Lesbians Living with HIV in the Bay Area

by

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This thesis is dedicated to the women who shared their lives with me:

Deborah
Beverly
Helen
Josephine
Arlene
Gwen
Corky
Pat
Jolene
Irene
and
Wanda

Thank you. I will always be grateful, and I will always remember you.
Table of Contents

Acknowledgements iv
Introduction: Lesbians, HIV, and Divine Intentions... 1
Why this study? 2
Contexts 5
Language 7
Lesbians and men 8
Lesbians at risk 11
Risk: emotional and social factors 12
Lesbian voices 15
Methods 17
Selection processes 19
Representation 20
Fractured by the data 21
No seamless point of view 22
Demographics 24
Introductions—The Women 26
The Lived Experiences of Eleven 29
Lesbian or Bisexual Women Living with HIV 29
Family reactions to being HIV positive 29
Family reactions to being lesbian or bisexual 31
Dates, partners, lovers, wives: discordant couples, reactions to HIV infection, safer sex, and love 33
Communities and support: support groups, retreats, speaking out, race, religion, HIV, men, and other lesbians 36
I thought lesbians didn’t get AIDS 45
Grief and loss 47
Violence 48
Addiction, relapse, recovery 51
Case workers and counselors 56
Doctors, nurses, and hospitals 58
Hopes, goals, and inspirations 61
Conclusions 64
ICW: What Do HIV-positive women need? 68
References 70
Appendix A—Flier 76
Appendix B—Interview Questions 77
Appendix C—Selection Challenges 80
Appendix D—Attachment D: Participant Information Sheet 83
Appendix E—Human Subjects Approval 84
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Introduction: Lesbians, HIV, and Divine Intentions

"How many lesbians in the US have HIV/AIDS?" asks the headline of an information page of HIV InSite, the University of California, San Francisco's extraordinarily comprehensive website about HIV and AIDS (Salome, 1999). The question is posed by a visitor to the website, and is used in the section called "Ask HIV InSite." The answer? "[It is] difficult to answer your question," responds Salome. And although she continues sincerely and earnestly, she does not answer the question. Although she uses the information provided by the Centers for Disease Control and Prevention (CDC) regarding HIV, AIDS, and lesbians, she cannot answer the question.\(^1\) Yet this is the question on everyone's mind—when lesbians with HIV or AIDS are on their minds, which, truly, isn't often.

\(^1\) Salome cites the CDC web page/fact sheet "HIV/AIDS & U.S. Women Who Have Sex With Women (WSW)" (CDC 1999b). The fact sheet says: "Through December 1998, 109,311 women were reported with AIDS. Of these, 2,220 were reported to have sex with women; however, the vast majority had other risks (such as injection drug use, sex with high-risk men, or receipt of blood or blood products). Of the 347 (out of 2,220) women who were reported to have sex only with women, 98% also had another risk— injection drug use in most cases. Note: information on whether a woman had sex with women is missing in half of the 109,311 case reports, possibly because the physician did not elicit the information or the woman did not volunteer it" (emphasis added).
I address the question of “how many?” immediately, although my work does not answer the question; in fact, my work does not ask the question. Yet I anticipate that for the reader, as for nearly every person with whom I have discussed or mentioned this research in the last three years, this question is at the forefront of the mind. You will not discover ‘how many?’ from the pages ahead, but in exploring the experiences of eleven lesbians living with HIV in the Bay Area, I address some of the problems associated with the widespread belief that lesbians are not at risk for HIV infection.

**Why this study?**

I, too, was intrigued by the question of numbers. I was drawn by the knowledge that lesbians with HIV are few, but not none. A Jew since birth, a lesbian since I first fell in love, I have always been one of few. In this context, I developed both a personal and a professional commitment to social justice, particularly for those who are disenfranchised. This naturally flowed not only from my personal struggles but also from my Jewish culture. As a Jew, I was taught from early on, both by word and by example, the Talmudic principle of *tikkun olam*, which speaks to one’s obligation to “repair the world.” Combining this commitment with my interests in health and self-care, HIV related work became very important to me.

Some who do not understand the nature of HIV transmission have grouped lesbians into the category of “carriers” of HIV, due to their being gay
and HIV being a "gay" disease. But those who well understand HIV infection usually know that sex between two women often involves very little exchange of high-risk fluids. For this reason lesbians have been seen as free from the risk of HIV infection. For a long time, a lesbian with HIV was unheard of. This led to a "one-liner" that in many ways inspired my study. Its origin lies in the opinion of some that AIDS is "God's curse," a concept which began as a vehemently homophobic attack on gay men. Someone clever one day said: "Well, if AIDS is God's curse, then lesbians must be the chosen people" (source unknown).

Years ago, when I, too, believed that lesbians didn't get HIV, I loved this poignant retort. It tore apart the prejudice of the "God's curse" concept. If God is punishing the gay life, then why would lesbians be "divinely spared" (Mays, 1996a, p. 7)? It also lent itself to a twisted kind of pride: there was another, even better advantage to being a lesbian besides not having to worry about birth control.

