I dedicate this paper to the raging spirit of Kathleen Martindale: leftist, feminist, educator, lesbian. Kathleen was killed by breast cancer on February 17, 1995, one of 5,400 women in Canada who will die of breast cancer in this year.²

In this presentation, I use the experiences and insights of women afflicted with breast cancer to illustrate how our understanding of breast cancer reaffirms, yet draws into question, cultural stereotypes of womanhood. I argue that what we 'know,' that is to say, what we believe to be true about breast cancer as disease and lived experience is profoundly shaped by the fact that women are the primary sufferers. Adopting the metaphor of women's bodies as a site of struggle, I explore three themes which shape the experience of breast cancer as disease.

First, I will examine how our knowledge of the causes of breast cancer is shaped by what the medical community believes to be true about women and their bodies, as much as by the scientific study and observation of the disease. The medical and psycho-social understanding of this disease is rooted in stereotypes and often assumes that women's bodies are inevitably or naturally defective. It often focuses on confirming these stereotypes rather than coming to grips with the skyrocketing incidence of breast cancer and providing sound, health-promoting strategies for prevention and avoidance of recurrence. This section is called, "Who Is To Blame?"

¹The author wishes to acknowledge the help of Rena Isenberg in writing this paper.

definition of women's bodies — breasts in particular — as sex objects means that breast cancer has the potential to 'disfigure' and defeminize women. Women with breast cancer inevitably subvert cultural stereotypes of femininity/beauty even as they struggle to conform. I argue that our society's fetishistic definition of women's bodies as sexual leads to an understanding of the experience of mastectomy and, to a lesser extent, chemotherapy as, first and foremost, threats to a woman's femininity, even though the women themselves are more likely to focus their energy and anxiety on the elemental issues of living and dying. I call this section, "Whose Breast Is It?"

Third, in response to the question, "Who Is in Control?" I explore how diagnostic and treatment protocols assume that women are compliant, 'good girl' patients, even as the lived reality of incomplete information, limited options, and invasive treatments pushes women with breast cancer to challenge the medical establishment on which they must rely.

Anticipating that these claims may seem improbable, I begin by offering a similarly structured argument as a guide to my reasoning. In her article entitled, "Sperm Meets Egg: The Story of a Scientific Romance," anthropologist Emily Martin demonstrates that "the picture of egg and sperm drawn in popular as well as scientific accounts of reproductive biology relies on stereotypes central to our cultural definitions of male and female." Martin shows how scientific descriptions of the fertilization process have both assumed and affirmed the traditional (aggressive and assertive) boy meets (passive and compliant) girl story. For many years, she notes, biology and medical texts characterized the egg in the story as a damsel in distress or a Sleeping Beauty awaiting her prince's charmed kiss. Even the updated editions of these texts continue to employ imagery which relies on traditional gender stereotypes. In the revised version of the romance, the egg is likely to be cast in the role of wicked and entrapping femme fatale. (The sperm, by contrast, has been consistently portrayed as the heroic male struggling to do his duty.)

Here, we find evidence that popular notions of what it means to be female and male in this society are so deeply embedded, so commonsensical, so invisible, that detached, scientific minds imbue microscopic bits of matter with human personality. However, the importance of this fairy tale is not that scientists are foolish sexists, rather, it lies in the unconscious use of a way of understanding and interpreting scientific

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evidence which first presumes, then proceeds to prove certain biological ‘facts.’ In this case, the sperm and the egg story induces the reader to accept as fact the commonly held belief that men, by nature, are aggressive and assertive while women are ‘naturally’ passive and compliant. The consequences for women are obvious and severe.

And so it is for breast cancer, I argue. Here, too, presumption blends into science.

Who Is To Blame?

In her cancer journal, the poet Audre Lorde wrote, "I had grown angry at my right breast because I felt as if it had in some unexpected way betrayed me, as if it had become already separate from me and had turned against me by creating this tumour which might be malignant." The threat of bodily betrayal, such as Audre Lorde experienced, is a common theme in cancer narratives. Many women write as though their breasts are the enemy. "Get them off me," one woman pleaded with her surgeon. It was liking have "two loaded revolvers pointed at my chest," another recounts. "Did I mourn for my breasts?" my friend Kathleen asked herself. "No, not exactly," she wrote, "I thought they were killing me."

Information on the causes and prevention of breast cancer encourages women to identify their bodies as the source of their misery. "Are you over fifty?" the pamphlets ask. "Have a mother or sister with breast cancer?" "Never had a child?" "Started your period before age twelve?" "Menopause after age fifty?" These are the risk factors which medical science associates with breast cancer.

This message fits well within a culture that sees women's bodies as defective and troublesome. Every day, women risk being exposed and humiliated by their bodies: hips/waist/thighs that are too big; hair that persists in growing in the wrong place; sexual desires that lead to untold consequences.

