved in the consultation at all:

[The doctor] said, well, I really wouldn't feel comfortable, in talking to [your partner]. So I said, 'well at least you're honest, you got that much.' He just said, 'OK, then I'll explain it to you.' So I said, 'OK, explain ahead.' I go, 'you know this is really ridiculous.'

Lesbians who spoke with us also described not having certain 'privileges' that heterosexual couples and traditional families had. Theresa described what it was like when visiting hours came to an end, for her and the woman in the bed next to her. A nurse told the people around the other patient, **'oh, if it's family they can stay a little bit longer.'** **And yet: [my partner] would be there, and [the nurse would] say, 'OK, you have to leave now, right?'**

Theresa spoke back to the nurse, and ran into the 'don't get it' wall:

I'd say, well, she's my partner, right? And people go, 'oh, in your business?' [pause] [emphatically] 'She's my lover! Don't you get it?' ... So you know, it was/ every day it was addressed, that you were different. [Theresa]

A series of conflicts with health professionals 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 the room. The health professionals' 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.'**

Theresa described her attempts to convince the nurse to let her partner in:

I would say to the nurse... 'there, see, out there is my partner.' I said, 'this wouldn't happen if I was a straight person, right,' and she says, 'oh well, you know, there is the rules in the hospital,' and I said ... 'they're wrong. And it's wrong what you're doing.'

When the nurse continued to refuse to let her partner in, Theresa attempted to address the issue at a health system level:

I called the ombudsman ... [participant's partner] even called the ombudsman, right, and ... she never got back to us. And [my partner]'s like, should I write a letter? No, forget it. It ... it's more energy It's the energy (and) it's energy you don't have. Because (that's) how you feel, you know, you feel like they suck away your power. The little bit that you have! [Theresa]

Here, the heterosexist definition of family excludes Theresa's partner from the room; somehow, only a man and a woman make a family. Then the nurse declines any personal responsibility for the decision by referring to hospital '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, also fails to respond.

It is telling that Theresa speaks about the power being sucked out of her. 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 worn down, is also clear. We discuss the effects of heterosexism in cancer care on lesbians with cancer in more detail below.

Heterosexism and patient self-advocacy

This research showed us how heterosexism can link up with health professional-patient dynamics, and with the effects of cancer treatment, to compromise lesbians' capacities to advocate for themselves as cancer patients.

We noted above Kate's feeling that health professionals reacted to her family with "a fair bit of, **'why do we need these people here?'** In this context she also spoke about the other kinds of questions and judgements she heard and felt from health professionals:

“usual things about, you know, ‘why are you reading the journals, why are you looking on the Internet, you’re getting too much information.’ Which isn’t so much related to the lesbian issue, but ... just a lot of resistance.

Heterosexist frameworks render lesbian families ‘outside the box’, outside the boundaries of family; Kate’s family is thus perceived as a problem, or at least a challenge, to health professionals. Kate points to the ways that the ‘challenge’ of her family can pile on top of other challenges she offers to health professionals, like her self-education strategies. In this way, central parts of who she is and how she needs to deal with her illness come together as problems that health professionals do not understand, or resist. Jessica said a similar thing: she had asked to change doctors, and got a **“reputation for being a difficult patient.”** Being out as a lesbian **“made me extra different when I was already different.”**

It may be that lesbians with cancer sometimes get the message that they are asking for ‘too much’: health professionals might accommodate a lesbian ‘difference,’ or self-advocacy in health care, but not both. It is as if one can’t be anything else, if one is a lesbian; one can’t expect more.

Combined with the affects of cancer treatment, heterosexism can affect lesbians’ capacities to advocate for themselves as cancer patients. Several participants spoke about how the strain and fatigue of treatment meant they felt unable to ‘talk back’ to health professionals. Paddy, for instance, spoke about being a person who **“tends to say stuff”** when she’s confronted by homophobia. But in the hospital, **“I was feeling so weak from the radiation, and just so miserable that... I couldn’t be bothered with fighting with them.”**

Theresa said this:

After a while, you just became ... you know, you just say nothing. Because at the beginning you’re all gung ho, hoping that it’s going to be addressed, and then you speak to them, ‘well, you really need to address this with the nurses on the floor.’ ‘Yeah yeah yeah,’ you know... [eventually] you just let it go.

The effects of cancer treatment, entwined with the effects of persistent heterosexism – and the unresponsiveness of health systems – can lead to silence about the need for change in cancer care and support services.

It was also the case that at least for some women, silence led to more silence: silence and hiding around being a lesbian was linked with silence and hiding as a patient. Glenda said this about her interactions with health professionals at the hospital

At that time, I guess the fear about them finding out if I was lesbian, I just didn’t want to speak too much about it. I basically gave them all the power, they knew what they were doing with my treatment, so I didn’t ask too many questions.

For lesbians with cancer, not being able to safely claim a lesbian identity may mean that efforts to claim other kinds of rights – the right to participate in care decisions, for instance – are also compromised.

Theresa talked about how lesbians' difficulties advocating for themselves is linked to a whole system in which there is no recognition of lesbians, no visibility for lesbians:

You don't have the supports, the ... you know, you don't have the literature ... You don't have the places to go... I mean, sometimes I think, well, they just make you think less of yourself so you don't scream that hard.

And Kate points out that in speaking with health professionals, many of us feel "one down." This sense of being less powerful is linked for some lesbians with experiences of oppression beyond heterosexism:

My working-class life it follows me and is with me and is part of who I am. It's always there, right, it's always a kind of like, 'do I deserve to be here?'

We can see how the feeling of being pushed to 'think less of yourself' that comes with being invisible as a lesbian in cancer care can work like classism does, to push women to ask 'do I deserve to be here?'

These are crucial issues for lesbians with cancer, and the lesbian community more generally. Glenda, Kate and Theresa show us here how heterosexism and classism can link up with other aspects of being a cancer patient to compromise lesbians' capacity to advocate for care and support. Heterosexism means that lesbians with cancer do not get care services to which they are entitled. The ongoing encounter with heterosexism as a cancer patient can push lesbians to feel less entitled to care, and can make self-advocacy especially difficult.

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 as 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, and the only lesbian, and she wasn't sure at all that she wanted to go. (Being younger than most women with cancer was an experience a few of the women we interviewed

shared – age was an identity that 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:

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 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 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. [Jessica]

Here, Jessica makes the point that joining a support group, and encountering homophobia, is almost worse than not being part of the group at all. She speaks of a longing for connection with other women going through cancer, and about how the breaking of that connection by homophobia virtually wipes the benefits of the group.

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.

And, in fact, Glenda, Theresa, Paddy and Jacquie reported experiences that exactly confirmed Jessica's worries. As Glenda says, **I went because I didn't want to completely isolate myself this time. And yet, I didn't feel I could be myself... I sat on the couch thinking 'I can't talk about myself to these people.'** Jacquie said:

I've always found it a problem when you can't talk about your partner the way that heterosexuals can talk about their husbands, that really bugs me. And [in the support group] I just didn't feel comfortable enough... most of the time I'm out, I'm quite OK... but that was one place I didn't feel comfortable.

Speaking about her reluctance to come out in this group, Jacquie also referred to the wider context of the very conservative community she was living in at the time.

Theresa joined a support group at a hospital. She describes telling the group that she had ovarian as well as breast cancer, and the room going silent. She then told them the name of her main supporter, 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, and 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.' And it was like ... then I was even more isolated from the group, right, because I confirmed it for them.

Theresa had gone to the group because she wanted connection; she went in an effort to reduce her sense of being alone with her diagnosis. Yet once she came out, she was even more isolated than she had been before she arrived at the group. Paddy said she **"closed down, pretty much"** after experiencing other women's reactions to her coming out: **I said to the group, 'I'm a dyke...' And this one woman, the look on her face was sheer disgust.**

This was a theme in our research – lesbians joining support groups or programs in an effort to reduce their isolation, and then experiencing an even more profound sense of isolation once they were there. And as Glenda explains, the more meaningful and important a support services comes to be, the more isolated lesbians can become:

I went off to [cancer agency] and I did the one support group but then you're supposed to graduate to the other group and I just ah, it was too much to not be who I was.

The significance that the support group was coming to have to Glenda, and the knowledge that the next group could involve even more intimacy, meant that it became impossible to participate and not be out as a lesbian. So she stopped going.

