

# Lesbians and the Health Care System

## *Invisibility, Isolation and Ignorance—You Say You're a What?*

by Heather Ramsay

*L'auteure analyse les problèmes particuliers qui se présentent aux lesbiennes dans le système des soins de la santé actuel. Elle explique comment l'homophobie complique et compromet les soins que ces femmes reçoivent. L'auteure propose des suggestions pour faciliter et améliorer les soins que les lesbiennes*

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*reçoivent, soit une participation accrue du public, un renforcement des services de soins communautaires et une meilleure gestion politique du système.*

There is virtually no existing information on lesbian health or lesbian health needs. Most of the literature is concerned with heterosexual women, gay men, bisexual and heterosexual men (Honeyman). I have pooled my information from articles by Mary Louise Adams, Nancy Stoller Shaw, and Robin Barnett, among others, as well as from personal observation and interviews with other lesbians and health providers.

Lesbian health concerns are, for the most part, the same as those of heterosexual women. Lesbians experience all the same sexual and reproductive opportunities, physical changes, complications, and health problems that affect heterosexual women, although the incidence of gynaecological disease (for example, sexually-transmitted diseases) is higher for heterosexual women (Adams).

While there are no confirmed data, one might predict that lesbians' major concerns regarding chronic disease would also be similar to those of heterosexual women.

While heterosexual women may go to family planning clinics or to gynaecologists for reproductive health care, lesbians do not regularly attend such clinics because of fear of disclosure and/or past homophobic experiences. Therefore, lesbians are less likely to be screened for breast or cervical cancer. In fact, one study found that the average interval for a routine pap smear among lesbians was 21 months, compared to eight months for heterosexual women (Stoller Shaw).

Many people, including lesbians, are not aware that we can contract AIDS not only from injection drug use, blood transfusions, or unsafe sex with men, but also through sexual contact with other women. To date there have been

only two documented cases of "female-to-female" HIV transmission occurring most likely through menstrual or rectal blood (Adams). Nevertheless, while lesbians can still be regarded as a relatively "low-risk" group or a group of "least risk," we are not without risk (Einhorn).

What this means then, is that lesbians have been very slow in adopting safe sex practices. The belief that lesbians are "the group at least risk" and the assumption that lesbian sexual practices are relatively safe, has lulled the majority of lesbians into thinking that we do not need to take precautions to protect ourselves from AIDS and sexually-transmitted diseases. Although lesbians do seem to have fairly low rates of sexually-transmitted diseases, some doctors have begun to see more cases of chlamydia, genital warts, and herpes among lesbians (Adams, Stoller Shaw). And a woman who has yeast, trich, gardnerella, cervicitis, or vaginitis can potentially pass any of these on to her female partner through vulva to vulva contact, not washing hands, sex toys, and sharing bath water or towels and wash cloths (Honeyman). Currently, there is little information regarding woman-to-woman transmission of sexually-transmitted diseases and more research is clearly needed.

Not only is there a lack of safe sex literature for lesbians, there are few safe sex products specifically designed for women. The available products focus on the penis and penile penetration. In other words, the emphasis seems to remain on male sexuality and male sexual needs, ejaculation, and perhaps even on vaginal orgasm.

As more lesbians decide to have children, either through artificial insemination, through intercourse, or by adoption, we will begin to increasingly experience all the health problems and concerns associated with pregnancy or infertility, childbirth, and parenting. Such issues could include legal access to fertility services, the quality of prenatal care, childbirth, childrearing, and the stress of being a lesbian parent or coparent (Stoller Shaw). At present, lesbians do not have legal access to medical fertility clinics, nor can we legally adopt. Therefore, many lesbians who wish to become pregnant use informal, unregulated, community-based artificial insemination networks.

Another area of health concern is for mid-life and older lesbians. There are currently no published data on the relationship between female sexual orientation and life expectancy. We know that as women age, prevention and treatment of chronic illnesses and disability become more crucial to our quality of life. Yet we also know that lesbians will be less likely to be screened for certain illnesses like cervical and breast cancer, and may, therefore, be more likely to develop them (Stoller Shaw).