In recent times, thinking about this quotation gave me pause; I had now met lesbians with HIV. This raised questions:

- Are these women as invisible as they seem?
- What is it like to find yourself the living proof that lesbian invulnerability is a myth?

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2 The Human Immunodeficiency Virus (HIV) is spread through body fluids. Blood, semen, and breast milk contain HIV in levels great enough to infect another person. It is unclear whether women's vaginal secretions can infect another person (Sheon 1998b). (For a quality discussion and citations see Kennedy, Scarlett, Duerr, and Chu [1995]). Activities known to risk spreading HIV include sharing needles, breast feeding, vaginal intercourse, anal intercourse, and blood transfusion. There is a constant debate regarding the possibility of infection from sexual activities such as oral sex or putting fingers in a woman's vagina.

3 Living under hostility and stigma produces this kind of thinking!
• What about experiences of community and support? If most gay people with HIV are men, and most women with HIV are heterosexual, and most lesbians think HIV infection is a problem outside of their community, then is there a place where lesbians living with HIV can find comfort, familiarity, and understanding?

I developed a study in which I could explore these questions and others by sitting with some HIV positive lesbians and talking with them about their lives.

I met with eleven self-identified lesbian and bisexual women living with HIV. I recorded my conversations with them and subsequently conducted a qualitative examination of these conversations. The heart of my interviews and my interests was encapsulated in this question: "I am trying to understand experiences of community among HIV positive lesbians. Do you consider yourself part of any particular communities?" In the pages that follow, I share the experiences, emotions, struggles, and triumphs that emerged from these interviews.

\[4\] For a complete discussion of methods, please see section entitled Methods.
Because I spent much time in HIV prevention and safer sex education, the concept of risk group versus risk behavior was often central to my thoughts and work. Are you at risk because of who you are: gay or an addict (a risk group); or because of what you do: have unprotected sex, share needles (a risk behavior)? For every person, this distinction is crucial, both for realizing that who we are is not inherently dangerous and for realizing that what we do might be. Gay men have had to (and still must) strive to recover from the association of gay identity with HIV infection and death from AIDS. But for much of the American population the latter point is the vital yet elusive one. Each year the rates of new AIDS diagnoses for gay men have been decreasing, but for heterosexuals, women, youth, and many peoples of color the rates are increasing (CDC, 1999a; California Department of Health Services, Office of AIDS, 1999).

HIV/AIDS education now focuses on raising awareness of individual risk based on behavior; it targets many of the vulnerable populations, and makes some headway, bit by bit. Confounding the efforts to switch perceptions of risk from groups to behaviors is the phenomenon of believing that some groups "by definition" do not participate in certain behaviors. Many believe, for example:

- that heterosexuals do not have anal sex with each other;
- that men who identify as heterosexual and monogamous do not have sexual encounters with other men;
- that white middle class people do not inject drugs,

and so on. It is precisely along these lines that a lesbian's risk of HIV infection is
observed. "Lesbian" is a low-risk identity because sex between women carries either low or no risk of HIV transmission (Bevier, Chiasson, Heffernan, and Castro, 1995; Chu, Hammett, and Beuhler, 1992; Kennedy et al., 1995; Lemp, Jones, Kellogg, Nieri, Anderson, Withum, and Katz, 1995; Raiteri, Fora, and Sinicco, 1994; Raiteri, Fora, Russo, and Sinicco, 1997; Sheon, 1998). Lesbians are categorized sexually; the sexual category is low risk. The analysis ends there—prematurely: as a group, lesbians are not considered to be at risk for HIV infection. But this thinking belies some fundamentals of human nature. We do not always do what we say, and we surely do not always say what we do. And we have many identities. A woman may be a lesbian, but she may also be an injection drug user. A woman may be a lesbian, but she may also be trying to get pregnant. A woman may be a lesbian, but she may also be exchanging sex with men for drugs or money. A woman may be a lesbian, but she may, recently or long ago, also have been in love with a man.

Literature on lesbians and HIV infection only began to emerge in the very late 1980's. From its inception, a central theme of this literature has been the plea that we strongly differentiate between identity and behavior, especially sexual identity and sexual behavior (Bevier, Chiasson, and Heffernan, 1996; Cole and Cooper, 1991/1990; Denenberg, 1991; Hollibaugh, 1994; Hollibaugh, 1994/1993; Hunter and Alexander, 1997; Kennedy et al.; 1995; Lemp et al., 1995; Mays, 1996b; Rankow, 1996; Stevens, 1993; Stevens and Hall, 1997). (During the same

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5 Kennedy, et al. provide citations for case reports of possible woman-to-woman transmission.
6 Whether sex between women can transmit HIV is a great debate. I will touch upon it only to point out that regardless of the infectious potential of vaginal secretions, or lack thereof, menstruating women bleed approximately one day to one week every month. Contact with blood carries the greatest risk of HIV infection.
time, the general HIV literature began to make this long overdue distinction as well.) While it is not such a stretch to imagine lesbians also being drug users, it is very difficult for many to reframe lesbians as women who sometimes or often have sex with men. One may wonder, well then, wouldn’t these be bisexual women? But that is the very point: no. The behavior may be “bisexual,” but many women who engage in bisexual behavior call themselves lesbians. The reverse is also true; some women who have exclusively lesbian relationships identify as bisexual (or even heterosexual!). The importance of understanding identity and behavior as interrelated but separate concepts has been realized by many researchers and theorists, as reflected in the literature, but this concept has yet to become implanted in the minds of either the general populace or the health care community.