Kate also eventually stopped going to the support group she joined. For the time she was there, she felt she was **'trying to glean what I could out of a very difficult situation ... as opposed to feeling I was really part of it.'**

The feeling of being 'not quite part of it,' not quite 'there' in the group, was a common one. Glenda also pointed out one of the familiar consequences for lesbians of heterosexism – being called to explain lesbians' lives to heterosexual people.

[The other women in the support group said] **"Well, 'why the flag?' like I would wear my hat, 'well why do you have to have this parade?" And that's not why I was there, I was there just to get support just like you're there to get support... that's what happened in a lot of the support groups.**

Anticipating similar experiences, some of the women we interviewed never even attempted to access existing services:

I never joined a breast cancer support group because ... you know, it's like, oh, cripes, I don't want to deal with the closet thing. It's too ... it's like, it's tiring and

it's ... So, I did not connect with ... the cancer support services, because of that. That was a barrier for me. And not because I was terrified or because whatever, but it was like ... I don't want to be a minority of one, thanks. [Marcia]

It became clear in this research that lesbians can be excluded in many different ways. When Theresa's nurse told her that her partner could not come into the room, the nurse excluded her in a clear and obvious way. As Marcia and Glenda describe it here, exclusion is more quietly achieved. Yet the result is exactly the same: the service is essentially not available. The absence of lesbian positive support services often means no support services for lesbians.

Some support programs failed in more material ways to enable lesbians to 'be there' as part of a group or service. At a cancer agency, Glenda asked about the agency's policy about providing transit tokens for women to get to services, and was told that no tokens were available. Services that require money to be part of them are not accessible to poor lesbians:

I didn't get what I went there for... What I went there for was to get what everybody else got and that was the coping with cancer and all the techniques but I didn't have the money to pay for the stuff. I didn't have the money to pay for the tapes, I didn't have the money to pay for the videos, \$150 only covers your time there for the weeks. But I didn't have the money to pay for all of that, and they told me, well, you can pay so much a month, well I can't pay so much a month. So that was that.

Differences between lesbians become apparent in Glenda's comment here – lesbians with money can at least afford to attend services that are sub-standard because of heterosexism; lesbians without financial resources cannot even make this choice.

It was of course not always the case that women felt unsupported by mainstream services. One woman we interviewed was in fact facilitating a breast cancer support group, though she was not out to the group. **"It's OK, because it's like ... it was part of my decision that I need to give back ... because it's kind of like a circle and you take out of the breast cancer resources and then you need to give back, and that feels OK to give back. [Marcia]**

Sherry spoke with a great deal of affection and admiration for the women who are part of the breast cancer support group she attends in a mid-sized Ontario town. The women, she says, are **"absolutely fabulous, I love them, they're dolls, each and every one of them... They're inspirational."** At the same time she's aware of differences between herself and the other women:

I'm removed from the group twice, being a lesbian and the choices I've made [the choices not to have chemotherapy or radiation]. Maybe that's my feeling, maybe it's not true – I don't feel unaccepted from the women or anything but certainly our experiences are completely different. Maybe not so much with our

families or spouses or whatever but, you know, like, I leave the meetings early to go play hockey. Um, you know, I mean, it's glaring, kind of the differences between us, you know, and I show up in my track slacks and they've got their frilly blouses. I do paint my nails but I don't care, go right ahead, I'm more than willing to start my religion and my own group of lesbians that paint their nails... You know, we're all different, you can't put us into boxes, even lesbians.

Here Sherry speculates about how much her differences from the rest of the women really matter. As she says, she does not feel unaccepted by the women, and takes a certain satisfaction in attending the group "to be a different story":

But, yeah, I mean, I think I would have, um, emotionally felt more surrounded, if I had a group of lesbians to talk to, you know, because you just forget all the other stuff, you know what I mean and you just sort of focus in, you know, what I mean? Like you don't need to explain... you just skip all that and get right to the meat and potatoes, you know what I mean?

In a few instances, research participants had made deliberate efforts to get their needs as lesbians met, in situations where this was not happening. 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 who took part in this research. With this comment, efforts to provide care and support that includes 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 also 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"**

I: 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.

‘Not our mandate’ comments reveal how services compartmentalize women’s lives – as is so clear in Glenda’s experience, where the social worker was only willing to talk with her about her cancer, even though her experience of cancer was intimately connected with her experience as a poor woman. For so many women, an experience with cancer cannot be separated out from other oppressive realities, and other identities. These realities and identities must be part of a service or program for it to be genuinely accessible for all women with cancer.

The important message for organizers of support programs and groups is that support is only possible and real for lesbians with cancer if they and their experiences and realities are, as Theresa says, integrated. Support group facilitators play a critical role here, helping to determine who will feel and be welcomed in the group. Yet the more significant decisions about accessibility are made higher up in agencies. Boards of Directors and senior management of health and community services determine whether a service will serve only heterosexual women and women with money, or whether it will genuinely serve all women.

The fallout from heterosexism

It was clear in this research that the ongoing lack of ‘getting it’, the lack of recognition of lesbians and lesbian relationships, alongside more obvious homophobia, can have a profound effect on lesbians with cancer – effects on relationships, health, and sense of self.

At one point in our interview with her, Theresa described her feelings about cancer and cancer care this way:

You know, you’re just so sick and beaten up with treatment, surgery, and everything, your mind / and then you’re thinking, am I going to lose my partner because of this? [Theresa]

When Theresa asks here, ‘**am I going to lose my partner because of this?**’ the ‘this’ she refers to is her cancer – she worried that she would lose her partner because of the seriousness of her diagnosis. Yet we can see from this report that ‘this’ may also be her interactions with cancer care professionals. It is possible that the lack of recognition of her partnership – and,

further, the active discounting of it – served to heighten Theresa’s worries about her relationship dissolving. Certainly the actions of cancer care professionals did nothing to affirm the relationship between Theresa and her partner during a very difficult time.

Sarah also spoke about how it feels to encounter heterosexism as a lesbian with cancer. She used the metaphor of a reservoir filled with liquid, and the liquid represented the energy she has to cope with and respond to what she encounters in her life.

It’s like I’m portioning out how much I can give to this whole process, so when I have to go into the hospital and explain why my husband’s not here, one more time, because I don’t have a husband and I’m a lesbian, it’s like they’ve just drawn off a little bit more liquid out of that almost depleted reservoir. And if I have to explain one more time that there’s no possible way that I could be pregnant... because I’m a lesbian woman, I’m in a committed relationship, I shouldn’t have to say anything more. And then, because they don’t honour my situation, I have medical personnel who keep insisting ‘well just in case you have to pee in a cup’. The emotional energy that that kind of phrase takes out on me, it’s almost like you’re being punched in the gut or you’re getting slapped across the face or you’re basically being denied your own truth. And that is emotionally depleting, and it’s insulting and it’s like, ‘I only have so much energy to give to this process, don’t take away some of the little bits that I have left.’ And with the doctor, when he stepped back into the room and said, ‘well, you know if you and your husband need to talk about re-constructive breast surgery after the mastectomy, let me know’ – it’s like he might as well have taken an axe and just cracked open that last little bit of reservoir that I had left.

Sarah’s words capture a theme in this research. Dealing with cancer and cancer treatment is an energy-draining process – and so is dealing with heterosexism. Sarah’s point here is that confronting heterosexism in cancer care and support services is one part of the ongoing, energy-draining encounter with heterosexism that lesbians experience. It takes energy to come out over and over, and it takes energy to hide; it takes energy to explain what it means to be a lesbian with cancer, and to stand up to, and to endure, heterosexism.

It was apparent from this research that ongoing demands placed on lesbians with cancer in a heterosexist care system can damage lesbians’ health:

After that appointment it was like my last reservoir got drained out and for the next two months, I found that didn’t tolerate the medication regime that I am on, my diet really lacked a lot, I lost a lot of ground, I lost a lot of health ground too. It really took the wind out of my sails... [Sarah]

Theresa makes a similar point:

It's permanently part of your world to be defining [yourself] for health care people... And then after a while you even lose that much respect for yourself.