Although many mid-life women have employer-pro-

vided group health insurance, the majority do not. Only a few group medical plans cover same-sex partners.

### Barriers

Although many lesbian health problems are the same as those of heterosexual women, our experience with the health care system is radically different. Even though lesbians comprise at least ten to twelve per cent of the female population, I would expect that many health professionals would say they have never treated a lesbian or even seen one. We are usually invisible, for when people talk about "gays," we know that they are really talking about gay men.

For the most part, lesbians must deal with health professionals who know very little about us and the realities of our lives, and who can be quite open about their contempt for us. This makes us feel powerless and vulnerable (Adams). The result is that many of us do not seek health care when we need it because we are afraid of being ignored, isolated, or abused.

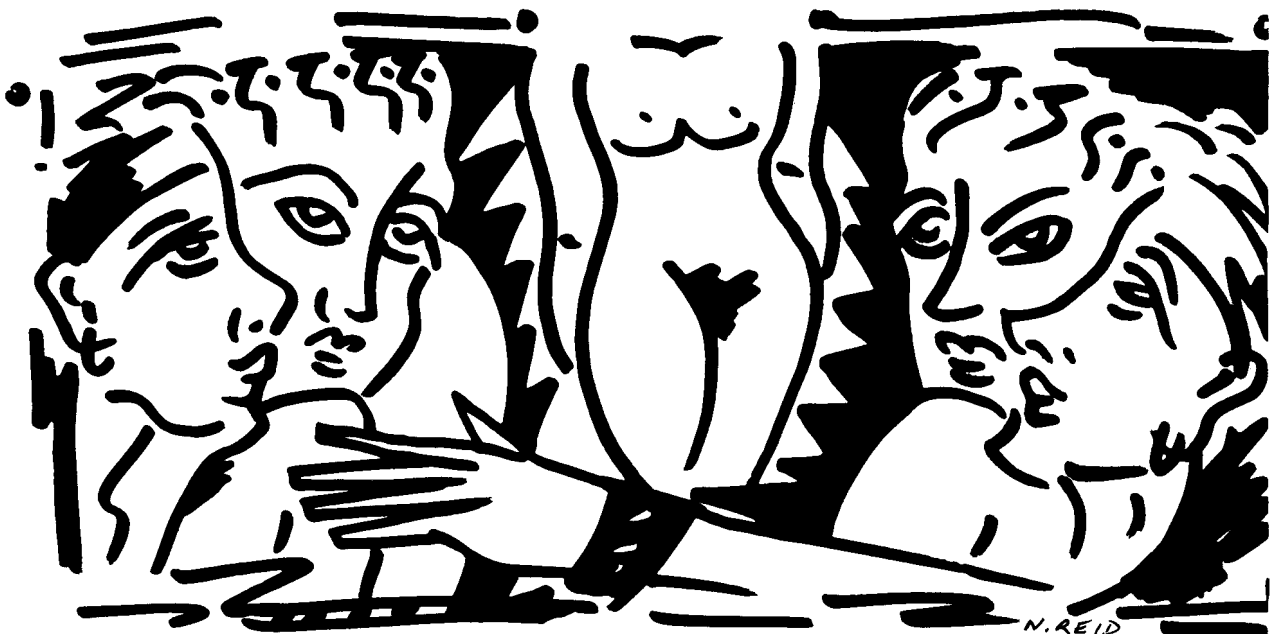
Many lesbians firmly believe that their health care would suffer if their doctor knew that they were gay (Adams). Furthermore, health care professionals regularly assume that their clients/patients are heterosexual and rarely ask otherwise. Nor do they take the time to use more inclusive language, which would create a safe environment for a lesbian to disclose her sexuality.

