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### Introduction: Leading Lesbians Fight Disease and Disability

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## **Introduction: Leading Lesbians Fight Disease and Disability**

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*This thematic issue of the Journal of Lesbian Studies focuses on the ways in which lesbian leaders have dealt with disease and disability. In the articles that follow, eight prominent lesbians describe what it means to cope with serious illness and medical treatment in the context of lesbian identity and community. This introduction provides an overview of some of the themes that arose in the various articles, focusing on lesbian support systems as well as best medical practices.*

**KEYWORDS** *lesbian leaders, lesbians fighting disease and disability, lesbians and medical treatment, lesbians coping with illness, lesbian support systems, best medical practices*

*Note from Esther: The impetus for this journal issue arose when my close friend Nanette Gartrell, a physician and leader in the lesbian community, experienced serious medical symptoms that no one seemed able to diagnose or treat. Our conversations during that time focused on the large number of lesbians we knew who had experienced a disease or disability. We decided to focus an issue of the Journal of Lesbian Studies on personal accounts of lesbian leaders coping with serious medical issues.*

How do lesbians fare during times of illness and disability? Although this topic has not had much attention, lesbians who came out during the women's and gay liberation movements in the late 1960s and 1970s are growing older and experiencing health problems. Because leaders in our lesbian communities have been at the forefront of analysis and activism about many issues, we believed that we could also benefit from learning about their health challenges and triumphs.

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The lesbians included in this issue span a variety of leadership positions—in health advocacy, law, athletics, psychotherapy, the corporate sector, medicine, research, poetry and fiction, information technology, philanthropy, and community activism. Most of them are considered leaders in more than one of these fields. Yet being a woman, a lesbian, and a leader can be complex. Elana Dykewomon reflects on lesbian leadership as fluid and situational, rather than hierarchical.

Due to their prominent roles in our lesbian communities, we had heard either directly from them, or through the grapevine, that they had experienced serious illness or disability. Their medical symptoms and diagnoses were diverse, including breast cancer, ovarian cancer, thyroid cancer, leukemia, kidney disease, dysphonia, pancreatitis, ALS (amyotrophic lateral sclerosis), and a genetic deficiency. We also know of many lesbian leaders who are not included in this issue who suffer from diseases and disabilities not covered in the present volume.

We chose to focus on lesbians in the United States because the United States is somewhat unique (and infamous) in not having national health insurance. Consequently, there is a vast and confusing array of health services and choices that vary enormously in cost and quality. This means that a number of authors needed to make sudden, crucially important medical decisions at a time of maximum physical pain, stress, and emotional fragility.

We gave each author a choice of writing about her own experiences or being interviewed by us. For those who elected the latter, interviews were audiotaped, transcribed, edited, and sent to the author for final changes and approval. At the time that we began inviting leading lesbians to contribute to this special issue, we learned that Barbara Brenner had passed away. We are extremely grateful that Suzanne Lampert, Barbara's partner of 38 years, was willing to be interviewed about Barbara's life and illness.

Each author described her illness and/or disability, gave an overview of the treatments, and provided advice to others who have similar health conditions. We also asked each contributor to comment on her support systems, to discuss how she managed her work responsibilities while ill, and to explain how her life's work, her identity as a lesbian, and her community influenced her ability to cope. Elana Dykewomon points out that "pain is a citadel guided by privacy." We are grateful to the authors for making their experiences public. In the sections below, we discuss some of the themes from the articles that follow—first those related to lesbian identity and community, and then the implications for medical practice.

## LESBIAN IDENTITY AND COMMUNITY

Most of the lesbian leaders had extremely supportive partners, some with relationships spanning several decades. They described how their partners

provided reassurance and emotional support during this difficult time. Vivian Stephenson described her partner Margarita Gandia as “the source of my inspiration.” Margarita is her healthcare ally, urging Vivian to exercise and socialize even when Vivian is feeling sick. Urvashi Vaid’s partner, Kate Clinton, accompanied Urvashi to every appointment and took notes. When Urvashi was very weak from chemo, Kate also accompanied Urvashi to the classes she was teaching at Columbia University to make sure that she was okay. Nanette Gartrell’s partner Dee Mosbacher, also a physician, kept telling Nanette that she *would* get better with time. Dee also provided constant companionship and medical expertise while they were trying to unravel the mystery of Nanette’s symptoms.