Sarah talks about the effects on her physical health, of dealing with heterosexism; Theresa speaks about the damage to her emotional health and her sense of self. These, then, are among the key consequences of heterosexism, for lesbians with cancer: physical and emotional depletion, at a time when they most need their physical and emotional strength.

Getting good care, and 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. Laura talked about how she figured out when she would come out, and when she would not:

I made decisions based on their ... I guess their ... their openness to gay life. I would have to gauge them first before I felt comfortable to do so. If they made derogatory remarks in any way I would just not bother.

Another woman we interviewed described watching very carefully for indications of homophobia as health professionals asked about next of kin and her relationship to next of kin, when she said a woman's name and 'partner.'

Every time I did it, I sort of watched them, I thought, 'someone's gonna...' No, they were all good, nobody turned a hair, I was very pleased. [Constance]

Maureen 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]

Other woman spoke about the value to them of making their sexual orientation apparent early on in the process. Jacquie, for instance, spoke about indicating she was a lesbian in the 'marital status' section of the forms she had to fill out, **"just so that they knew, so we didn't have to play charades."** Mary Lou said:

Well, we're just very upfront, this is my partner, you're the surgeon, if you need to call somebody, it's that person. And if we sense discomfort on their part, we'll ask them, "do you have a problem with that?" And if they say, "yes" we're on to another.

As Maureen, Mary Lou 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.

We have a physician who's very good and she's very good about saying, 'I'm going to refer you to so and so and if you have any concerns let me know', she said, 'but I think, you know, there's no reason to be concerned'.

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.

For instance, Jessica came out to her art therapy group, because for her, being out meant:

I could be myself, they could be their selves and there was a lot of art going on and storytelling and, it was a very meaningful experience.

Along similar lines, Sarah made a point of coming out and explaining what being a lesbian might mean in terms of her cancer care, to some of her health professionals.

I said, 'it's going to be hard for me to walk into a teaching hospital where most of the oncologists are males and specialists and most of the people intern-wise are males'. I said, 'that's going to be hard for me because I deal better with women.'

Sarah also explained to a nurse what her breasts meant to her as a lesbian – and, thus, explained just how difficult it was 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 health 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 cancer care. 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.”** Glenda said:

The only place I’ve never been out is in the hospitals. I had fear, I don’t know, I had such fear going into that surgery room. It’s crazy how your thinking gets distorted and I thought, ‘maybe they’re going to think I’m a lesbian and I’m better off..., maybe I’m not going to come through this, maybe I won’t come out of this room.’

Glenda talks here about her thinking being distorted, and of course illness and strain can cause us to feel especially threatened. Yet as is clear in this report, lesbians have had experiences with cancer care that support Glenda’s worries about different, and worse, treatment for lesbians.

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 Glenda and Laura, 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.

Because being out and remaining closeted can both be strategies to get the best possible care, research participants had different feelings about how information about lesbian identity should be handled by health professionals.

Some women were frustrated that awareness of their lesbian identity was rarely integrated into the health system; they resented having to come out to each new health professionals they met. These women wanted health professionals to pass on the knowledge of their lesbian identity to others on the health care team. Other women, perceiving the risk of being outed to unfamiliar health professionals, worried about this. As Jessica said, **“you don’t know how many**

other people on the health care team they'll share that information with and what their reactions will be in terms of your care."

The key here, of course, is for health professionals to provide lesbians with options about how information about their identity can be handled – and to work to make the care system as safe as possible for lesbians to be out.

Looking for lesbian health professionals

Some women who took part in this research had sought out, and found, lesbian family physicians who were immensely supportive to them over the course of their cancer experiences.

My GP called me into the office and gave me shit. She's a dyke, and she said, [laughs] 'you get your ass down to [hospital] – there's an appointment made for you, now you go to that appointment. I've really been worried about you ...' Her compassion and her empathy and her ... her just straightforward no-nonsense approach to all of this was just really helpful.' [Paddy]

Lesbian health professionals were sometimes important simply because they were lesbians, and there. Pauline, for instance, said it was 'just nice to know,' that there was another lesbian in the hospital system, **"I just felt ... reassured that there was at least one."** At the same time, Pauline made a point of noting that a palliative care specialist helped her profoundly **"not because [she was] a lesbian, but because of [her] humanity" – because of her warmth, and the way she would pull up a chair and sit at eye level and talk. "It's the difference between coldness and distance, and warmth and closeness,"** she explained.

Some women we interviewed believed that lesbian health professionals would better understand what cancer meant to them:

The male doctor's standing there talking to me about re-constructive surgery... I don't know if he can visualize what it means, you know, what it really truly means. If a lesbian doctor was sitting there talking to me about re-constructive breast surgery and that component, I would believe her. I could possibly believe her, you know. [Sarah]

I don't think a straight woman could possibly understand what it means for a dyke to be told that you have breast cancer. You know ... our bodies are such a part and parcel of ... all that we are and all that we do, and ... certainly our sexuality. [Paddy]

In keeping with the idea that lesbian health professionals would better understand what cancer means to lesbians, heterosexual health professionals were sometimes seen as effective and

empathic *despite* their heterosexuality: ‘she was straight but she was really good’ was a phrase used by some participants.

In one instance, a woman we interviewed spoke of being pleasantly surprised that her nurse was a lesbian. Yet the nurse did not come out to her, and Maureen was **“a little disappointed”** by that. Maureen is a health professional herself and believes in maintaining boundaries with patients. At the same time,

When I said, ‘I’m so glad that you’re our nurse, this is really helpful, emotionally so,’ it would have been helpful [for her to come out], and also because my children are there too, and they’ve had to be in the closet as we all know, and it’s just helpful for the family. I think it would have been more helpful for them to have her say, ‘gee, how are you guys doing?’ To share a bit more on a personal level. [Maureen]

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.’

Several women also spoke about having advocates with them to protect against poor health care in a general way. Maureen spoke about this issue in her interview, not specifically in relation to her cancer diagnosis:

I had a hysterectomy and I was at [hospital] and you know, I just wanted to get out of there, I mean just with the cutbacks in staff. It had nothing to do with the staff, the staff are great... [but] there are things that can go wrong and do go wrong and yeah, so I wouldn’t have felt comfortable being alone. [Maureen]

It may be that with current conditions in the health system, with fewer nurses and more acutely ill patients, there is an increased sense that we need advocates with us simply to ensure that nothing goes wrong with our health care. This may create particular anxiety for some lesbians, who risk being identified as lesbians when it becomes clear that their supporters and advocates

are other women. This is one way, then, that cutbacks in the health system have specific and difficult effects on lesbians with cancer.

As noted in other sections of this report, 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:

When I was in [the hospital] I had fierce nasty, lesbian friends to say, ‘no, she can’t have that, no she can’t’ and when they said, ‘who are you?’ they lied and said, ‘we’re her sisters, all of us’ [Lillian].

Some days I’d say it was my sister and they’d be like ‘OK ... but yesterday you told me that was your roommate!’ And I go, ‘ah, today she’s my sister.’ [laughs] ‘Feeling a little closer to her today.’ [laughter] [Theresa]

Pauline also spoke about the confusion that health professionals must have felt at the parade of women and men (many from her church, a faith community that welcomes and affirms gays and lesbians) who appeared in her hospital room, taking careful notes about what each health professional said, providing support and advocacy twenty-four hours a day amidst the rainbow flags. **“I’m sure they didn’t know who or what I was, you know? Except that... definitely there was something queer going on!”**

It’s clear that a history of homophobia shapes lesbians’ experiences with health care and community services. Lesbians with cancer work hard to avoid homophobia, and take considerable responsibility for arranging lesbian-positive care. As we said at the beginning of this report, however, responsibility for quality health and social care should not lie with lesbians themselves.

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.

More about being out, and not being out, in cancer care

Above we talk about how being out, and remaining closeted, can both be strategies for achieving the best possible care. The women we interviewed spoke about other aspects of being out and being closeted that mattered in terms of cancer care.