If lesbians are unable to come out, we are not free to ask for the information we need to help us maintain good health. If health professionals want to make an adequate assessment of the physical and mental health of their patients, they need to know who we are, and they need to

have some understanding of the realities of being a lesbian in an heterosexist and homophobic world. They need to receive adequate education and training regarding sexual orientation, but they do not. According to the health professionals I spoke with, there is nothing in any medical school curriculum specifically on sexual orientation. And they thought that it was quite conceivable for someone to earn any kind of health-oriented degree without ever once receiving positive information on sexual orientation or on how to address homophobia.

The Ministry of Health's Mandatory Health Programs and Services Guidelines includes a Program Standard called "Sexual Health." Its goal is to enable people in the community to attain an integration of the physical, emotional, intellectual and social aspects of their sexuality. Content of this program is to include "sexual orientation." So while public health has the mandate to address sexual orientation, what is actually being done? Well, very little. Only the East York Health Department has initiated a yearly sexual orientation education session geared primarily to high school students. What happens now is that information about homophobia and sexual orientation is, by default, tacked onto AIDS education. As both are discussed within the context of AIDS, this means that information about lesbianism is not being addressed. Furthermore, it is doubtful that racism would be treated in a similar manner, i.e., only as part of an add-on to a particular health issue.

So lack of information, research, and education all act as barriers both to lesbians and to health care providers. But the real issue is homophobia. Like racism, homophobia awards power to members of a dominant group and denies privileges to members of the minority group. However,



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unlike racism, homophobia takes discrimination and hatred a little further, for when we as lesbians or gay men disclose our sexual orientation, we immediately become "phenomena," things of clinical interest whose existence must be explained. For example, when was the last time a therapist suggested to his/her heterosexual client that their problems would be solved if they became a lesbian? Given such an environment, what lesbian would even consider stating her sexual preference to her doctor, her social worker, her public health nurse, or to her co-workers? We are afraid of losing our jobs and our children.

I would now like to relate some true stories which reflect

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how homophobia and the assumption of heterosexuality operate within the health care system to ultimately disempower lesbians.

Two women arrived at a hospital emergency ward. One of them was experiencing severe abdominal pain. The intake nurse asked for the name of her next-of-kin. The woman responded with the name of the woman who had accompanied her. When asked what the relationship of this individual was to the woman, she replied "lover." The nurse recorded "friend" on the intake sheet.

The attending physician immediately asked the woman if she was pregnant. She said no. He asked her how she could be so sure, and when was the last time she had sexual intercourse. The woman informed him that she is a lesbian and had never had sex with a man. The doctor again asked her if she was sure that she was not pregnant and besides "how could she never have slept with a man?" The woman assured him that she knew the difference and had not slept with any men. He asked her again. The woman became upset. She reaffirmed that she is a lesbian. The doctor then asked her, "What is it that lesbians do anyway?" Without waiting for her response, he then told her that her problem could be due to some sexual disease that lesbians transmit to each other. The woman became extremely agitated and was crying. She described feeling like she was receiving a medical interrogation on the basis of her sexual orientation, rather than a medical exam for her health problem.

The doctor refused to examine her further, until what he perceived to be her *real* next-of-kin, that is her mother, not her lover, was contacted. The woman's mother came to the hospital and assured the doctor that "no, my daughter could not possibly be a lesbian." The woman's lifestyle was again denied. The examination continued and the diagnosis was "ectopic pregnancy." The woman was rushed into surgery and was subsequently found to have a

very large ovarian tumour, not an ectopic pregnancy. Because her hospital experience was so traumatic and very clearly related to her sexual orientation, this woman and her partner have not seen a doctor for seven years.

Another woman was experiencing severe bleeding and cramping during her menstrual cycle. Her physician's first question was, "What kind of birth control are you using?." She replied none. The doctor told her that was dangerous and irresponsible on her part. Feeling pressured to justify her status, the woman informed her doctor that she did not need birth control because of the type of sexual activity she takes part in. Her doctor replied, "Oh, so your husband's had a vasectomy?" The woman took a deep breath and said no, and explained that her sexual partner is a woman and that she is a lesbian. The doctor responded very fast, "Really, uh, well, it's okay with me if you're a homosexual. So, in that case then, since you won't be having children, I think you should have a hysterectomy." The woman was shocked and told her doctor that she had not yet decided if she wanted children or not. The doctor responded, "Why would a female homosexual want children? You don't like men! And you wouldn't want to raise a homosexual child now, would you?" Needless to say, the woman decided to go to an alternative health clinic.