Language

I would like to take a moment to comment on my use of the term “lesbian” throughout this writing. I have chosen to call my study “Lesbians Living with HIV” rather than “Lesbians and Bisexual Women Living with HIV” or, even better, “Women Who Have Had Sex With Women Living with HIV.” Normally I advocate for and strive to use this kind of inclusive language. Some of the women I interviewed don’t use the word “lesbian.” Some say “gay;” some identify as bisexual; one uses the word “girls” for other lesbians. It may be more appropriate for me to use the term “WSW”: women who have had sex with women. But I chose “lesbian” for the shock value, for the unrecognized point: women that either think of themselves as lesbians, or that we think of as lesbians, can and do become infected with HIV. I retain use of the presumably narrow
identifier “lesbian” in order to encourage association of that identity with a wide variety of life experiences and behaviors.

Lesbians and men

How many self-identified lesbians actually have sex with men? “A number of surveys on behavior have been conducted in groups of WSW, primarily among women who self-identify as lesbian or bisexual. Previous sexual contact with men, even among those women self-identifying as lesbian, was reported often in all the surveys” (Kennedy et al., 1995, p. 104). The following is a sample from four surveys conducted between 1985 and 1993 (see Table 1 for a summary of the data presented below):

- The Michigan Lesbian Health Survey was completed by 1,681 lesbians and bisexual women from Michigan in 1989. 86.1% identified as lesbian, of which 5.0% reported sex with a man in the past year; 79% of the total women surveyed reported sex with men in their lifetime (as cited in Cochran, Bybee, Gage, and Mays, 1996).

- The National Black Lesbian Survey was completed by 605 lesbians and bisexual women from across the country in 1985. 83.6% identified as lesbian, of which 10.5% reported sex with a man in the past year; 90.7% of the total women surveyed reported sex with men in their lifetime (as cited in Cochran et al., 1996).

- The National Lesbian Bisexual Women’s Health Survey was completed by 6,243 women from across the country in 1993. 87.2% identified as lesbian, of which 12.1% reported sex with a man in the past year (as cited in Cochran et al., 1996).
Lemp and colleagues (1995) surveyed 498 women frequenting San Francisco and Berkeley clubs, bars, cafes, and community organized social events attended by lesbians and bisexual women in 1993. 68.1% identified as lesbians, of which 74.6% reported sex with a man in the last three years. The study by Lemp and colleagues is particularly relevant here, as their participants were encountered in San Francisco and Berkeley, and mine were found in San Francisco, Oakland, and Martinez (cities near Berkeley).
Table 1

Sex with men among self-identified lesbians; examples from four studies.

<table>
<thead>
<tr>
<th>Study</th>
<th>Sex with men during lifetime</th>
<th>Sex with men in the past year</th>
<th>Sex with men in past three years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michigan Lesbian Health Survey, 1989</td>
<td>79%‡</td>
<td>5.0%*</td>
<td>--</td>
</tr>
</tbody>
</table>
| 1,681 women
1,436 (86.1%) lesbians | | | |
| National Black Lesbian Survey, 1985 | 90.7%‡ | 10.5%* | -- |
| 605 women
506 (83.6%) lesbians | | | |
| National Lesbian Bisexual Women’s Health Survey, 1993 | -- | 6.0%* | -- |
| 6,264 women
5,236 (87.2%) lesbians | | | |
| HIV Seroprevalence and Risk Behaviors among Lesbians and Bisexual Women in San Francisco and Berkeley, California, 1993 | -- | -- | 74.6%* |
| 498 women
339 (68.1%) lesbians | | | |

‡percent is of total women surveyed
*percent is of lesbians surveyed
Lesbians at risk

Intravenous drug use and sharing needles, exchanging sex for money, sex combined with drug or alcohol use, hospital or laboratory work, exchanging sex for drugs, artificial insemination, or sexual assault—whether or not women do transmit HIV to each other sexually, whether or not a lesbian engages in sex with men, lesbians are at risk for HIV infection. Recent studies of lesbians and bisexual women reveal two alarming findings:

- Lesbians and bisexual women may engage in high-risk behaviors in greater proportion than women in general.
- Lesbians and bisexual women may have higher rates of HIV infection than women in general.

Four of these studies will be cited here; they are representative but not comprehensive. The study by Lemp and colleagues concludes:

Our results are consistent with those from previous surveys of lesbians and bisexual women, which revealed high rates of injection drug use, needle sharing, and unprotected sex with men. . . . We found that 1.2% of lesbians and bisexual women [in the study] . . . were infected with HIV. This prevalence is higher than that reported for childbearing women (0.2%) or for women sampled through population household surveys (0.4%) (1995, p. 1551).