For some women, the seriousness of a cancer diagnosis was part of what prompted the decision to come out to cancer care professionals:

Because of facing what I was facing in terms of this life threatening illness, I just didn't have the patience or the time to deal with homophobia... I guess there's part of me that feels like I was more confident in being out with these people because of this life threatening illness... I just feel like this was one of the times in my life where [I felt like saying], 'no, you're not going to get that opportunity to demonstrate your homophobia to me.' Like, this is a sacred time for me and if I'm going to get better, I have to repel any kind of negative energy. [Maureen]

In our interview with her, Laura talked about what it might be like to be out with her support group. Like Maureen, she suggested that her breast cancer diagnosis may make her more likely to come out:

In your head you have to go through it and say, well, 'should I, could I, will it change things, what will happen; will I feel comfortable, will they feel comfortable...' And you know, I'm considerate of other people's feelings but ... what's more important are my own, now. And you do, you know, breast cancer does change you.

Yet the vulnerability of being a cancer patient, combined with the lack of energy that comes with being in treatment and the anticipation of homophobia, sometimes made it impossible for lesbians with cancer to be out. Jann described being in a support group where she sensed from the conversation that her coming out would cause discomfort, so she chose to remain closeted.

Usually I'm quite an activist but, to anyone who's not had cancer treatment, it's such a wearing thing, it's hard to explain, just how wearing it is. You know, you have to choose your battles wisely when you're working full time, part-time, having chemo and dragging your butt in the door at the end of the day.

Sarah talked about how even the salesperson at her car dealership in the small city where she lives knows she's a lesbian. But when she walks into a hospital **"that bravado that I bring out to the rest of society is kind of hiding."**

Not being able to be out in the cancer care system and in support programs took a toll on some of the lesbians we interviewed. Laura, for instance, spoke about her regret that she cannot be honest with women in her support group.

And Glenda said she felt very bad – even guilty, in a certain way – about not being out.

“You know, you’re denying, I was denying that part of myself, that for so many years that was something I worked on to be who I am.”

It is also the case that cancer care, with its multitude of specialists, makes it especially difficult to be out. Laura pointed out that it is not easy to be out **“unless there’s a bond there of some sort”**. When lesbians encounter so many health professionals, as is so often the case with a cancer diagnosis, **“you don’t know who they are and you sometimes might not see them for quite some time afterwards.”** This contributes to the difficulty of coming out.

Alternative treatments

Maintaining a healthy diet and trying alternative therapies was something that many research participants did during treatment. Laura suggested that lesbians may be especially likely to take charge of treatment decisions for cancer because, as she says, **“we’re used to being independent.”** Along similar lines, Sherry speculated about the link between her decision to pursue alternative therapies rather than chemotherapy or radiation, and lesbian identity:

We don’t have men in our lives so we make our own decisions, right? You know, we do our own mortgage financing, right? We buy our own insurance, we negotiate our own cars, you know what I mean?... So we’re going to go and take control of something versus letting somebody tell me, you know, ‘okay, little girl, this is what you have to do and this is how you’re going to do it and you know, why and when.’

Sherry and Lou both noted that there is very little support or information for women who choose not to take conventional therapy; Sherry talked about feeling **“alone from both things”**, both being a lesbian and her treatment choices.

Paddy, an Aboriginal lesbian, she wishes she could have done a sweat lodge when she was diagnosed with breast cancer. Her history of heart problems, however, means she can’t take the heat of the lodge. Considering other possibilities, Paddy said **“I had thought about trying to find a Native healer... and gave it up because I just couldn’t get the energy up.”**

As was true for so many of the women we interviewed, being depleted from cancer and conventional treatment meant that lesbians could not always organize the kinds of care they needed. Paddy’s story points to the importance of cancer care professionals, and supporters in lesbian community, to actively work to connect lesbians with cancer with resources that support all of who they are, as they are facing cancer.

As many women pointed out, care outside of the conventional system can be expensive. We discuss this further in the section on Families and Finances.

“I never got a hiccup, but I never got much further also”: What’s missing in cancer care and support

A few women who took part in this research described feeling very well supported as lesbians by health professionals. In speaking about these instances, and also in articulating what was missing in their interactions with health professionals, research participants defined some of the features of lesbian-positive cancer care.

One research participant, Teagan, described receiving ‘incredible’ support from her primary nurse:

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

Mary Lou said that an oncology nurse told her and her partner about a film made by a lesbian facing cancer. While Mary Lou felt that her own process was quite different from the one portrayed in the film, she nevertheless appreciated that the nurse was **“trying to help us both feel really comfortable.”** Two other participants spoke about how well supported they felt, as lesbians with cancer, by their family physicians.

More commonly, however, as noted above, lesbians who took part in this study were grateful for the absence of homophobia. While the absence of homophobia is obviously important, it’s not exactly lesbian-positive care! Marcia’s comment captures the tension of recognizing progress against homophobia, and at the same time knowing that care for lesbians could be so much better:

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

This comment, and the form it takes, echoes with others in the study. Many women explained that they did not experience what they would call homophobia from health professionals. And yet for some, something was missing. Marcia explained it this way: **“I never got beyond, ‘how are you doing?’”** Health professionals were ‘very nice about’ her lesbian partnership,

but at the same time they never reached into her life, never actually asked her about her partnership or tried to figure out what mattered to her so that the health care interaction could be more genuinely about her. As Bonnie said, **“the doctors are really good, but it’s not like they hand you a pamphlet and say, you know, here’s a lesbian group and maybe the two of you’d like to go.”**

When Pauline described her experience in the hospital, she said there was **“never once... a single indication that [my partner] ... was not an appropriate person to have around.”** And yet when we went on to ask whether she and her partner felt supported or recognized by health professionals as a couple, Pauline said:

No, I wouldn’t say ... I wouldn’t say they supported us as a couple. [pause] I don’t know that I could say they supported me as an individual, to be honest. [pause] They were clinical. They were clinical in their approach to me... I’m a case.

Kate echoes this comment. Kate received internal radiation as treatment for cervical cancer. After the treatment was over, she had to use a dilator, a dildo-like device designed to stretch her vagina, several times a week. The physician and primary nurse gave Kate a pamphlet about internal radiation – and that was it.

[They] said nothing to me. Said nothing in the whole experience about how I deal with my sexual life, said nothing about the effects this might have on my life. Absolutely zero, nothing about that, which I think is ... Again, I don’t know if she would have said more if I was heterosexual...

I mean it’s not like [the nurse] didn’t answer my phone calls if I had to call and I had a problem here and there. But there was absolutely no real patient-focused care or contact that allowed me to talk about my life at all. And she really was the point person. So if your point person can do that for you, you can ... deal with a lot of other things. That didn’t happen. [Kate]

One would think that the nurse’s explanation about the dilator would have prompted a discussion about Kate’s life, her feelings, her sexual relationships – but it didn’t. The nurse said the dilator would make it **“easier for the doctor to examine you later”** and **“easier for intercourse.”** The ways she spoke about the dilator, and failed to ask or speak about Kate’s own experience as a woman and a lesbian, meant that the interaction was not actually about Kate. As well, as Kate points out, care that is genuinely patient-focused is not only a value in its own right; it often enables people to deal with the strain of illness and treatment beyond any one particular meeting with a health professional.

Marcia and Kate both noted that it was sometimes hard to tell whether less-than-satisfactory health care experiences were the result of usual patterns of health practice, or whether they resulted from health professionals’ discomfort with lesbians. And of course, as Mary Lou

pointed out, it is not always the case that lesbians wish to have ‘the lesbian part’ of their identities a focus of attention.

Yet the more general point is clear: while both Kate and Marcia were at pains to let us know that health professionals had not discriminated against them as lesbians, they also perceived that health professionals failed to engage with who they are, and the wider social context of their lives, in any meaningful way. And for many of the lesbians we interviewed, engaging meaningfully involves engaging with lesbian identity.

Ideas for Change : The version with **quotes** & **additional ideas**, from research participants and beyond

When [my friend] e-mailed me about this project I was just really grateful that it was happening and hoping that it does sort of grow and flourish and something comes out of it. That would be really great. [Jessica]

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**

It's about people with cancer, queer people with cancer talking about their experiences publicly, writing about it. Cancer has to come out of the closet in our community. [Marie]

There needs to be some poems out there, and words out there for lesbians who are journeying with breast cancer. [Sarah]

It's like finding your heroes, you know. People need to read Audre Lorde. The fact that Sandra Butler's partner was a cancer survivor, that was hugely profound for me. [Marcia]

Like what if there was an ad in Siren that, every time it would give some sort of statistic or you know, like I've heard that lesbians are at higher risk than women in the general population. Or it would list, 'did you know, that if you're a lesbian and experiencing a cancer diagnosis, you can link up with such and such.' And then the next ad would say, this, right? And then through repetition, you know, you're eventually going to reach most people and then later if something happens to them, they'll go, "oh, yeah, I can go there" and then they won't feel alone. [Jessica]

→ A float in the dyke march, with lesbians with cancer, perhaps also lesbian health professionals!