Many authors described the support they received from friends and relatives, both lesbian and heterosexual. Friends and family offered assistance with transportation, hospital visits, and general emotional sustenance. Martina Navratilova’s therapist told her that having five or more friends helping out during cancer treatment was associated with a better prognosis. When Laura Brown lost her voice, feminist friends searched the Web for information about her condition, set up an appointment for her with a medical specialist, and invited her to stay at their home. Elana Dykewomon and her partner Susan Levinkind had considered moving from California to Vancouver. But when Elana was hospitalized and many friends converged to offer assistance, they realized that their Berkeley community was too important to leave. Friends also provided caregiver respite to the authors’ partners. Thus Suzanne Lampert was able to keep up her daily exercise regimen while friends stayed with her partner Barbara Brenner. Susan Love was surrounded by her vigilant family, including a younger sister who donated stem cells for Susan’s transplant.

Friends served an important networking function as well, connecting the authors to medical experts. Urvashi Vaid’s friends urged her to see a renowned oncologist and then got her an appointment with him. She found the “old dyke network” extremely helpful in providing information about cancer treatments. Two authors who are physicians themselves—Susan Love and Nanette Gartrell—belong to a lesbian physician group that provides consultation and referral for its members.

In a couple of cases, the authors described how their extended and supportive network amazed heterosexual family members or hospital staff. No friends came to visit Suzanne Lampert’s father during his recovery from surgery for lymphoma. While Barbara Brenner was undergoing surgery for cancer, Suzanne’s mother was surprised at the number of friends who were providing support to Suzanne in the waiting room. Susan Love’s extended family took turns sleeping in her room during the weeks she was in the hospital.

The Internet was not only helpful in providing medical information to the authors, but also in communicating with other people. Urvashi Vaid used

MyLifeLine to keep dozens of friends informed about her progress; those same friends used the site to post pictures and messages of support. Barbara Brenner joined Lotsa Helping Hands so that she could arrange rides to and from the airport, or have someone stay with her when Suzanne was out.

Many lesbian leaders continued their activism while they were ill. Sometimes their activism directly related to their diseases. Barbara Brenner created the blog “Healthy Barbs” to critique routine healthcare practices and policies. Urvashi Vaid published a book of political essays while she was undergoing cancer treatment. Both Barbara and Urvashi questioned the role of environmental toxins as cancer risk factors.

### IMPLICATIONS FOR MEDICAL PRACTICE

There is a stereotype that lesbians avoid traditional Western medicine in favor of Complementary and Alternative Medicine (CAM) practitioners. That was not borne out by the authors of this issue. All of them sought Western medical treatment, although their experiences varied widely. Some had CAM treatment as well. For example, Laura Brown was successfully treated by an acupuncturist after being misdiagnosed by physicians.

A few authors were diagnosed with a disease during a routine medical exam; others sought healthcare after they experienced symptoms. Martina Navratilova was surprised to discover that it had been four years between mammograms when her breast cancer was detected. She urged lesbians to get regular medical exams.

While all of the lesbian leaders in this volume had health insurance, about 15% of Americans still lack health insurance as we approach the implementation of the Affordable Care Act (Haynes, 2013). This figure may be higher for lesbians, who often cannot obtain health benefits via a same-sex partner through work, and who tend to be underpaid for their level of education (see Rothblum, Balsam, Solomon, & Factor, 2007, for a review of lesbians, education, and income). Urvashi Vaid felt lucky to have good health insurance. Even so, health insurance plans differ widely in co-payments, cost ceilings, and networks of providers. As Martina Navratilova describes in her article, the cost of her radiation treatment in France was one-third of what it would have been in the United States.

Some authors discussed a desire for standardized care, so that all people have access to the best medical practices regardless of diagnosis, geographic location, or ability to pay. Susan Love urged women to go to the best facility for their disease and then not to second-guess the decisions of those healthcare providers. Other authors benefitted by questioning standard care, and might not be alive today if they hadn’t done so. Urvashi Vaid requested magnetic resonance imaging (MRI) for her breast cancer, which detected more serious lesions. Nanette Gartrell and her partner Dee Mosbacher relied on their own medical expertise to uncover Nanette’s genetic enzyme deficiency.