Women's bodies are constantly threatening to veer out of control. In the case of breast cancer, the problem, we are told, is too much of the female hormone, oestrogen. The growing incidence of breast cancer,
according to one researcher, results from the modern woman's 'incessant ovulation.' Earlier onset of menstruation coupled with fewer children — one or two instead of eight or nine — cause an 'excess' of menstrual cycles, he argues. 7 It's not 'normal' for women to ovulate four hundred times over their lifetimes, says Montreal's most prominent breast cancer specialist. 8

There is less science here than women have a right to expect. By targeting the production of oestrogen as the cause of breast cancer, the medical community pathologizes the natural functioning of women's bodies. According to Samuel Epstein, an expert in occupational and environmental medicine, cancer specialists remain "myopically fixated on obsolete 'blame-the-victim' theories of breast cancer causation." 9

Rather than an open-ended inquiry, researchers have latched on to the limiting assumption that women's bodies are naturally disease-producing. As a result, other possible causes, most notably environmental contaminants and diet, are ignored by all but a few.

The fixation on women's bodies as the source of the disease ignores the fact that seventy to eighty percent of breast cancers are 'unexplained;' that is, seven or eight out of ten women who develop breast cancer have none of the known risk factors, except age. 10 We know, as well, that one in ten women in North America — some say one in nine — can expect to develop breast cancer during their lifetime. Seventeen thousand new cases in Canada each year — an epidemic by any standard — and yet women are told only that their bodies produce too much oestrogen or that breast cancer runs in their families.

This woman-blaming approach to understanding breast cancer is compounded by the message that early detection is almost as good as a cure. 11 You've seen the ads: "Do breast self-exams." "Have regular mammograms." "See your doctor at the first sign of a lump." "Breast cancer can be cured!"

Breast self-examination and regular mammograms are touted as life-savers, implying that women who fail to 'look after themselves' are the

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10Batt, Patient No More, 198.
11"When breast cancer is discovered early and treated early, the chances for recovery are good!" Canadian Cancer Society, "Information about Breast Health," 1991.
cause of their own illness. Yet, breast self-examination is of unknown usefulness. There has never been a study that shows that it reduces the death rate. But this should not be surprising: a breast lump large enough to be palpable is already ten years old.\textsuperscript{12} So much for the benefits of early detection.

"The standard line is that women feel empowered by self-exams," says Susan Love, a surgeon and breast cancer specialist, "but that's not my experience . . . We use it to put the blame on women." "By pushing BSE so hard," she continues, "we've alienated many women from their bodies — they're taught to do it like a search-and-destroy mission, like their breast is the enemy that will do them in."\textsuperscript{13}

The facts about mammograms are no more encouraging. The most enthusiastic adherents to the breast screening programme are women under the age of fifty;\textsuperscript{14} yet, we know that mammograms are an unreliable diagnostic tool for pre-menopausal women whose relatively dense and fibrous breast tissue can obscure, or even resemble, tumours. For women under fifty, the proportion of breast lumps incorrectly identified as likely to be cancerous — in which case, the lump may be benign but the overall experience terrifying — is a startling thirty-eight percent. Even more worrying is the risk of false negatives and the accompanying false sense of security: If mammograms were given "to every woman in her forties who had breast cancer too small to feel, nearly forty out of one hundred cancers would be missed."\textsuperscript{15} For these reasons, \textit{Ms} magazine advises pre-menopausal women to avoid mammography except to evaluate suspicious lumps detected by other means.

For women over fifty, a group for whom regular mammograms are recommended by the medical community and the Canadian Cancer Society, a single mammogram fails to detect cancer thirteen percent of the time.

My intent, here, is not to discourage women from performing breast self-examination or having mammograms; rather, my purpose is to emphasize that early detection is \textit{not} prevention. How to avoid the disease is what women want to know for themselves, their daughters, and their nieces. What we are offered instead is the possibility of early detection, high tech interventions, and hope of a cure. Moreover, the

\textsuperscript{12}Batt, \textit{Patient No More}, 59.
\textsuperscript{13}Morgan, "The Politics of Breast Cancer," 65.
\textsuperscript{14}Batt, \textit{Patient No More}, 40.
\textsuperscript{15}Morgan, "The Politics of Breast Cancer," 60.
widely accepted understanding of breast cancer as caused by women's bodies 'gone wrong' encourages researchers to look for ways to alter and 'fix' what is defective. Thus, we find that vast sums of money and ingenuity are being directed to research, the outcome of which is to 're-engineer' women's endocrine system.

The controversial tamoxifen trials are part of this enterprise. Tamoxifen is a synthetic hormone that inhibits the natural production of oestrogen. Because it has proven beneficial to certain groups of women (notably women over the age of fifty whose tumours were classified as oestrogen dependent), researchers have begun testing tamoxifen — an expensive drug with known adverse health effects — on healthy women with an elevated, that is to say, a two percent, risk of developing breast cancer within five years. Adrian Fugh-Berman, a physician with the National Women's Health Network in the US, believes these trials herald a new era in preventive medicine. In her words, "Where previously we battled external sources of harm, we have now turned our sights towards internal enemies. The war against normal physiology has begun."

In the meantime, nothing much is being said or done about the contaminants in our food, water, and air. Despite numerous examples of site-specific, breast cancer 'hot spots' such as Montreal and Long Island, New York, only a few studies explore the possible causal connections between exposure to chemicals and breast cancer. Most hopeful from these is the hypothesis — not yet proven — that fat-soluble chemicals such as chlorine compounds mimic or amplify the cancer-causing effects of oestrogen.