→ Possibility of using the 519 Church Street Community Centre (The 519 is a meeting place and focus for queer community activity in Toronto) as a platform to support lesbian community action, building a lesbian community of support for cancer; and, as platform for activism to call for change in cancer services.

- 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

You could talk about breast self-examination but you can always say, “make it fun, get your partner to do it” [laughs] I don’t know, things just something so there’s always something out there. I mean I think we are still ... I think the lesbian community is still also at the place of, we don’t trust physicians, and so therefore, you know, we’re not even going to go and deal with mammograms. [Marcia]

I remember my first visit to the oncology (floor,) and I remember, I thought I saw a brochure that said, lesbians with breast cancer. And I didn’t / I don’t know if there’s one that exists but when I saw that, I remember thinking, oh my God, there’s a higher risk when you’re a lesbian to get breast cancer. And so, (missed or) false notions and ideas that I might have, you know, those are the kinds of things that I might discuss. [Teagan]

A conference is another way to start... And ... you know, let’s bring in lesbian oncologists. I mean I don’t even know whether there’s medical stuff we need to know about. You know, it’s hard to know what it is you need to know, [laughs] when you don’t know, right? [Marcia]

→ research about lesbians’ real risk for cancer

→ fundraising in lesbian community to support lesbians with cancer

CREATE OPPORTUNITIES FOR CONNECTION AMONG LESBIANS WITH CANCER

I still haven’t found, I haven’t been able still to create a safe place where I can go and talk about being a lesbian with breast cancer. [Glenda]

- Support networks or groups

I think the people that were most helpful were breast cancer survivors... it would have been really cool to have met a lesbian breast cancer survivor [Marcia]

Benefits of connection among lesbians with cancer:

Ease sense of isolation

Every now and again it’s nice to know that there’s someone else out there my age, kind of like me, who’s gone through this. Whether I need to have

conversation with them or not, it's just nice to know that I wasn't the only one.
[laughs] [Teagan]

Safety

If you aren't out... or they're just not ready, or they're coming out, or they're questioning their sexuality, it would be so much safer to be with another dyke... You know, if it's your partner, you'll know that there's somebody there to help to support your partner. You know, if you have kids and they arrange for dykes to baby-sit your kids you don't have to worry about suddenly your kid going to some strange place, you know where they're gonna have things said about them or said about their moms or whatever. [Lillian]

Being understood / not having to explain/ getting to the most important issues

Communication and simplicity of language, I mean I can say to another lesbian woman and a lesbian woman with cancer, how thinking about having prophylactic mastectomy messes with my brain, and messes with how I define myself, and messes with how my lover will interact with me and they go, 'yes' and I don't have to say anymore than that. [Sarah]

[A lesbian breast cancer support group] would be excellent. It would really ... it would ... help enormously... That you don't have to skirt around things, you know, and stuff like that, you can just sit there, be open and honest [Theresa]

Greater openness; ability to talk about the more difficult + personal issues

I think it would be more comfortable and more open and more honest... and more intimate sharing, I would say. It would be more healthful. [Laura]

I still feel really, really uncomfortable in this body and maybe that's something I can give to you, maybe your people you work with could do something or a group for lesbians and body image after cancer. [Glenda]

Place to find language for experience; articulate the particular experience of being a lesbian with cancer; articulate needs → this supports lesbians' partner and families

Being able to talk with other lesbians about this experience ... is sort of finding the language for talking about ... all that stuff about sexuality and health and cancer and disease and ... all that stuff coming in the same package, in some ways... just, the fact that that wasn't available made it much more difficult for me to articulate what I needed or ... what I needed to do at that point.... And I really would have liked to have ... known other lesbians who are going through that ... and have a chance to talk about that. I think it would help my partner too. It would've been easier for us as a couple ... [Kate]

Gain strength and courage

I think that when lesbians who have cancer get together and talk, we talk about the lesbian component of having cancer, we do. And I think it's because we can't talk about it anywhere else or it's not heard or it's not understood. So when we have that venue or that forum to do so, it's almost like, 'lap it up, eat it up,' you know, 'stroke, stroke, stroke, stroke, stroke' because we're going back out into the barren world of, that sterile health care world, and we just need to be able to feed ourselves, feed those reservoirs a little bit more. [Sarah]

A place for us to meet, so that we know that there are other lesbians who have cancer that we can share and gain strength from each other [Jessica]

➤ **Connections between lesbians with cancer not focused specifically on cancer (for instance, wellness activities)**

An exercise thing... something that is health promoting and yet connecting you through that... because I feel so busy already and I don't want to be so busy. But, I guess that, that meets two needs simultaneously. [Paula K.]

Something similar to what they have at the wellness program where any cancer patient can just walk in for any kind of treatment, not treatment but um, Reiki or acupuncture or anything like that, you know, without having to pay for it.... Mainly for lesbians. [Anette]

It would be, it would be great... We could all go play baseball together. [Jessica]

➤ **Connections between lesbians who share experiences beyond the initial diagnosis (for instance, lesbians with cancer who are a similar age; lesbians with metastatic cancer)**

There's very little for pre-menopausal women, whether you're lesbian or you're not. [Bonnie]

I'd like to meet lesbians who have raised children. If anything in my life, that is where I've felt very isolated. And then to be diagnosed with cancer on top of it, that would have been something, that would have been really helpful. And how did they cope with it and how are they getting along and my children having other children to talk to. [Maureen]

➤ **Opportunities for partners and children of lesbians with cancer to meet**

I think for the children, what would have been helpful for them would have been a children's group. How do they deal with that if they have to talk about lesbian issues. A partner's group, how does my partner talk about that? [Kate]

→ Services for kids that are not just about coming together to talk about your mom having cancer – focus is other than cancer.

CREATE SERVICES FOR LESBIANS WITH CANCER, THROUGH EXISTING CANCER AGENCIES

I don't think we have to duplicate ... I don't think we have to reinvent the wheel. I think we can become part of the [cancer agency], but we need to become more visible. [Marcia]

➤ Service where lesbians meet (face to face) with a lesbian cancer survivor early in the process; a 'buddy' through cancer

A very meaningful thing for me would have been a program similar to the 'Reach for Recovery' program that the Canadian Cancer Society runs. What they do is, they link a woman who has been through breast cancer and survived with someone who is just going through it. And they bring that person all kinds of information, they bring them a little prosthesis, a temporary prosthesis that they can wear when they come out of the hospital. And they, you can call them and talk to them and they sort of, you know, "oh, you're just starting treatment, oh, don't forget to go buy your wig or, you know, or did you feel this? Or did you feel numbness here? Or whatever". But it links you with someone that you can relate to and talk to. So it would be great, I think, if there was a program like that.

Interviewer: For lesbians?

For lesbians. Don't you think that would be great?

Interviewer: I do.

And then you just wouldn't feel, like, so alone all the time. Like, I don't know another lesbian who's had breast cancer. [Jessica]

People that will come in and they've gone through breast cancer and they're there to help you and they've survived and help you through the process and tell you what's going to happen and everything else, but it would be nice to have dykes to do that with.[Lillian]

Idea that buddy would be active, taking initiative to contact the woman:

Some of us when we get our diagnosis, some of us when we're going through treatment, were too ill to make that call. So we need something else in place... [Glenda]

- Service that link lesbians by phone

A match... somebody who's walked your journey. Now, I don't know whether there are lesbians on that (cancer agency) list. [Sarah]

→ Idea of a lesbian peer support volunteer or staff at Willow (Willow is a breast cancer agency offering current, comprehensive information about breast cancer and survivor-to-survivor emotional support. It also offers workshops and resources to a network of breast cancer support groups).

- Support groups for lesbians and their partners

There would be a support group at [cancer agency] for lesbians and for sure, that would be one thing... a service... more geared to my needs [Jessica]

- 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.

The institutional support has to be there – someone has to keep it alive. It can't be a one-day-a-month thing. It has to be part of someone's job description.