Cochran and colleagues, who analyzed and compared three large surveys of lesbians and bisexual women, determined for two of the surveys that “even after stratifying by age, [self-] reports of crack, cocaine, and heroin use were greater in these two samples [of lesbians and bisexuals] than in population estimates for women in general” (1996, p. 28). Moore, Warren, Zierler, Schuman, Solomon, Schoenbaum, and Kennedy examined characteristics of 870 HIV-infected women in four U.S. cities; they concluded that, “Compared to heterosexual women,
women who identified as lesbian or bisexual were more likely to report injection
drug use and sexual risk behaviors” (1996, p. 50). Finally, Bevier and colleagues
investigated HIV seroprevalence and risk behaviors of 1,518 women at a sexually
transmitted disease clinic in New York City; their findings include the following:

Forty-eight percent of women reporting same-sex contact
acknowledged exchanging sex for money or drugs at least once
since 1978, compared with 12% of heterosexual women. . . . Women
reporting same-sex contact were more sexually active, with 38%
reporting three or more partners of either sex in the last six months
compared with 13% of heterosexual women. . . . Women reporting
same-sex contact also had more high-risk sex partners since 1978,
including injection drug users, bisexual men, and persons infected
with HIV. . . . HIV seropositivity was more common among women
reporting same-sex contact. All 10 women who had sex exclusively
with women since 1978 were HIV seronegative. Bisexuals,
however, were more likely to be HIV seropositive than

Do lesbians and/or bisexual women have higher HIV seroprevalence rates than
women in general? These studies alert us to the concern, but there is not yet
enough data to draw this conclusion. Nevertheless, lesbians—who are thought of
as not at risk for HIV infection—and bisexual women (who may be perceived as
lesbian, based on their recent or primary relationship) not only engage in high-
risk behaviors, but seem to be doing so at higher rates than women in general.

Risk: emotional and social factors

The most important aspect to the issue of risk behaviors among lesbians,
aside from popular and practitioner awareness, is the question of why risks are
taken. Indeed, this is the question at the heart of all prevention programs. To
assist or encourage people to make different choices, we must understand the
motivations behind the choices made. In this light, the most interesting study
regarding HIV risk among lesbians and bisexual women may be Stevens and
Hall’s 1997 study “Emotional and Social Contingencies Affecting HIV Risk Reduction Among Lesbians and Bisexual Women.” 563 lesbians and bisexual women were interviewed as part of a combination study and community intervention: “the size and scope of this research are almost unprecedented in qualitative work” (p. 12). Each participant was asked “open-ended questions about her HIV risk-taking, HIV prevention activities, and risk-reduction difficulties” (p. 7). They found that:

Lesbians and bisexual women in this study reported engaging in a number of behaviors posing risk of HIV transmission, categorized as: unprotected sex with women, unprotected sex with men, emotion- and intuition-based unprotected sex, alcohol/drug intoxication during sex, and injection drug use (p. 7).

Although the women reported both drug-related and sex-related risks for HIV infection, when asked about difficulties in reducing HIV risk, the concerns they shared were sex-related (with the possible exception of the category “lack of community awareness” [p. 12]). In assessing the data regarding difficulties in reducing risk, Stevens and Hall determined that:

Their HIV risk reduction attempts are hampered by a lack of specific information about woman-to-woman sexual behaviors and a lack of acceptable latex barriers. Most powerfully influential in their HIV risk-taking, however, are emotional and social contingencies. . . . According to the results of this research, a web of emotions and social relations influence risk behaviors. This area of concern is often ignored in studies about HIV prevention because what is usually prioritized is cognition (p. 13).

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7 This was, in part, due to their innovative research methods. 20 self-identified lesbian or bisexual “peer researchers” were recruited; 40% of the peer researchers were women of color. They were given a 35 hour training with evaluation and had biweekly meetings. The peer researchers performed 20-30 minute, open-ended field interviews on 70 occasions over the course of one year: at 38 lesbian/bisexual community events and 32 times at eight different women’s bars and dance clubs. 41% of participants were women of color. At the end of the interview the peer researcher provided “context-specific” HIV prevention education to the participant. Additionally they gave 40 HIV prevention presentations to a total of 2,350 women; the presentations were also designed to increase the visibility of the project and attract participants.
The following are examples of emotional and social factors described in the study:

- Participants’ actions to prevent HIV rested heavily on perceptions of trust, honesty, and fidelity in their social relationships.
- Monogamous partnerships were seen as islands of safety from HIV and therefore the definition of monogamy was “stretched” to include almost any relationship.
- Talking about sex was considered too revealing among “strangers,” yet too threatening for intimates.
- Alcohol and drug use further dampened intentions to use safer sex, and contributed to “heat of the moment” action (p. 13).

The kind of exploration created by Stevens and Hall’s study is vital for our understanding of those to whom prevention messages are or will be targeted, both in public campaigns, and in the privacy of the clinical or therapeutic setting.