These kinds of studies, which look for risk factors outside of women's bodies, may lead to prevention strategies that will save women's lives; whereas, three decades of conventional cancer research has not slowed the death toll. The medical community must set aside assumptions that categorize women's bodies as inherently defective. Women are not at fault; we're at risk.

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17 Ibid., 195.
18 Ibid., 192.
Whose Breast Is It?

Descriptions of the experience of mastectomy — still the most common treatment for women with breast cancer — are often agonizing accounts of body hatred that persists for months, occasionally years, after the surgery. Some women talk of being 'repulsed' by their new body image. They describe themselves as 'mutilated' and 'deformed;' they cannot look at or touch themselves; they feel less attractive, less sexy. Anecdotal evidence suggests that breast cancer patients are anxious about their physical appearance and their worth as women. In one instance, a woman searched for months for a breast form with just the right nipple. Another reported that she solved the problem of having only one breast by wearing her bra to bed.

The socialization of women places great emphasis on the importance of the body as sex object. It is women's role to be viewed, admired, and judged. From puberty onwards, breasts are central to that project. Breasts define who women are in this culture. They are the markers of our femininity; the outward sign that we conform to the social expectations of what it means to be a woman. Even though we have almost no control over breast size, this does not prevent us from worrying, being ashamed, being proud if we feel — or others make us feel — that our breasts are too small, too large, or just right. Watching our breasts grow and develop is closely associated with the process of coming to terms with, and taking on, the responsibilities of adult women in this society — as sex objects, lovers, and mothers.

So, when we begin to look at the literature on breast cancer, it does not seem surprising to find that a great deal of attention is focused on the 'disfiguring' aspects of breast surgery or to see the amount of effort and emphasis devoted to the subject of breast reconstruction to re-establish a woman's outer (unchanged, apparently 'healthy' and 'normal') appearance. The medical and scientific community has rallied around this view of mastectomy as profoundly disruptive to a woman's sense of self. Many studies are predicated on the hypothesis that "the fundamental female role is seriously threatened by breast cancer." Breast cancer is generally thought to be a "particularly catastrophic

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22Ibid., 75.
experience" that entails "special problems associated with adjustment."  

We learn, for example, that breast cancer patients are referred for psychiatric counselling at a significantly higher rate than other cancer patients.

The prevailing view is that women with breast cancer wish to — or, at the very least, ought to — hide the 'disfiguring' consequences of the disease. Thus, we can observe the popularity of reconstructive surgery, breast forms, wigs, and the "Look Good . . . Feel Better" campaign sponsored by the cosmetics industry that teaches women how to mask the enervating effects of the disease and its cures.

As in many other areas of women's experience, however, it is important to ask whether this is really how most women feel, or do we accept this description as true because of the assumptions that most of us (including women) bring to the subject and take for granted. There is considerable evidence that the push towards understanding the loss of a breast as the major trauma in breast cancer arises from a "tendency to draw conclusions that may be founded more in stereotypes of women than in sound data." To put it somewhat more colloquially, we need to ask whose script this really is.

Interviews of women with breast cancer suggest that the socially constructed choice between life and femininity is more laid on than truly felt. There is little empirical evidence "to support either the primacy of body image concerns for most breast cancer patients or the psychological importance of helping women 'look feminine' as quickly as possible." In one study, only six percent of breast cancer patients thought the breast was a uniquely sensitive or troubling site for cancer. What heightened their levels of distress were changes in their health, not changes in their physical appearance. Other studies have shown similar results: breast loss was not the primary cause of psychological problems experienced by women with breast cancer.

What are the important concerns? 'Future health' was overwhelm-

24 Ibid., 80.
25 See, for example, "Look Good . . . Feel Better," Canadian Images (Summer 1994), 50pp insert; and Batt, Patient No More, 228-29.
26 Meyerowitz, "Sex Roles and Culture," 76.
27 Ibid., 81.
28 Ibid., 84.
29 Ibid., 80.
ingly chosen ahead of changes in physical appearance as the central concern of women with breast cancer even as their friends and loved ones incorrectly assumed that breast loss, rather than the cancer, was the sufferer's primary concern. Based on responses from breast cancer patients and from disease-free men and women, one researcher identified three perspectives:

[Those of] men (who distinguish cancer from breast cancer quite strongly, and focus on breast loss); [those of] women (who make less of a distinction, and emphasize breast loss less); and [those of] women with breast cancer (who made a distinction between breast cancer and cancer at other sites, but who do so mainly on a medical basis, and who feel that breast loss is a matter of secondary concern).  

Many women's cancer stories tell how the conventions of womanhood are enforced by others even when the woman, herself, is struggling to build a new physical identity. Audre Lorde, seeing her surgeon after her mastectomy, was told that she should wear her prosthesis because without it she lowered morale in the office. And there is Barbara Rosenblum who, sick from many weeks of chemotherapy, dutifully donned a wig at her mother's insistence. And Darlene Betteley, who rejected the idea of wearing prostheses after her double mastectomy. She was 'fired' from her position as a Reach for Recovery volunteer for the Canadian Cancer Society. "The real truth," Audre Lorde wrote, "is that certain other people feel better with that lump stuck into my bra, because they do not have to deal with me nor themselves in terms of mortality nor in terms of difference."