A teenage girl informed her parents that she is a lesbian. They immediately took her to the family doctor who did an internal examination. The doctor concluded that since she had found the girl's ovaries to be in the correct place, she is, therefore, not a homosexual. The doctor then recommended that if the girl were to persist in thinking she is homosexual, she should be referred to a psychiatrist.

A university student went to her doctor. She had just broken up with her female lover and was very depressed. Although the doctor knew she is a lesbian, she told her patient that the breakup of this relationship was probably the best thing that ever happened to the woman. Two prescriptions are then written up: one for an anti-depressant and the other for birth control pills.

A lesbian and her partner who was in hospital because of a terminal illness decided that they should speak to the hospital social worker regarding bereavement counselling and information on wills and power of attorney. They also wanted to know if there were any homecare services or hospices that would be lesbian-positive and supportive. The social worker was at a loss. Although she wanted to help, she did not know where to begin to find the information the women needed.

### Suggestions

Part of the process of achieving good health is to have people participate in improving and controlling their own health, rather than simply being passive recipients of health services and programs. The best way to enable people to increase control over and improve their health is through health promotion. This means the empowerment of communities and people. It means freedom of choice

and access. It means focusing on self-care, mutual aid, and the creation of healthy environments. It involves fostering public participation, strengthening community health services, and coordinating healthy public policy. Most health care providers believe that it works best if it is community-based. I think health care providers would also agree that it must address the reduction of inequities—social, physical, or economic—in people's health situations.

There is an obvious lack of information and data regarding lesbian health issues. There is also very little information concerning the health needs of bisexual women

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and the needs of lesbian and gay adolescents. About all we do know is that there is little appropriate and positive information available to young people about sexual orientation. In addition, this lack of knowledge concerning health needs is even more evident for lesbians from other cultures and for lesbians with disabilities. Clearly, more research should be undertaken. Such research should be community-based and community-controlled, and include community-defined needs assessments. This means that such research would be intended for the community, first and foremost.

The lesbian and gay community, in particular, is very suspicious of "academic researchers." We have been examined and objectified far too often as deviants and aberrations. A good point of mediation between scientific expertise and community expertise would be a hospital whose administrators and staff respect and respond to the internal and external community and are, in turn, well-respected and trusted by the various communities they serve. However, to access the lesbian community for any purpose, a hospital will need to go further than inviting us to sit on a panel. Lesbians are not simply a homogenous group, but include a variety of women from different class, cultural, economic, and differently-abled backgrounds, including bisexual women. Reaching us can begin by identifying and linking up with other lesbian and gay organizations. It should involve the creation of a hospital advisory committee composed of representative members from both the lesbian and gay community. It means trying to expand the hospital resource base of community expertise by not using the same people over and over again. It also means that the lesbian community will need to deal with our own internalized homophobia and will need to take some risks inherent to being more visible.

An effective and representative hospital advisory com-

mittee should also address the issue of homophobia within the medial establishment. If truly serious about dealing with homophobia, the message all hospital staff should receive is that homophobia and homophobic comments and behaviour, like racism and racist comments and behaviour, are inappropriate and will not be tolerated within the health care environment.

This means establishing an internal education program which will reach all levels of staff. It could be included as part of orientation programs for new staff. There are a number of community groups to consult with and to help develop such programs: Gays and Lesbians in Health Care, Lesbian and Gay Youth, Toronto Counselling Centre for Lesbians and Gays, Ontario Bisexual Network, Hassle Free Clinic, to name only a few.