My study was informed by that of Stevens and Hall. While I looked at neither risk factors nor transmission issues, I did strive for an exploration of the many emotional and social factors woven through the lives of these eleven women living with HIV. My goal, rather than prevention, lies in the possibility of increasing the support available to these women, or to any woman with HIV.
Lesbian voices

The two major themes in the literature on lesbians and HIV are risk behaviors and woman-to-woman transmission. The literature contains very little about the lived experience of lesbians with HIV. A number of short, first-hand accounts (one paragraph to less than two pages) can be found in popular sources, such as newsletters and newspapers (Denison, 1990-2000; Fernandez, 1996; National Lesbian/Bisexual HIV Prevention Network; Phoenix, 1991; and Terson, 1993). I have encountered about a dozen, the majority in the WORLD newsletter (Women Organized to Respond to Life-threatening Diseases), a wonderful publication by and for women with HIV (Denison, 1990-2000). I also found three books by women who are both street activists and academic writers which each include one full (4 pages to 12 pages) first-hand account of a lesbian living with HIV (Acevedo, 1990; Stoller, 1998, pp. 15-21; and Arnold, 1997).

Important books such as Experiencing HIV: Personal, Family, and Work Relationships (Adam and Sears, 1996) and In Changing Times: Gay Men and Lesbians Encounter HIV/AIDS (Levine, Nardi, and Gagnon, 1997), which address many psychosocial aspects of the HIV/AIDS epidemic and utilize many first-hand accounts, do not discuss lesbians infected with HIV. Even Lather and Smithies seminal work Troubling the Angels: Women Living with HIV/AIDS, which is remarkably overflowing with the voices of women, contains only one paragraph in which one is aware of hearing a lesbian or bisexual speak (1997, p. 110).

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¹ There is actually a third major theme that falls under the title “lesbians and HIV”: that of lesbian caretaking and community activism in the HIV epidemic. This is about lesbians’ involvement with other people who have HIV; it is not about lesbians themselves having HIV or being at risk for HIV infection.

² From an edited volume which also includes a brief (less than two page) account (Anonymous, 1990).
Although this woman's voice (Alisha) appears numerous times in the text, one does not know she is lesbian/bisexual until encountering this paragraph midway through the book, when Alisha mentions her partner and refers to her as "she." There are no other passages in the book in which she speaks to issues or experiences related to being lesbian or bisexual. Lather and Smithies state, in an informational text box on the previous page, that "Two of the women in our study who had previously identified as heterosexual found lesbian partners after being diagnosed" (p. 108). I was unable to discern who the other woman might be, despite the tremendous amount of personal information in the book (see later discussion of this text).
Methods

I wanted to hear the voices of lesbians living with HIV. To this end, I conducted interviews from November 1998 to February 2000 with women who responded to a flier (see Appendix A), which asked “Are You a Lesbian Living with HIV?” The flier was posted and handed out in a variety of places that are frequented by HIV positive women in the Bay Area, including AIDS clinics, AIDS organizations, a women’s clinic with a large lesbian clientele, and a lesbian, gay, bisexual, and transgender therapy center. Some of the women I interviewed passed my flier on to others, thus my recruitment techniques included both convenience sampling and snowball sampling.

I developed this study as part of Adele Clarke and Kit Chesla’s extraordinary course “Qualitative Field Research” (1998/1999, Sociology/Nursing 285, University of California, San Francisco). We were trained in interview and participant observation strategies and studied numerous types of qualitative analytical models. Grounded theory coding approaches were applied to analyze this data, although the presentations of results and analysis here are not traditional, thus do not fall under the usual rubric of grounded theory (Denzin and Lincoln, 1998a, 1998b, 1998c; Strauss, 1987).

Interviews were one-on-one, semi-structured, open-ended, and lasted from 45 minutes to over two hours. They took place where the women were living, which was often a drug recovery facility. These facilities ranged from places for those who recently entered into recovery to transitional housing
apartments for women in their second or third year of continuous recovery. Interviews were tape recorded and later transcribed. Women were paid $30.00 for giving their time, energy, and openness. A list of interview questions and probes was developed and used as a guide during the interviews (see Appendix B). The questions focused on community involvement and support issues, and addressed experiences with family, friends, partners, health care providers, diagnosis, living situation, and communities, including lesbian, HIV, African American, religious, housing, and recovery communities.

I coded the interviews using grounded theory's coding paradigm, in which the researcher looks for "conditions, interaction among the actors, strategies and tactics, and consequences" (Strauss, 1987, pp. 27-28) as she codes, first in an unrestricted fashion ("open coding") and later with a more focused view. In coding, the data is "fractured" or broken apart analytically (Strauss, 1987, p. 29). Two types of codes were used: sociological constructs and in vivo codes. Sociological constructs are codes which I formulated. In vivo codes were taken or derived directly from the language of the women I interviewed (Strauss, 1987, pp. 33-34). As coding progressed, I searched for themes and wrote both analytical and stream-of-consciousness memos in order to develop my analysis. The interviews were coded on computer, using the QSR NUD*IST software (Qualitative Solutions and Research Pty Ltd., Australia).