The intertwining of personal and social pressures makes it difficult for women with breast cancer to sort out whose body it is. Most of us have been programmed to view our bodies only in terms of how they look and feel to others, rather than how they feel to ourselves. Having been told she was bad for office morale, Audre Lorde realized that this

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31Ibid., 83.
33Sandra Butler and Barbara Rosenblum, Cancer in Two Voices (San Francisco: Spinsters Book Company, 1991), 113.
34Batt, Patient No More, 224-27.
35Lorde, The Cancer Journal, 64.
36Ibid., 64.
attitude towards breast prostheses was an index of "society's attitudes towards women in general as decoration and externally defined sex object." The emphasis on looking normal, Lorde argued, reduced the experience of breast cancer to a cosmetic crisis. For her, the challenge was clear: "either I would love my body one-breasted now, or remain forever alien to my self."

The sensibility of "Look Good . . . Feel Better" threatens women's ability to see themselves as they are. To look as 'normal' as possible denies what is happening to the body; disguises the fact that it refuses to conform to the feminine script; and encourages women to disown their 'imperfect' selves. In Audre Lorde's view,

The emphasis upon wearing a prosthesis is a way of avoiding having women come to terms with their own pain and loss, and thereby, with their own strength . . . When other one-breasted women hide behind the mask of prosthesis or the dangerous fantasy of reconstruction, I find little support in the broader female environment for my rejection of what feels like a cosmetic sham . . . I believe that socially sanctioned prosthesis is merely another way of keeping women with breast cancer silent and separate from each other.

What good are these replacement parts to women? In other amputations, with other prosthetic devices, function is the main point of their existence. Neither a breast form nor a reconstructed breast is functional: neither helps a woman perform daily tasks; neither offers her any sensation or feeling. The recreated breast is 'functional' only if we accept that looking 'normal,' looking 'feminine' is a central, daily task for women. Audre Lorde wrote:

When I mourn my right breast it is not the appearance of it I mourn, but the feeling and the fact. But where the superficial is supreme, the idea that a woman can be beautiful and one-breasted is considered depraved, or at best, bizarre, a threat to 'morale.'

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38 Ibid., 44.
39 Ibid., 49, 16.
40 Ibid., 63.
41 Ibid., 65.
Who Is In Control?

The experience of breast cancer leaves many women feeling alienated from their bodies and estranged from their treatment 'team.' Sharon Batt, a journalist and breast cancer activist, explains:

We are labelled 'patients.' We are thrust . . . into a medical system governed by undisclosed rules. Here, 'compliance' gains approval. Physicians speak to us in the private jargon of medical science, or with an infantilizing 'there, there dear' paternalism.42

Even when the physician's words are comprehensible, their meaning and importance can be elusive. Told that her lymph nodes must be removed, Sharon Batt realized that she didn't know what lymph nodes were exactly, but thought she might want to keep hers. Was the operation risky? Batt asked. It could leave your arm paralysed, the surgeon replied. "Permanently?" she gasped. "Perhaps permanently," was all he was willing to say.43

This is not an unusual story. In the name of full disclosure, oncol­ogists and surgeons often convey important information in a form that is both confusing and frightening for the patient. Time and again, women report that they are offered choices without real alternatives. Betty Rollin, a sharp and tough TV personality decided that her surgeon's suggestions sounded reasonable enough. "Anyway, what did I know?" she asked herself. "I had checked out his reputation and it was good. I had to trust him." My friend, Kathleen, found herself in a similar predicament. "Why, then, did I do it?" she asked after recounting the horrors of radiation and chemotherapy. "I felt I had no alternative," was her response.45

Health-care professionals speak of patient empowerment and consumer choice when, in fact, all of the important decisions have already been made. It is thin "choice" indeed to decide whether or not to have some combination of surgery, radiation, and chemotherapy because these are the only treatments on offer. The treatment protocol dictates the next move; the woman's only choice is to proceed or not. The issue seems stark: Do you want to be cured or don't you?

42Batt, Patient No More, 287.
43Ibid., 9.
44Rollin, First You Cry, 58.
Throughout the ordeal compliance is expected. Sharon Batt and my friend Kathleen were labelled "resistors" when they insisted on more information than the system was used to providing.46

Breast cancer is commonly experienced by women as men in control . . . of everything except the emotional burden of the disease. On hearing the news, Betty Rollin fainted, whereupon her surgeon left the room. Coming to, she overheard him say, "You never know about these things. Her doctor said she could take it . . . Everybody wants you to be honest . . . and look what happens."47

There is nothing soft, that is to say, feminine about cancer treatments. It's all 'big guns' and high tech: yet another war on women in which medical weaponry is trained to search and destroy female bodies. Both radiation and chemotherapy are domestic applications of war technologies and military descriptions of their effectiveness are commonplace. The cancer is 'bombarded,' there are 'mop-up' operations and strategy debates: Are a few big hits better than many smaller ones? Is it better to attack in the morning or late in the day? Should we take the offensive before serious trouble develops, or keep 'the big guns' as a last resort?48

There is little interest in, even tolerance of, 'softer' treatments that do not invade and sicken the body. Sharon Batt describes what she believes is the oncologist's "tumour-centred view of the world."49 Like most women, Batt was not 'sick' when she was diagnosed with breast cancer — just the contrary, she was on a month-long bicycle tour of France when she discovered the lump. Batt became 'sick' only when she started treatment. She suffered all the classic side-effects: hair loss, nausea, deep fatigue, and the early onset of menopause.