Not only will the lesbian and gay community feel more comfortable dealing with a hospital which exhibits some understanding of and respect for the health needs of lesbian and gay men, but this more supportive environment should allow lesbian and gay hospital staff to feel more confident in speaking out and involving themselves in lesbian and gay health issues. This concept of front-line worker participation is not new. Lesbian and gay staff on the inside are in a perfect position to affirm community reality as well as present their own requests for positive change. But they will not do so unless they believe that their employer is making a serious and studied effort to create a homophobic-free and thus healthier work environment. Furthermore, health workers who are open about their sexual orientation can be valuable role models for young lesbians and gays. And they will probably experience less on-the-job stress because they will be "out" to colleagues.

More resources must be made available, accessible, and pertinent to lesbians. This means making health promotion programs and programming, outreach, and outpatient clinics more inclusive to lesbian health issues. It is imperative that health services be made relevant to lesbians in the same thoughtful and targeted way that such services have been designed to meet the needs of other minority groups. This can start by liaison with the lesbian community and the establishment of a representative hospital advisory committee as discussed earlier.

There is a need for a range of health promotion interventions which go beyond the realm of strict service. For example, hospital-linked family planning clinics must recognize that more and more lesbians are having children. The kind of artificial insemination services and family planning and family counselling available to heterosexual women need to be available to lesbians.

There needs to be more information regarding safe sex practices for lesbians, and more knowledge about the transmission of sexually-transmitted diseases and AIDS.

We know that breast feeding reduces the risk of breast cancer. That puts the majority of lesbians at higher risk, yet, cancer self-help groups are focused on heterosexual women and their concerns.

Adolescent lesbians and gays need access to services which are sympathetic, non-judgmental, and non-threatening. Such supportive services could be instrumental in reducing the suicide rate among this group of young people, a rate which may reflect 30 per cent of all teen suicides (*Toronto Star*).

In addition to having advisory committees, there could be liaison with existing organizations; for example in Toronto, Central Toronto Youth Services and Hassle Free Clinic have already set precedents in programs for lesbians and gay men. As well, programs and agencies set up in other countries should be investigated for their potential

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effectiveness here. For instance, there is a National Lesbian and Gay Health Foundation the United States (Stoller Shaw) but nothing comparable in Canada.

In dealing with clients and patients, health care professionals must address the automatic assumption of heterosexuality. This can be as simple and as inexpensive as encouraging and training staff to adopt more inclusive language, improving sensitivity and communication skills, and avoiding value judgments based on a client's or patient's answers or lack of answers to certain questions. For example, rather than ask a patient: "When was the last time you had intercourse?" Ask: "Are you sexually active?" If a client has a sexually-transmitted disease, it is inappropriate to ask "Are you married or do you have a boyfriend?" More information could be gained by saying, "This illness can sometimes be spread by sexual contact. Have you been having sexual relations of any kind?" (Jones).

When a woman says she is a lesbian, a practitioner should not respond with: "Oh that's okay, it doesn't matter to me." Such a response is heavily value laden. It indicates denial on the part of a health care worker who perceives his/herself as a "liberal." The disclosure obviously *did* matter, or it would not have been brought up (Hepburn and Gutierrez). This type of response comes from a practitioner who will probably never ask his or her client the kind of questions vital to a true assessment of that individual's health needs. A better response might be: "Thanks for telling me." Or the truth: "I don't know a lot about lesbians, so I hope we can both work together in dealing with your health concerns. I will probably ask dumb questions, but I hope that you will continue to share information with me and to ask me questions." Someone who asks questions in a respectful non-judgmental manner will get respect and confidence in return. A practitioner might also ask how much information a lesbian

wishes to have formally included on hospital records, and what she would prefer to have as informal only.

## Conclusion

As a group, lesbians have been excluded from overall community life. We have been labeled, rejected, and marginalized. Because we have become used to being alienated from mainstream health care and support services, we have become used to being independent of these and resigned to their inadequacies and inability to meet our health needs.

We now need to feel empowered and be empowered. Health care professionals know that one of the ways to make people feel empowered is to involve them in community health actions, and to encourage them to input into healthy public policy.