The strategy of theoretical sampling was employed. In grounded theory, a theoretical sample typically is used in order to identify, investigate, and describe as many different experiences as possible. "The analyst decides on analytic grounds what data to collect next and where to find them" (Strauss, 1987, p. 38).
In this study, I applied theoretical sampling to the evolution of the questions that I asked during the interviews as my experiences opened my mind to new ideas about the subject of inquiry.

**Selection processes**

Eleven interviews are included in the study. I met five additional women who are not part of the study. These five women were all encountered at the same place, a combination shelter, drug treatment program, transitional housing facility, and day center. After I came for a prescheduled interview with two women at this facility, word spread about my study and numerous women asked to participate. I spent two days there, interviewing seven women and scheduled with an eighth, but only three are included in the study. Appendix C describes briefly the experiences with these women who were not included in the study.

In retrospect, I realize that it would have been helpful for me to have chosen a minimum time period for having been lesbian or bisexual and for having been HIV infected in order to participate in the study. No negative interactions between any woman and myself ensued due to these difficulties. Only two women were informed that they could not be part of the study, and these conversations remained friendly.
Representation

As I moved through the process of listening to the interviews, coding the text, and analyzing the experiences, thoughts, and emotions of the women I had met, I began to question my role as interpreter of their words. At the same time, I had been reading Lather and Smithies innovative book *Troubling the Angels: Women Living with HIV/AIDS* (1997). Lather and Smithies, who conducted group interviews at support groups for women with HIV, chose to present their findings in an experimental manner. The women’s words stand alone, without direct commentary or analysis by the researchers, and are presented as support group-like discussions, although they were rearranged from the original and reorganized to follow themes. Many pages of their book also have a split-text format in which the women’s words appear in the top half, and the bottom contains writings by the authors, consisting of journal entries, educational discussions, personal experiences, issues raised in that section, and more. Additionally, text boxes with educational information about HIV are scattered throughout. Finally, there are five “intertexts” between sections, composed of theoretical and academic discussions.

I was captivated by Lather and Smithies’ style and its powerful results. I became eager to situate myself, as they did, “not so much as expert ‘saying what things mean’ in terms of ‘data,’ but rather as witness giving testimony to what is happening to these women” (1997, p. 127).10 We had been introduced to

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10 Altered from the original in order to conform to the singular rather than the plural subject.
questions of representation in Clarke and Chesla’s course and were supplied with excellent reading on the subject. With excitement, I began to read and review the sections on ethics and representation.

Fractured by the data

My own instinct to show myself clearly in my writing was affirmed by Michelle Fine in “Working the Hyphens: Reinventing Self and Other in Qualitative Research” when she said: “As researchers, we need to position ourselves as no longer transparent, but as classed, gendered, raced, and sexual subjects who construct our own locations, narrate these locations, and negotiate our stances with relations of domination” (1998, p. 142). I came to realize that following this instinct is the first step toward allowing those studied to maintain their own voices in the research process. Other writers also encouraged self-reflexiveness. Kleinman, Copp, and Henderson say: “We are asking students to violate the folk belief that researchers’ emotions are a bias and thus should be excluded from their data” (1997, p. 479). Self-exploration seems to me to be a key element in avoiding simply molding the women’s words into my own meanings.

Grounded theory teaches us that coding the data “forces the analyst to fracture, break the data apart analytically, and leads directly to the excitement and the inevitable payoff of grounded conceptualization” (Strauss, 1987, p. 29). While coding my data, I read Patti Lather’s article “The Validity of Angels: Interpretive and Textual Strategies in Researching the Lives of Women With HIV/AIDS.” Much to my surprise, I found myself fractured open by this writing. She discusses a colleague’s concern that the lives of people with AIDS are “represented only as sad testimonials” (Francisco Ibanez-Carrasco, as cited in
Lather, 1995, p. 61). When she said of her own research: "These women deserve better than sentimentality," (p. 53) I was stopped in my tracks.

I realized that I, too, was looking for sad testimonials, that I am loaded with sentimentality. It is my commitment, no?—the plight of the disenfranchised (see page 2 above). I was driven by a vision of these women falling between the cracks, existing at the margins of their communities, lacking support for their lives. Combined with veneration of their noble struggle and their ability to rise above, this scenario just wouldn't do. While I continue to admire the resilience of these women, and I would do no justice by muting the harsh experiences of their lives, I recognized the need for more balanced visions of their lives. I began to apply Norman Denzin's "image of overlapping, conflicting, de-centered circles" of identities (cited in Fine, 1998, p. 148) to my understanding of the women, and hoped that my methods of representation would convey this image.