The price of adjuvant radiation and chemotherapy — more and more, the standard treatment after surgery — is women's good health, a commodity the cancer community systematically undervalues, Batt argues. "For me, good health was a precious resource I wanted to guard; for [the oncologist], it was a signal I could withstand greater devastation."50

The choice between good health now and more months of life later

46Batt, Patient No More, 9-10; Martindale, "My (Lesbian) Breast Cancer Story," 140.

47Rollin, First, You Cry, 36.

48Batt, Patient No More, 93.

49Ibid., 106.

50Ibid., 99.
on is profoundly unsettling. But having embarked on the project there is no turning back. Kathleen described the need to psych herself up for her bi-weekly self-poisoning with nitrogen mustard tablets. She wrote:

I'd meditate before taking them. I never lost the feeling of profound conflict about what I was doing to my self. Of course, you don't know whether chemotherapy has worked until you have a recurrence, then, as with the other cancer treatments, you know it hasn't.\textsuperscript{51}

Oncologists typically define quality of life more narrowly than do patients. Few physicians think to ask what breast cancer means to their patients. Were they to do so, they might realize that 'no treatment' is a real alternative for some women, not evidence of craziness or blind rejection of the benefits of modern medicine, as is often thought.

The demand for 'softer' treatments — treatments that do not invade and sicken — is one measure of the growing determination of women with breast cancer to assert control over what is happening to their bodies. In many ways, women with breast cancer are resisting the 'good girl' role that has forever been theirs. The willingness to adopt a new diet, the popularity of the cancer narrative, the religious quest, all bear witness to a woman's need to understand and take ownership of the breast cancer experience. For their efforts, women are more likely to be belittled than praised by a medical community that gives little credence to approaches not its own.

The deadliness of breast cancer pushes women to organize and speak out about the disease. Inspired by the AIDS movement, organizations such as Breast Cancer Action Montreal seek to provide women with real choices. From opposing the tamoxifen trials to demanding that researchers investigate environmental causes of cancer, women are insisting that they have a role in the decisions that affect their lives. Sharon Batt writes, "From the moment of diagnosis, we are protagonists in a drama which may end in our death. If ever we should feel fully engaged, it is now."\textsuperscript{52}

\textsuperscript{51}Martindale, "My (Lesbian) Breast Cancer Story," 145.

\textsuperscript{52}Batt, Patient No More, 287-88.
THE FUTURE OF HEALTH CARE: LESSONS FROM THE AIDS MOVEMENT

Alan Sears

The 1990s are seeing health care systems scrutinized and rethought at many levels. In Windsor and Essex County, the District Health Council is directing a reconfiguration of health care which is couched in the highly optimistic terms of a "Win/Win Solution." However, the major dynamic driving this rethinking of health care delivery is actual or anticipated cutbacks in government funding.

The AIDS movement has important lessons to contribute to debates about the future of health care. The activist response to AIDS has produced a challenge to the established social relations in health care. The central focus of the AIDS movement has been to promote the control of people living with HIV/AIDS over their own bodies and lives. This has meant challenging the power of experts (such as doctors) and state officials to decide what is best for those affected by HIV/AIDS. This challenge has been accomplished through various forms of collective mobilization.

There is much of value to be learned from this challenge to the health care system. There is also, however, reason to fear that the wrong lessons will be learned in the present context. The AIDS movement was not about developing 'community-based' alternatives to the medical system. People living with HIV/AIDS need extremely expensive high-technology medical care as well as a variety of community-based services providing information, support, education, and advocacy. There is a great danger that policy-makers will use the rhetoric of the AIDS movement to put a progressive gloss on a straightforward reduction of services.

People living with AIDS in the early years of the epidemic faced blame, rejection, condemnation, inaction, and indifference at the highest levels of the health care system and the state. They organized, along with others affected by the epidemic, to struggle against that response. It would be the ultimate disservice to this mobilization to use it as a cynical justification for cutbacks to health care services. The real
lesson of the AIDS movement is not about the effectiveness of community-based services, but rather about the relationship between health and social justice.

The AIDS Movement — Official Inaction

The AIDS movement developed as an already politicized community mobilized to confront the epidemic in the face of official inaction. AIDS was first constructed as a syndrome in 1981 based on the reporting of clusters of cases of PCP and KS among gay men in New York and San Francisco. From the outset, AIDS was constructed as a 'gay disease.' Indeed, one of the early names given to the syndrome was GRID (Gay Related Immune Deficiency). In more popular terms it was known as 'gay cancer' or 'gay plague.'

The construction of AIDS as a 'gay disease' had an enormous impact on its development. The initial official response by governments in Canada, the United Kingdom and the United States was silence and inaction. The early years of the epidemic (approximately 1981-1985) saw virtually no government action in the areas of treatment, prevention or advocacy for people living with HIV/AIDS, not even in the limited form of official pronouncements that identified the problem. Many sources argue that this initial phase of inaction was connected to the construction of AIDS as a gay disease which would do no damage as long as it didn't bridge over into the 'general population.'