It should be something that has some continuity to it, that's always there. Not some sort of pilot project that lasts two years and then it's gone. [Jessica]

**If you went to the [queer community agency] or a place like that, you'd have, I think, more challenges because you'd have to deal with issues of long-term funding and if you could tackle that hurdle, I think that that would be a good place because it's safe there and there's lots of groups there that have an element of anonymity to them. So that would be a safe place to go. [Jessica]
*[Specific suggestion: start a group at a cancer agency; if outgrows space, shift to a lesbian agency]***

'All purpose' lesbigay group, with men and women, different kinds of cancer, partners as well as people living with, may not work especially well over time: "we all had different things." [Lillian]

Accessibility

With the 1-800 number, you don't have to be geographically accessible. [Sarah]

[The teleconference is] too distant, and ... well that's the main thing, it's too distant. I need to be able to be face-to-face. [Pauline]

Things that don't cost money or that don't require tokens. You always must remember that, you got to make a point of that, whenever you're doing anything, you must always include tokens for women. Women will come, women can't get here if they don't have tokens. If women only have enough money to buy milk, guess what they're going to do. [Glenda]

Promotion

Interviewer: If it doesn't specifically say lesbian, then you expect it to be a place where you have to be in the closet?

That's right. Or, I'll have to do some explaining. But if I saw in Xtra, 'lesbians have joined cancer connection – isn't that wonderful, then that gives me another message.

I think also, I mean that needs to be advertised. Because if my experience is not advertised then every time I look at these resources, I go, do I have to explain to this person ... [Marcia]

→ importance of promoting service widely so women do not have to ask someone for it (and thus come out, AGAIN.)

The most important part of that is the outreach to women and letting them know that it's there. I don't know how you can reach everybody but... it would never occur to me to go to [cancer agency], like it would never occur to me to go there. [Jessica]

→ Organizations that fund research and community projects requiring proposals to pay attention to lesbians.

→ Cancer conferences and events to include attention to lesbian issues.

→ Lesbian teams in the Canadian Breast Cancer Foundation's Run for the Cure

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

- Financial support [financial planning, and funds for bandages, 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.]

With [AIDS agency]... they seem to try and make people's lives a little more comfortable. They give a very good food box from Foodshare. They give haircuts because they know a lot of the people are low income because they, you know, there's all kinds of stigma with that. They take, they give them tickets to go to Wonderland, there's camps they go to, there's different things [Glenda]

Somewhere for people to stay, in the gay community, who come from out-of-town for treatment. [Constance]

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.

I never saw the word partner in a [cancer agency] pamphlet. It was about husbands. Well, it's like, come on folks ... you know. [Marcia]

I'm a dyke, I describe, I define myself as a dyke. That word has never been used in any of the pamphlets on cancer I've read so far. [laughs] [Sarah]

I think one good thing is having pamphlets that have the word lesbian written on them in waiting rooms of breast clinics... It would just be sort of comforting as a lesbian to go into a clinic and see the word lesbian written somewhere. [Maureen]

→ Availability at cancer agencies of resources focused on lesbians with cancer – examples: *My Left Breast* video, books *Cancer in Two Voices*, *The Cancer Journals*, *A Burst of Light* (see Resource List, Appendix B).

Sexuality

* Like there would be, there'd be something about sexuality. There'd be something written by a dyke about what to expect from a dyke's point of view.

There'd be some, some connection to somebody to talk about sex with. There'd be a workshop at [sex-positive shop] that talks about, you know, sex adaptations, no sexual adaptation, if you'd had surgery that's affected some part of your body that you normally use for sex, how do you get like, what are other things you could do to ensure that you're, you know, you're still getting orgasms regularly, and that, you know, how can you bring your lover in on that and that kind of thing. That would be a huge bit. [Lillian]

Spousal rights and benefits

*** There'd be a section in ('the lesbian pamphlet') on spousal rights, powers of attorney for personal care, those sorts of issues, how to make sure your spouse always gets, that your spouse always access to you, that they are the decision maker you want, that they're in place, if you need to ... how to work your benefits. [Lillian]**

Sports

*** There'd be a bit in there about sports rehab (especially thinking about lymphedema)... if you're a sports dyke, you may want to talk about, can you still play golf. Should you wear a brace, like if you play tennis, for example, which has, you know, a lot of arm and hand stuff, you know, what sort of thing could you do about that. Like some sport stuff in there, for those of us who are sports dykes.**

There'd be somebody that you could contact if you were a sports dyke, there'd be somebody that could do physiotherapy specifically for types of sports around breast cancer... [Lillian]

Income

→ List of resources for low income women [promotion of Willow's resource on income support services]

Gynecological cancer

And to have some visible resources around gynie cancer, period ... there isn't a lot of material generally around gynie cancer. [Kate]

ADDRESS HETEROSEXISM IN CANCER CARE; CREATE 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.

More services, more resources that lesbians can access without having to educate people, without having to feel shame when they walk in, and be thinking in your mind, 'what, should I take my rainbow off today, what should I do, should I just sit there and not say anything about who I am?' [Glenda]

I would have really, really liked to have had a support group of lesbian women with breast cancer... or least a mixed group that you felt comfortable enough, where I could say 'my partner', like to mention it without people shrivelling, you know what I mean? [Jann]

I wish when I'd called, before I had to say anything, she said: 'we have a lesbian counsellor...' [Teagan]

→ Idea of training for cancer care professionals by lesbians with cancer.

For example:

➤ Intake forms that allow for self-identification as a lesbian. When a woman identifies as a lesbian, discussion about the meaning of her identity in relation to cancer and cancer care; and choices offered about how and with whom the information is shared.

When we're vulnerable, we're very unlikely to be talking about race, disability, sexual orientation on top of everything else. But to assume that these things don't affect our experience or are things we wish to talk about if someone dared to ask is a totally different matter. [Kate]

→ Practice that sexual orientation is part of every form filled in. This not only allows women to come out; once this is part of a protocol, health professionals are required to learn about it.

➤ Intake procedures make clear that all of our identities are welcome. 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 question: '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.'

If [service providers] don't know about our identity, they you're not using our strengths and you're also not identifying our vulnerabilities, how we might be injured by the system – it's what happens to us when identity is overlooked. [Kate]

➤ Intentional support for lesbian partnerships

I mean it's as simple as going for one more mammogram and walking into the radiology department and them saying, 'hey, does your partner [name] want to stay with you?' 'Yeah, thank you'. Rather than, 'did you bring your husband with you today?' [Sarah]

➤ 'Positive space' campaigns

→ A positive space campaign, where stickers on a door or on nametags show that this health professional or community worker is lesbian positive (beyond value of actual sticker, this promote dialogue in the agency).

→ Specific sections in resource centres identifying lesbian material. Having the word 'lesbian' on the website, having rainbow symbol, indications of positive space.

- A lesbian cancer 'advocate' and resource people

They should have a lesbian worker in every hospital so that when people come in and identify themselves as being lesbian ... You know, we'll have someone to help you if you have any problems, you know, that can help you, you know, address your needs. Because when you read the pamphlets, [laughs] they only address, you know, your husband, your family, like, just that heterosexual thinking, right? Not, 'oh, have you just come out, is it / you know, that must be really hard, and' ... and all that kind of stuff, you know. Does your partner need any support... You know. But I really think if they had a worker in each hospital, I know it's not realistic, but ... [Theresa]

→ A few women referred to social work and chaplaincy as having a particular role in being advocates for lesbians with cancer. Idea that staff in this role would ensure that, if a woman chose, everyone involved in care would understand that the woman is a lesbian (so that lesbians with cancer do not have to continue to come out) and would relay needs through the system.

→ Idea of a counsellor (free) with skill and experience in addressing issues especially important to lesbians with cancer (including sexuality, body image, emotional life).

- Lesbian and gay cancer care professionals coming out: recognizing that this requires workplace support

It would have meant the world to me (if a health professional came out to me). If it's OK for them to be here, it's OK for me to be here.

→ Workplace support for lesbian cancer care professionals coming out involves human rights policies, culture of safety and support, raising issues at provincial and national levels – for instance, Ontario Hospital Association.