**No seamless point of view**

I decided that piecing the women's words together into a single, authoritative narrative, using their words to punctuate my conclusions, was unacceptable. Therefore, I was delighted to read R. Ruth Linden's discussion of finding inspiration in cultural and literary critic Walter Benjamin's ideas. Benjamin's "greatest literary aspiration was to fashion a work entirely out of quotations—a text akin to a mosaic, [or] patchwork quilt" (as cited in Linden, 1993, p. 6). She says that: "For Benjamin, claims made in a single, authoritative voice falsified history. Modern narratives told from a seamless point of view betrayed phenomena as they appeared in reality" (as cited in Linden, p. 6). Following Lather and Smithies lead, I have chosen to present my "results" in the
form of extensive quotations from the interviews. Although each interview was one-on-one and occurred independently of all other interviews, I have formatted the quotations as if the women were in a support group or discussion, in which one woman after another shares stories, in both closely and loosely connected streams of thought.

I do not pretend that I am not imprinted on these words. From the questions I chose to ask, to the connection between each woman and myself, to the mere fact of my presence at the interviews, my influence is inextricable from the materials. Furthermore, both consciously and unconsciously, my analysis is manifested in my choice of themes, my choice of quotations, my categorization and then juxtaposition of each quotation, as well as in every word I write in my own voice. In fact, I have constructed and presented here a conversation between these women which never actually occurred. Nevertheless, I am not the "expert" who is going to tell you what their words "really" mean. In using extensive quotations my goals are three-fold:

- I seek to maintain the vibrancy, reality, and integrity of the women's voices.
- I hope to be perceived, not as the maker of meaning, but as the witness of their stories.
- I want the reader to be challenged by the variations and contradictions, as well as captured by the points of similarity.
Demographics

Any missing data from the demographic information is not due to a participant’s refusal to give the information. Rather, there were very few standardized demographic questions in the interview questions (Appendix B), thus some interesting points were not covered with all participants.

Age:
- They range from 37 to 51 years old; the mean age is 44

How long they have lived in the Bay Area:
- The range is from 10 years to 48 years
- 8 grew up in the Bay Area
  - 3 were born and raised here
  - 5 have been here since childhood
- 1 has lived in the Bay Area for 20 years
- 1 has lived in the Bay Area for 15 years
- 1 has lived in the Bay Area for 10 years

Ethnicities:
- 8 are African American
  - 3 identify as Afro-American
  - 3 identify as both Black and African American
  - 2 identify as African American
- 1 is white, she identifies as Italian and German
- 1 identifies as Mongolian-Chinese and Puerto Rican
- 1 identifies as American Indian, French, Black, Mexican, and Cuban

How long they have been HIV positive or have known they were HIV positive:¹¹
- They have been HIV positive from 4 to 15 years, with a mean of 8.5 years. (This is among 10 women only. I did not mention how long she had been infected.)

¹¹ There was not a clear distinction between these two categories; it was not a pre-determined interview question.
Drug use and addiction:\(^{12}\)
- 10 revealed that they are in recovery for drug or alcohol addiction.
- The major drugs used by these women were:
  - alcohol: 1 woman
  - heroin and crack: 5 women
  - crack only: 2 women
  - heroin and speed together (speedball): 2 women
  - other drugs mentioned: pills, acid, speed, cocaine
- Intravenous drug use: 5 explicitly stated that they had injected drugs

Children:
- 3 women have children
  - 1 has two children
  - 2 have three children

Partners:
- 6 women were in relationships at the time of the study\(^{13}\)
  - 1 woman had been with her partner for two months
  - 4 women had been with their partners between 5 and 20 years
  - 1 woman did not mention the length of her relationship
- 5 women were single at the time of the study

Education:
- 1 woman has completed 9\(^{th}\) grade
- 2 women quit high school during the 12\(^{th}\) grade
  (1 of whom also attended Junior college)
- 2 women graduated from high school or had a GED
- 5 women have taken some Junior college classes
- 1 woman spent two years at a University of California campus
- 1 woman has an Associates degree

Me:
I am a 33 year old lesbian.
I have lived in the Bay Area since I was four years old (almost 30 years).
I am white and Jewish.
I am currently HIV negative and not addicted to any drugs or alcohol.
I have no children yet but am now trying to get pregnant by insemination with a friend who is a gay man.
I have been with my partner for five years. We were married last year by our Rabbi.
I am a medical student in a joint degree program and will receive my Masters degree after finishing this thesis.

\(^{12}\) Questions about drug use were not asked of everyone, as it was not a pre-determined interview question. Therefore, this information is not necessarily comprehensive.

\(^{13}\) All of their partners were HIV negative.
Introductions—The Women

To protect the identities of the women interviewed, their names and other identifying information have been changed.

Deborah is 48 and was born in the Bay Area. She is Afro-American and has been HIV positive since 1992. She lives alone in a one room apartment in a housing facility which has some places reserved for people with disabilities (hers is HIV). She and her lover have been together since 1991. She speaks out as a person living with HIV, and she wants to get a support group together for Afro-American lesbians.

Beverly is 44, and is originally from the East coast. She is white, Greek and French, and has been HIV positive since 1989. She lives in an apartment with her partner of eight years. She has been in recovery from alcoholism for almost twenty years, with one relapse when she discovered she had HIV. Pottery is her newfound passion. She is an HIV activist and would like to make things better for the women out there.