The silence of this period was broken only for bouts of 'just say no' moralizing. AIDS was presented as the symptom of a moral problem, to be treated by campaigns which promoted rectitude through fear. Early British AIDS campaigns, for example, employed dire images of death to show the dangers of AIDS, yet offered no concrete advice on how to prevent infection except to avoid 'promiscuity.' Gay men were told to avoid sex rather than how to have sex safely. This reflected an attitude that gay sex was something that could (and perhaps should) be avoided. It is difficult to imagine a similar injunction against heterosexual sex.


Of course, AIDS is not the first medical condition to be approached in moral terms. Early in the twentieth century, tuberculosis was regarded as an indicator of 'moral degeneration' among the working classes in the urban centres of Britain, Canada, and the United States. AM Brandt discussed the parallels between early AIDS campaigns and those mounted against sexually transmitted diseases at the time of World War I. This moral dimension to public health campaigns has generally focused the blame for ill health onto those who suffer from it, shifting the spotlight away from the social conditions which promote ill-health (such as poverty) or the gaps in health care delivery.

The response to AIDS in terms of inaction combined with 'just say no' moralizing is very much connected to the construction of it as a 'gay disease'. From the earliest days, AIDS was associated with an 'epidemic of blame' which has impaired prevention and treatment endeavours. Preventive efforts have been hampered by an unwillingness to speak frankly about gay sex (or sexuality in general) combined with a resilient belief among heterosexuals that a 'gay disease' could not infect them through straight sex. Treatment has been impeded by the persistence of AIDSphobia, the irrational fear of AIDS. The rational fear of AIDS, based on the use of effective measures to block the known routes of transmission, can help combat new infections. In contrast, the irrational fear of AIDS leads to various forms of 'quarantine' based on totally unfounded fears of casual contagion.

AIDSphobia has been remarkably resilient despite improved AIDS education. This resilience can be explained largely in terms of the correlation between AIDSphobia and homophobia, prejudicial attitudes against lesbians and gay men. Studies show that individuals with anti-gay attitudes are far more likely than others to have irrational fears about HIV transmission.

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The construction of AIDS as a gay disease has been maintained despite many kinds of evidence to the contrary. Cases of AIDS were identified among people who were not gay in the very early days. Scientific knowledge of the routes of transmission for HIV clearly shows that unprotected heterosexual intercourse is a high risk for both partners. The vast majority of cases world wide (75 percent according to the World Health Organization) result from heterosexual transmission. It is still true in Canada that the gay male community has been the most affected by AIDS, but it is only through homophobia that this statistic is transformed into a myth of heterosexual immunity. Anti-gay attitudes underlie the deeply-held belief that 'normal' sex is somehow inherently safer.

Community Mobilization

The construction of AIDS as a gay disease has had tragic consequences. The lives of people with HIV and AIDS are made far more difficult by the presence or anticipation of discrimination and irrational fears. Many people have been infected when that might have been prevented through effective intervention. Others carry on with unsafe activities with the false assurance that their 'normalcy' will save them.

At the same time, the development of AIDS in an already politicized community has led to important mobilizations in response to official inaction. These mobilizations, which I collectively label the 'AIDS movement', have ranged from informal networks through which people living with HIV/AIDS share knowledge about treatment to formal organizations which offer services (like the AIDS Committee of Windsor) or concentrate on political action (like AIDS Action NOW or ACT UP). The AIDS movement first developed in lesbian and gay communities, usually drawing on the skills and perspectives of people who had some experience in advocacy, community-building or political organizing.

The significance of the development of AIDS in an already politicized community goes beyond the presence of a skills base and an inventory of existing organizations. The AIDS movement built on the legacy of previous struggles for lesbian and gay rights. This legacy contributed to the development of an orientation to issues of health and illness, particularly around issues of the state, medical expertise, and the importance of collective action.

First, the AIDS movement developed with a somewhat oppositional approach to the state. The struggle against various forms of state
regulation has been a central feature of the lesbian/gay movement. People who had fought against censorship and police harassment were unlikely simply to trust the goodwill of states that would not even recognize their rights or their relationships. Certainly, the AIDS movement has made demands on the state (for funding and services) but it has generally opposed measures that would increase state power over people living with HIV/AIDS (such as reporting by name the people who test HIV positive to public health authorities).

Secondly, the AIDS movement has been highly critical of 'experts' in general and medical practitioners in particular. Through much of the twentieth century homosexuality had been pathologized, treated as an illness. It was only in 1973 that the American Psychiatric Association removed homosexuality from the list of mental illnesses. People were unlikely to hand themselves over without reservations to a medical system that until quite recently had been trying to 'cure' them of being gay.

Thirdly, the lesbian/gay movement had taught people the importance of collective action. The contemporary lesbian/gay movement grew out of the Stonewall riots in June 1969. The gains that lesbians and gays have made since Stonewall can be attributed to the militancy and activism that have shaped the movement at its highest point. This experience in building a social movement provided a framework for responding to the AIDS crisis. AIDS could not be approached as an individual medical problem to be dealt with only through health care. Only a collective response could challenge the inaction and the prejudice that confronted people living with HIV and others affected.