However, as we all know, it is often much easier to talk about fostering public participation than to actually do it. It requires a lot of work, and it takes time and sensitivity to listen to all the voices. It also means sharing the decision making, sharing the power, and sharing the "turf." It means being able to say: "We don't have all the answers—we need your help." For example, as we are aware, community organizations have been and continue to be notoriously under-funded; yet many somehow survive. These "survivors" might have some interesting suggestions for balancing increasing demands with reduced financial resources.

Change begins by talking and listening. It continues with the formation of joint community hospital advisory committees that include all the players—lesbian, gay, and straight. It must look at partnerships. It must involve the removal of institutionalized homophobia within the health care system. It ultimately must recognize the validity of lesbian and gay health issues, and examine how to include these as part of on-going hospital services. Academically-oriented community health services must mean more than microscopes and magnifying glasses. If the goal of improving health in Canada is to be taken seriously, then we must develop and implement inclusive strategies which promote and enhance active involvement for all communities in decision-making around their health.

*A longer version of this article was presented to the conference: "Improving Health in Downtown Toronto: Defining a Role for the Wellesley Hospital in Developing Academically Oriented Community Health Services," May 30–31, 1991.*

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## Lesbians and Breast Cancer: *Challenges and Concerns*

A recent U.S. epidemiological literature review has suggested that lesbians are at a higher risk for breast cancer than heterosexual women. This may be because lesbians are not necessarily bearing children; there may be differences in dietary and drinking patterns; and lesbians may be having fewer gynaecological exams and fewer breast cancer screenings. However, there has not been a data-based study of risk factors for lesbians.

Furthermore, although lesbians are thought to make up five to ten per cent of the general female population there is virtually no existing information on lesbian health, lesbian health risks or lesbian health needs. It is very important to know that there is no data, no real information on this population.

Various studies have suggested that fewer than 50 per cent of lesbians identify their sexual orientation to their physician. One study found that less than six per cent of women had ever been asked about their sexual preference by a doctor. Other studies have found that 30 to 80 per cent of lesbians have reported negative reactions from health care providers when their lesbianism was disclosed.

Given the above, should lesbians become a special focus for breast cancer research? Until there is some guarantee that a woman's disclosure as a lesbian will not be used against her, I would suggest that the focus be on what we currently know and believe to be true—lesbians, like all women, are at risk for breast cancer. However, lesbians have less access to the health care system. Thus, the real issue here is the ability to access needed services. The main emphasis should be on health promotion, prevention, and intervention programs which are inclusive of lesbian needs.

More health promotion resources and programs must be made available, accessible, and pertinent to lesbians in the same thoughtful and targeted way that such services have been designed to meet the needs of other minority groups. For example, a brochure called "Women and Breast Cancer" will not attract lesbians,

but a brochure called "Lesbians and Breast Cancer" just might. The majority of literature on breast cancer does not acknowledge a lesbian presence. How many pamphlets focus on the existence of husbands—but what about lesbian couples, single lesbians, and single heterosexual women? How about the use of the more inclusive term "partner" or "friends" in breast cancer literature?

Breast cancer self-help and support programs, groups, bereavement programs, and other services should be inclusive of lesbians and be aware that needs of a single lesbian and/or lesbian couple may be different from that of the heterosexual couple or single woman. It can be as simple as showing two women holding hands amongst a group of varied women as part of picture for a promotional piece.

When talking with clients and patients, health care providers must address the automatic assumption of heterosexuality. This can be as easy and as inexpensive as encouraging and training staff to adopt more inclusive language.

I would also like to make a few additional recommendations: any new research initiatives should include lesbian participants; we must be looking at "access" to health care issues, that is, breast clinical exams, mammograms, etc. to find out what access difficulties lesbians may be having, when, where, and why; we must also be looking at the effects of homophobia; and lesbians should be looking at what epidemiological role we can or should be playing before someone makes that decision for us.

To conclude: breast cancer does not discriminate against lesbians, but unresponsive and homophobic health care providers, prevention programs, and public policy can and do.

*Excerpted from a paper presented by Heather Ramsay at the National Forum on Breast Cancer held in Montreal, Quebec November 14-16, 1993.*