Ideas for Change : The short version

We look to leadership from cancer care agencies (starting with Boards of Directors) to identify access for lesbians as a priority, and 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

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available in waiting rooms and cancer information centres would also serve an important role in creating visibility for lesbians in the cancer care system.

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For example:

- Intake forms that allow for self-identification as a lesbian. When a woman identifies as a lesbian, discussion about the meaning of her identity in relation to cancer and cancer care; and choices offered about how and with whom the information is shared.
- Intake procedures make clear that all of our identities are welcome. 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 question: ‘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.’
- Intentional support for lesbian partnerships
- ‘Positive space’ campaigns
- Lesbian and gay cancer care professionals coming out: recognizing that this requires workplace support

APPENDIX A

How the Lesbians and Breast Cancer Project happened

The Project Team made the Lesbians and Breast Cancer Project happen. Here's what we did.

March 2002 A researcher with the Ontario Breast Cancer Community Research Initiative, Chris Sinding, invites a group of women to a meeting at the 519 Church Street Community Centre. We introduce ourselves and say why, both personally and in terms of our work, we care about lesbians with cancer. We talk about the idea of a Participatory Research Project focused on lesbians with breast and gynecological cancer. We tape record our discussion of possible research questions and make notes about how the project might actually happen.

Then we go off and explain the project to our agencies, and get letters of support for the project from each of them.

April Application for 'Lesbians and Breast Cancer : A Participatory Research Project' submitted to the Canadian Breast Cancer Foundation – Ontario Chapter.

July Ethics approval for the study from Sunnybrook and Women's College Health Sciences Centre.

September Letter from CBCF saying we have funding!

October Meet to celebrate funding. Everyone on the team pitches in to hire the Research Facilitator (deciding criteria, reviewing resumes, setting questions, interviewing...).

Breast Cancer Awareness Day – cheque presented to the Lesbians and Breast Cancer Project. Members of the Team swan about on the stage, speak words of thanks. A few people come up to congratulate us and express enthusiasm about the project. Others seem to turn away. Hmmm.

November Lisa Barnoff becomes the LBCP Research Facilitator. Begins churning out documents for discussion by Team. Begins lists of agencies that should receive promotional material about the project and starts faxing, phoning, e-mailing. Creates list of media possibilities; more faxing, phoning, e-mailing.

January 2003 Team meets to discuss key aspects of research design:

- Final list of topic areas to explore in the research
- Goals for reflecting lesbian community diversity in the research
- How to spread the word about the project
- Roles and responsibilities of members of project team in relation to research participants (all get out pens to sign confidentiality agreement...)

Recruitment begins in earnest. Women on the Project Team begin calling friends and talking to co-workers about the research. We make lists of people linked to various kinds of network and communities and e-mail them the promotional poster. A dozen knapsacks fill with stacks of LBCP flyers, to be distributed on our travels.

Interviews begin.

April Six month report submitted to CBCF. In this report, we're able to say that fifty-five organizations have received information about the project, and promotional material has appeared in twelve community publications/ websites. Forty-six individuals have been contacted personally to spread the word through their networks. We start witnessing the ripple effect.

Marvelous media for the project – Article in Xtra!, Pride Vision TV spots, and LBCP radio debut. Later in the project Siren magazine agrees to run a series of articles about lesbians and cancer, written by Project Team members.

April Project Team meets to review early interview transcripts. Members engage in a lengthy and lively discussion about the transcripts they have read. On the basis of this conversation the interview guide is revised, and a preliminary framework for organizing the research findings developed.

In qualitative research, we assume that we're going to learn things from participants, and that we may need to revise our interview guides and our ideas about 'what matters' as we go along.

May Heterosexism in recruitment... we start to hear demands that we justify why we needed to do a "lesbian" project – questions about why lesbians were deserving of this kind of special attention – how their cancer experiences could possibly be any different from heterosexual women's experiences. 'Cancer is cancer is cancer' is the theme. This is something we didn't adequately anticipate or plan for...

May Fabulous launch party for the book *My Breasts, My Choice: Journeys Through Surgery*, and promotional event for LBCP.

Focus group planning. Members of the team meet to talk about how to do focus group research, and to plan for focus groups with lesbians who have had cancer.

Our original intention was to hold four focus groups for lesbians with breast and gynecological cancer: with lesbians with disabilities, lesbians in Northern and rural Ontario, lesbians of colour, and a general group. We had thought the focus groups would be a draw, and would also give us a chance to have different kinds of conversations as participants' ideas and experiences bounced off one another. As it turned out, every woman who contacted us was willing to have an individual interview, and some said they would rather not be part of a group interview. So, with some regret, we abandoned the focus group plan.

May Team members interested in doing individual interviews for the project meet with Pam, Lisa and Chris to discuss and plan for research interviewing.

June Ethical dilemma: LBCP offered funding from a drink-and-party fundraiser sponsored by a cigarette company. After a civilized and enlightening e-mail debate, we decline.

June Pride Weekend and the Dyke March! Hundreds of small posters advertising a drop-in focus group are strung together with clear tape and plastered around poles and along buildings on Church Street. Team members distribute posters as they weave in and out of all manner of queer events and gatherings.

The drop-in focus group pre-Dyke March was against the better judgment of some members of the team, who felt quite certain that no one would appear (they predicted everyone would be in party mode for Pride). They were right... But three women, seeing posters, later called to take part in interviews, so we figure it was worth the effort.

July Lisa leaves the position of Research Facilitator to take up a faculty position in the School of Social Work at Ryerson University (happily, she remains active on the Project Team). Pam Grassau comes on board as Research Facilitator and swings into action, organizing the final rounds of recruitment and interviewing many women.

Pam and Chris finalize coding framework for the study.

Coding is the process where themes in interview transcripts are marked and then grouped (in our case, using a computer program), so that all the comments that each participants made on a particular issue (sexuality, for instance, or sports) appear together.

Much coding ensues.... Pam still wildly coding.
Chris starting to write... wildly writing...

July It was clear in early interviews that research participants had rarely met another lesbian with cancer – and most would welcome the opportunity. Members of the Team meet to think about and plan for a workshop to bring research participants together.

September Draft of the first four sections of the research report completed.

October First of two half-day meetings at which several women who took part in the research review the draft research report. At this first meeting a very strong message came forward: ‘we can read stuff relevant to women with cancer anywhere: you need to make the lesbian voice louder!’

Also at this meeting a few women expressed discomfort with the ways participants’ stories had been divided into categories – a quote in ‘support,’ a quote in ‘families and finances’ and so on. A suggestion came forward to ask participants to submit short profiles, to introduce themselves in an integrated way and in their own words. We sought and received approval from the Ethics Board for this, and the profiles are included early in this report.

Revising the research report... writing remaining sections...

December Second meeting at which participants and project team members reviewed a draft of the report. *These two meetings transformed the report, and also showed us all just how important it is for lesbians with cancer to have a chance to come together to talk about their experiences and the kinds of changes they want to see in cancer care and community services.*

January At a Team meeting, we check in with each other about how we think we're doing with this project. We discuss the fact that the 'success' of LBCP depends on the standards by which it is judged... Judged as a research project, LBCP has achieved important successes in involving community agencies and research participants. Assessed as a community project, or in relation to social action research in the past, some members of the Team feel that more could have been done to put lesbians with cancer at the centre and to challenge usual ways of doing research. We celebrated the 'amazing fact' of a project about lesbians with cancer, done by lesbians; and spoke of our regrets about not achieving the kind of diversity among participants we had hoped to achieve.

February 2004

Workshop for research participants and their partners held in Toronto, a collaboration between Willow and LBCP designed to build community among lesbians in Ontario who have been diagnosed with breast & gynecological cancer, and provide energy and direction for improving mutual support and care. The workshop was tremendously appreciated by both research participants and their partners. It also provided us with useful feedback on the almost-final report, and provided direction for emerging community programs and initiatives.

We had some debate about inviting partners to this workshop... On the one hand, we wanted lesbians with cancer to be fully present and able to speak freely, and wondered if partners would be a distraction or inhibit discussion. As well, not all participants have partners, and we worried that the presence of partners might be hard for women who really feel the absence of a partner in their lives. We worried about partners who were not especially supportive being present. It was also a logistical complication, and an increased cost.