**Challenging Health Care**

The accomplishments of the AIDS movement have been crucial for people living with HIV/AIDS and others affected. The first accomplishment was the invention and popularization of safer sex education. The seminal 1983 pamphlet "How to Have Sex in an Epidemic" by Berkowitz, Callen and Dworkin is regarded as the first serious guide to the safer sex practices that are commonplace today. These practices

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did not originate with public health officials, who in the early period had focused basically on anti-sex and anti-promiscuity messages. The safer sex message was carried into the community by AIDS organizations who developed innovative, appropriate, and erotic ways of disseminating it in a variety of situations. The result was one of the most successful behavioural change campaigns in public health history. The use of safer sex among members of the gay male community is impressively high, even if there is still important work to be done in certain areas.

The second important accomplishment of the AIDS movement was the development of a network of support and advocacy services for people living with HIV/AIDS. AIDS service organizations across North America formed support groups and offered other services such as case management. Buddy systems linked people living with HIV on a one-on-one basis with trained volunteers who could help in a number of ways ranging from daily chores to personal discussion. AIDS service organizations acted as advocates for people living with HIV/AIDS in their dealings with the health care system, government services and other institutions. This has contributed to breaking down the isolation of people living with AIDS, provided a single point of entry to the wide variety of health and social services that may be required and challenged discrimination in treatment and service provision.

The third area of accomplishment for the AIDS movement has been in the dissemination of treatment information. AIDS-related medical conditions are particularly complex as they consist of a whole range of opportunistic infections developed in response to immune deficiency. It is a tremendous challenge for anyone to keep on top of this very wide range of medical problems as well as ongoing treatment developments. People living with HIV/AIDS often learned more from informal folk networks of peers than from their doctors. These networks have been formalized and it has become a major priority for AIDS services to get useful and accessible information into the hands of people living with HIV/AIDS.9

A fourth accomplishment of the AIDS movement has been winning demands for improved funding and services. Following the period of official inaction, the late 1980s and early 1990s saw a tremendous increase in funding to AIDS services as well as the release of

9See, for example, the impressive self-help publication, M Whitehead, and B Patterson, Managing Your Health: A Guide for People Living with HIV or AIDS (Toronto: Community AIDS Treatment Information Exchange and The Toronto People Living With AIDS Foundation, 1993).
experimental treatments and other important changes. The AIDS movement succeeded in placing considerable pressure on governments, drug companies and other organizations. These improved levels of service are certainly at risk as the wave of cutbacks sweeps through health, education, and social services in Canada, the United States and elsewhere.

Finally, the AIDS movement has succeeded in developing new ways of grieving appropriate to the memories of people who have died from AIDS-related causes and to those they leave behind. This has included the development of innovative forms of memorial service for individuals as well as public projects such as the AIDS quilts in the United States and Canada and the AIDS memorial in Cawthra Park in Toronto. At their best, these memorials have combined specific recognition of individuals who have died with a general sense of community loss, particularly in lesbian and gay communities where the losses have been devastating. They are often secular in tone, reflecting the diversity of the communities who have most directly felt the losses and the exclusion that members of these communities have felt from traditional religious institutions.

These accomplishments add up to a challenge to the social relations which shape health care in contemporary society. The AIDS movement has used collective action to increase the power of those whose health is at stake over their own bodies and lives. This has meant making the resources and information available to people affected so that they can make choices about treatment and prevention. The emphasis on the active role of those whose health is at stake is demonstrated even in the terminological preference for the label 'people living with HIV/AIDS' rather than 'AIDS victims' (implying passivity) or 'AIDS patients' (describing only a specific location in medical relations).10

The debate about HIV testing in the late 1980s and early 1990s provides an important example of the challenge mounted by the AIDS movement.11 At that time, AIDS organizations generally supported anonymous testing which would permit people to find out their HIV status without providing identifying information that could be reported to public health officials. The test was exclusively for the use of the people being tested, permitting them to control completely information concerning the results. The AIDS movement argued that anonymous

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testing would provide the conditions under which more people would come forward to get tested as the first step in a process of taking control over their health.

Public health officials often opposed anonymous testing. They tended to support procedures compatible with the reporting of HIV-positive cases. They wanted to know who was infected to permit the tracing of previous sexual contacts and to monitor safer sex practices. AIDS activists fought against the use of these traditional public health practices on the grounds that they compromised the privacy and safety of people living with HIV/AIDS. They were concerned that these procedures might drive people underground, creating a situation where it was preferable to forego testing in order to avoid the intrusion of public health officials. In Ontario, the AIDS movement won on this issue and anonymous testing is now available at numerous locations across the province, including sites in Windsor.

None of this would have been possible without the support and participation of committed individuals within the health care system. The AIDS movement has, to a large extent, approached the health care system as an outsider, but it has relied the work of insiders in many areas. In cities across North America particular doctors and nurses invested tremendous time and good will in the up front learning required to assist with the medically highly complex treatment of people living with HIV. The AIDS movement has not necessarily been anti-medical, though it has certainly been highly critical of the health care system and the medical establishment.12

The AIDS movement did more than fill the vacuum left by official inaction. It developed an approach to health care that challenged established social relations in medicine. The movement's origins in the lesbian/gay community contributed in crucial ways to this approach. Yet this has also raised issues as the face of AIDS changes. It could be argued that a coalition model has been followed (with more or less success) in work with other politicized communities (women, ethnocultural communities). This has certainly created stresses and strains and battles about priorities, though it has also produced some very useful programs that have taken the AIDS movement's approach in appropriately adapted forms to new communities.13 The issue of how

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12 There is a current within the AIDS movement which is avidly anti-science and therefore anti-medical. The debates about the relationship of the AIDS movement to science and medicine lie outside the parameters of this paper.