Coincidentally, at this year's Women in Medicine Conference for lesbian physicians, Deb Shapiro, an internal medicine physician at Harvard Medical School, moderated a panel called "Physicians as Patients." Many of the long-term attendees of this conference are in their 60s and 70s, and the percentage of those with serious illnesses has risen in recent years. The panelists included lesbian doctors with breast cancer, leukemia, and secondary progressive multiple sclerosis (MS). Although physicians typically have access to the best possible care as members of the "guild," the panelists described many of the same frustrations with the healthcare system that we heard from the leading lesbians in this special issue.

Some of the issues that panelists raised were the following:

1. Despite being physicians, many panelists had experienced insensitive treatment by healthcare providers—typically of the type that medical students are advised against early in training. For instance, a lesbian primary care physician was scheduled to see a new gynecologist. A health assistant took her into an examining room and said, "Undress and get in the stirrups." The primary care physician responded, "But I haven't even met the gynecologist yet." The primary care physician refused to undress until she had a conversation with the gynecologist, because that is considered the standard of care for first-time visits with a health provider. This lesbian physician was concerned that patients without clout (e.g., those who were not MDs) might be penalized for that type of assertiveness in subtle ways that affect their level of care.

Another lesbian physician described her first visit with a neurologist. Distraught upon receiving a diagnosis of MS, she said, "But I still want to climb Kilimanjaro!" The neurologist replied, "Sometimes you just have to give up your dreams."

2. Even lesbian physicians spoke of feeling obligated to work when they were very ill because of the cost of running a medical practice. Disability insurance rarely made a dent in their overhead costs, so they had difficulty making ends meet when they were not generating revenue.

The need to continue working while coping with disease or disability is a universal challenge. People who are ill may have limited medical leave from their jobs or may even lose their jobs when taking time off to recover.

3. Some lesbian physicians on the panel expressed frustration about the length of time it took to obtain appointments with specialists. Although physicians are typically placed at the head of the line when they are ill, a few panelists had to wait a month or more to see specialists. Others encountered delays in obtaining the results of diagnostic tests. These experiences gave the panelists a new appreciation of the anxiety involved in waiting for results when a patient is eager to begin treatment as soon as possible.

4. Panelists with cancer diagnoses discussed the complexities of choosing among numerous protocols at a time when they felt frightened and distressed. This theme also emerged for our authors. Vivian Stephenson and Urvashi Vaid, for example, commented on the stress of selecting the best doctor, hospital, and protocols for cancer treatment. Currently, clinicians and facilities vary in cancer treatment protocol selection—sometimes in sequence (surgery then chemotherapy, or vice versa), sometimes in length (number of radiation treatments), and sometimes in the specific medications used in the chemotherapy regimen itself. When patients seek second opinions, they must then select doctors, care facilities, and protocols that suit them. These choices are frequently overwhelming to frightened, newly diagnosed patients, who see them as life-and-death decisions. Patients who don't have the resources to be seen at major cancer centers or university hospitals (at which the latest government-funded clinical trials are conducted) fear their chances of survival may be diminished without access to cutting-edge treatments.

In sum, there are two important messages from leading lesbians about dealing with disease or disability. One is to become your own expert. Urvashi Vaid described how she did not know much about cancer treatment prior to her breast cancer diagnosis, but learned to become her own advocate. Nanette Gartrell saw numerous medical experts, yet she was the one who correctly diagnosed that her medications were metabolized by an enzyme she lacked. As Laura Brown stated, it was important to go outside all of her boxes. As a lesbian and a feminist, she was used to questioning authority.

The other message, as Vivian Stephenson puts it, is not to let your disease define you. In that spirit, Barbara Brenner posted on her blog a list of things she was thankful for, up to the last week of her life. Elana Dykewomon described how pain taught her patience and compassion, which helped her become a better leader in her community. All of the women were open as lesbians during their treatment. As Susan Love stated, "if you live your life out loud—'here I am, take it or leave it!'—then that's one less thing you have to deal with." We were inspired by all the accounts, and hope they will provide advice and inspiration.

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