On the 'invite them' side, we felt that lesbians, especially those who were more isolated, may not come without their partners, and that we would end up making exceptions to allow for this. We recognized that partners might well take leadership around enabling support among lesbians with cancer. And perhaps the most compelling argument: our research made clear that one of the key problems for lesbians with cancer is that their partners are often not fully acknowledged at cancer agencies and treatment centres. To exclude partners from this opportunity would be to continue this oppressive practice.... So we did invite partners, and for Saturday afternoon partners and participants had separate workshops.

March Members of the Project Team move into high gear, planning for the Launch of the Lesbians and Breast Cancer Project. By March 31st the to-do list is only (!) 33 items long. Planning for the event has generated lots of emotion, too... So many human and logistical realities at play.

April 2, 2004 The Launch of the Lesbians and Breast Cancer Project Report

An utterly fabulous event. Standing room only at Buddies in Bad Times Theatre on a Friday night, for - a research report?! Yes, it's true... The Launch centred around a reading by women involved in the research, of quotes from the 26 lesbians with breast or gynaecological cancer interviewed in the study. It was quite an evening – moving, angry-making, insightful and hopeful all at once.

The Launch ended, beautifully, with an announcement of funding from the Canadian Breast Cancer Foundation, Ontario Chapter, for the Sherbourne Health Centre proposal **Making Us Visible**. The project is designed to increase accessibility to services and supports for lesbian and bisexual women who have had a breast cancer diagnosis, and to increase accessibility to breast health information and strategies for lesbian and bisexual women.

Applause and cheering... the research has made a difference!

April 3 Brunch at Gilda's Club, to celebrate and debrief. The women who took part in the research are still glowing... and yet days later sadness sets in for many of us: amidst the success of the Project, lesbians – research participants, friends – continue to struggle with cancer.

April Presentation of the research findings – in the same format at the Launch – at Queer Health Matters.

Planning for presentation in May to cancer care professionals at the Canadian Association of Psychosocial Oncology conference, and to researchers at the Qualitative Analysis Conference.

Submission of an article about the research to the Canadian Journal of Nursing Research.

April 30th The official last date of the project. A copy of the summary report is mailed to all participants, along with a letter inviting them to a meeting in May to talk about 'what's next' for lesbians with cancer in Ontario. The story isn't over...

APPENDIX B

Lesbians and Breast Cancer Project – selected resources

(to June 2004; please contact Willow for an up-to-date version of this list: [Toll-free: 1-888-778-3100](tel:1-888-778-3100); [in Toronto: 416 778-5000](tel:416-778-5000); [TTY: 416 778-4082](tel:416-778-4082); [Email: info@willow.org](mailto:info@willow.org)).

Personal and community stories

Aslin, Maureen; Brown, Barbara; Carey, Betsy. *My Breasts, My Choice: A Photographic and Narrative Journey* [PHOTOS AND TEXT].

Brownworth, Victoria (ed) (2000). *Coming out of Cancer: Writings from the Lesbian Cancer Epidemic*. Seattle : Seal Press.

Butler, S. & Rosenblum, B. (1991). *Cancer in Two Voices*. San Francisco: Spinsters Book Company.

Lorde, Audre. 1988. *A Burst of Light*. Ithaca, New York: Firebrand Books.

Lorde, Audre. 1980. *The Cancer Journals*. San Francisco: Aunt Lute Books.

Martindale, K. (1994). Can I Get a Witness? My lesbian breast cancer story. *Fireweed*, 42, 9-15.

Rogers, G. *My Left Breast*. 2000. Newfoundland, Pape Productions Ltd. [VIDEO]
www.myleftbreast.com

The politics of it all

Sedgwick, Eve Kosofsky. 1995. "Breast cancer: Issues and Resources." *Lesbian and Gay Studies Newsletter* www.duke.edu/~sedgwic/WRITING/CANCER.htm.

Confronting Cancer, Constructing Change. 1993. Midge Stocker, ed. Chicago: Third Side Press
1 in 3: Women With Cancer Confront an Epidemic. 1992. Judith Brady, ed. Cleis Press.

Websites, services, projects

In the past the Canadian Breast Cancer Network (www.cbcn.ca) has run a national teleconference for lesbians with breast cancer. To find out about possible future teleconferences call 1-800-685-8820 or e-mail cbcn@cbcn.ca.

The British Columbia Cancer Agency has a lesbian/ bisexual cancer support group – contact Sarah Sample ssample@bccancer.ca

Gilda's Club in Toronto has a social group for lesbians and their partners -- check with Teri Henderson: teri.henderson@gildasclubtoronto.org

Metropolitan Community Church of Toronto has been hosting a support group for lesbians diagnosed with cancer and their partners since October, 2003. The group will be moving to Wellspring (a cancer support centre in Toronto) in the fall. For more information, please contact Jennifer Alexander at jmalexander@sympatico.ca

Sherbourne Health Centre has received funding from the Canadian Breast Cancer Foundation, Ontario Chapter, for a project called **Making Us Visible: Promoting Access to Breast Health and Breast Cancer Services for Lesbian and Bisexual Women**. Sherbourne is moving forward with some of the key recommendations from the research presented here. To join the mailing list about this project, contact : **Making Us Visible**, Sherbourne Health Centre, 333 Sherbourne Street, Toronto, Ontario, M5A 2S5. Email: atravers@sherbourne.on.ca

In the U.S.

The Mautner Project for Lesbians with Cancer

<http://www.mautnerproject.org/>

The Lesbian Community Cancer Project

<http://www.lccp.org/>

The Seattle Lesbian Cancer Project

<http://www.slcp.org/>

The Lesbian Breast Cancer Outreach Project

www.lesbianbreastcancer.org

Community research and policy related work

Lynda Anderson, Theresa Healy, Barbara Herringer, Barbara Isaac and Ty Perry (2001). Out in the Cold: Lesbian Health in Northern BC. British Columbia Centre of Excellence for Women's Health and the Northern Secretariat.

Council on Scientific Affairs, A. M. A. (1996). Health Care Needs of Gay Men and Lesbians in the United States. JAMA, 275, 1354-1369.

- Duncan, K., Clipsham, J., Hampson, E., Kreiger, C., MacDonnell, J., Roedding, D., Chow, K., & Milne, D. (2000). Improving the Access to And Quality of Public Health Services For Lesbians and Gay Men Ontario: Ontario Public Health Association.
- Hudspith, M., Bastedo, S., & Ministers Advisory Council on Women's Health (2001). Caring for Lesbian Health: A resource for Canadian Health Care Providers, Policy Makers, Planners Canada: Health Canada.
- Ryan, B., Brotman, S., & Rowe, B. (2001?). Access to care: Exploring the health and well-being of gay, lesbian, bisexual and Two-spirit people in Canada Montreal: McGill Centre for Applied Family Studies.
- Wellness Project (2001). How well are we doing? A Survey of the GLBT population of Ottawa Pink Triangle Services.

Clinical and academic literature

- Aronson, J. (1998). Lesbians giving and receiving care: Stretching conceptualizations of caring and community. Women's Studies International Forum, 21, 509-519.
- Dibble, S. L., & Roberts, S. A. (2002). A Comparison of Breast Cancer Diagnosis and Treatment Between Lesbian and Heterosexual Women. Journal of the Gay and Lesbian Medical Association, 6(1), 9-17.
- Fish, J., & Wilkinson, S. (2003). Understanding lesbians' healthcare behaviour: the case of breast self-examination. Social Science & Medicine, 56(2), 235-245.
- Fobair, P., O'Hanlan, K., Koopman, C., Classen, C., Dimiceli, S., Drooker, N., Warner, D., Davis, H. R., Loulan, J., Wallsten, D., Goffinet, D., Morrow, G., & Spiegel, D. (2001). Comparison of lesbian and heterosexual women's response to newly diagnosed breast cancer. Psyco-Oncology, 10, 40-51.
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- Mulé, N. (1999). Social work and the provision of health care and social services to sexual minority populations. Canadian Social Work, 1(1), 39-55.
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- Sinding, C. (1999). Counting on Desire: Supporting a Lesbian with Breast Cancer. In M.Denton, M. Hadjukowski-Ahmed, M. O'Connor, & I. U. Zeytinoglu (Eds.), Women's Voices in Health Promotion (pp. 191-203). Toronto: Canadian Scholars Press.