13 There has been a specific debate around the 'de-gaying' of AIDS: E Rofes, "Gay Groups vs. AIDS Groups: Averting Civil War in the 1990s," Outlook 2, no.
this model relates to communities who are not organized and politicized (e.g. injection drug users) or those outside the parameters of organized communities (e.g. men who have sex with men but do not identify as gay) remains an important one which has not been fully addressed.

Health Care and Control

The AIDS movement is not the first to mount such a challenge to the relations of health care. There are notable parallels with the women's health movement and the struggle for workers' health and safety. In each of these cases, health issues emerged in an already politicized context with pre-existing forms of organization. The women's liberation movement of the 1960s produced the women's health movement, while health and safety struggles have been connected to workplace organization, particularly unionization.

The struggle for information played an important role in these movements. The women's health movement saw the publication of important sources such as the book, *Our Bodies, Ourselves*, which aimed to educate women so that they could take charge of their own health. The 'right to know' has played an important part in health and safety struggles, where workers demand accurate information about the risks associated with dangerous materials or situations. As well, each of these movements has gone beyond the right to know to demand the power to act. Unions have fought for the right to refuse unsafe work. Women's organizations have fought to develop the basic services (abortion clinics, women's health centres) required to offer women genuine choices.

Each of these movements has developed some embryonic form of the politics of health 'from below.' The central feature of this set of politics is an emphasis on people taking control over their bodies and lives through collective action. It is a challenge to the idea that health comes 'from above,' through the actions of the state or the medical system. Certainly, the struggle for health 'from below' necessarily includes demands for full access to comprehensive health care services.

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4 (1990): 8-17. Critics such as Rofes argue that the AIDS organizations have been ditching their lesbian/gay identities in order to 'pass' as health agencies. These critics see a broader focus for the AIDS movement, not as a step in the direction of inclusiveness but rather as a capitulation to homophobia.

14 These parallels are explored in detail in Sears, "Contradictions," 41-42.

It also includes demands about the way these services are organized, challenging the power relations implicit in the medical model, such as the control exercised by experts. It goes demanding a role for 'consumers,' a very popular term in health care planning drawn from the market place which describes the place of individuals in the purchase of commodities. The model of shopping does not place sufficient emphasis on the idea of people whose health is at stake as activists on their own behalf.

It is important, in the current context, to distinguish health-care-from-below from health-care-on-the-cheap. The critique of the social relations of health care can be appropriated to serve as window-dressing for cutbacks. That is certainly what happened through the program of psychiatric de-institutionalization in the 1970s and 1980s. Governments took up the language of community-based alternatives as they shut down repressive psychiatric institutions. They did not seriously engage in the development of alternatives and in the end people wanting or needing help for mental health problems were left with fewer available services. Paul Martin's 1995 budget makes it very clear that we are facing a context of cutbacks in which it is logical to suspect that any shift in the organization of health care delivery is simply a way of packaging service reductions and lay-offs.

People living with HIV and AIDS have benefitted from top quality hospital care as well as community services. No number of buddies, support groups, or case managers can replace good hospital treatment and care for those who need it. The aim has been to improve access to medical services, not to erode them. No amount of treatment information can replace the diagnostic and therapeutic skills of medical professionals. The aim has been to challenge the experts' monopoly on knowledge, not the existence of experts.

The final lesson from the AIDS movement concerns the limits of health care. It is possible to challenge and improve health care, to make demands for full access to comprehensive health care under the control of those whose bodies and lives are at stake. It is possible to win some victories that lead to genuine reforms. However, these reforms can only go so far in a society based on inequality.

For people to be truly healthy, we need a healthy society. On a global scale, poverty is the sharpest indicator of risk for HIV infection.

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(the poorer someone is, the more likely he/she is to be infected). The 1990s are seeing an intensification rather than reduction of poverty on a global scale. People living with HIV/AIDS will suffer from deep cuts in health care and social programs as well as the erosion of international assistance and chronically high unemployment. The return of public health threats such as cholera and tuberculosis is a sign of a world where absolute poverty is on the increase.

Poverty is not the only manifestation of inequality that is related to ill-health. Discrimination against lesbians and gays has contributed in many ways to the spread of HIV infection, whether through official inaction or the false reassurance among heterosexuals that they could not catch a 'gay disease.' Sexism contributes to ill-health, for example making it very difficult for women to insist on safer sex practices. Racism contributes to the chronic neglect of the health needs of people of colour and aboriginal peoples.

The control over our bodies and lives cannot be achieved through good health care alone. It requires an exhaustive challenge to social relations of inequality at every level of society. The AIDS movement has offered a number of important lessons about what health is and how to obtain it. It has produced important developments in services and programs It has shown the importance of collective action in the struggle for health. The ultimate lesson of the AIDS movement, however, is that the struggle for health is at the same time a struggle for social justice, against all forms of inequality and discrimination.

\[17\] Sabatier, Blaming Other, 4.