Helen is 42 and has lived in the Bay Area since she was a child. She is Afro-American and has been HIV positive since 1985. She lives in an apartment facility for women with HIV. She has been clean and sober for two and one-half years. She was an Olympic medalist in college. She is a romantic, loves cooking and candlelight dinners, and enjoys taking classes and being involved in the HIV community. She would like to work with other women who are HIV positive.
Josephine is 39 and was born in the Bay Area. She is Afro-American and has been HIV positive since 1994. For three months she has been living in a residential treatment facility for drug addiction. She has a partner of five years. She loves working outdoors and driving, driving anything. She would like to go back to school.

Arlene is 44 and has lived in the Bay Area for 20 years. She is African American and has been HIV positive since 1987. She lives in permanent housing apartments managed by a residential treatment facility for drug addiction. She has been clean and sober for two and one-half years. Her partner lives far away, but they are able to visit each other. She is a musician and is in school. She is focused on maintaining her sobriety and self-love.

Gwen is 43 and has lived in the Bay Area all of her life. She is American Indian, French, Black, Mexican, and Cuban, and did not mention how long she has been HIV positive. She lives in a transitional housing facility for women in recovery and has recently struggled with relapse. She has two grown children in their twenties. She is a dreamer and likes to draw. She wants to go back to school and dreams of being a commercial artist.

Corky is 49 and was born in the Bay Area. She is Burmese and Cuban and has been HIV positive since 1989. She is living in a transitional housing facility for women in recovery and has been clean for 16 months. She was an activist and speaker in the feminist movement. She likes to bowl and play pool and is a loner. She hopes to find a job, but because of HIV, it needs to be less physical than the manual labor she’s done in the past. She would like to see more agencies and organizations focusing on women.
Pat is 37 and was born in the Bay Area. She is African American and has been HIV positive for about five years. She stays at a homeless shelter with her partner of two months and has been clean for one year. She has three children, a 12-year-old, and two who are in their late teens. She likes watching sports and listening to music. She is planning on finding an apartment and getting her GED.

Jolene is 42 and has lived in the Bay Area since she was a child. She is Black and has been HIV positive since 1996. She lives in a residential treatment facility for drug addiction, where she has been in recovery for over four months. She is proud to be alive, and is hoping to move to a transitional housing facility.

Irene is 51, originally from California, but moved to the Bay Area 15 years ago. She is Black and has been infected with HIV since 1992. She lives in a county-sponsored apartment facility for people with HIV and has been in recovery for five years. She hopes her longtime lover will move to the Bay Area and live with her. She would like to go back to school.

Wanda is 48 and has lived in the Bay Area since she was a child. She is African American and lives in a transitional housing facility for people coming out of a residential drug treatment program. She has been out of jail for two months. She has three children: a twelve-year-old, a nineteen-year-old, and an adult in her twenties. She hopes to get together with her family again after her recovery is established. She would like to be an HIV peer counselor.
The Lived Experiences of Eleven Lesbian or Bisexual Women Living with HIV

Family reactions to being HIV positive

"They love me anyway"

Valerie: How's your family about your having HIV?

Arlene: I didn't tell my mother for ten years. So when she found out, I thought that she would hit the floor. She flew up here, and she surprised me, and she said "Well, you know what? You don't have to do this alone. I'm always going to be with you, and I'm always going to love you. And you don't have to do it alone." She's still got a thing about telling people, like—'cause she tell me, "You know, don't tell your Aunt Erma; I didn't tell them."

Beverly: My family wasn't good until they learned about it, you know. It's like, at first I came home for New Year's Eve, and my mom said, "What are you doin' here? I didn't invite you! Don't you know your nephew's gonna be here?" And that's what set me off. That was when my relapse started. And then I relapsed for a year. I lost my eight and a half years sobriety, but I have nine years back. Since then she got educated. Now it's, "When are you comin' home for Christmas?" [laughs] She wants to see me, but she was very afraid of me at first, because in 1989 people knew very little about the disease, you know. It was a very long time ago.

Valerie: How about your brothers?

Beverly: My brothers love me anyway. They hug me and they love me anyway. They don't care. My brother took my nephew and he shoved him in my arms [laughs]. He didn't care. He knew it had to come from blood to blood transmission, and I wasn't gonna do nothin'.

Helen: My youngest brother, I love him so much. He loves me too. He's in jail now; he's doin' time. But hopefully he'll be getting out soon. He's telling all his friends in jail about me, and he's saying, "My sister is cool, man. My sister goin' on. My sister is HIV. She's going around taking trips and meetin' other females, and she's out there teachin' people about HIV and AIDS."

Valerie: How is that with your family?

Josephine: To be honest, I just told them. I finally told them. They didn't treat me like most people treat their family. They still love me. They still ate after me. They still kiss me, all of that.
Deborah: My mom is very supportive, and my younger sister is very supportive, but my three sisters in the middle, it’s like, “Don’t—I don’t want you t’ come over my house. I don’t want you touchin’ my baby. I don’t want you eatin’—” They’re like that today. If I come over their house, they get the bleach out, and I’ve gotta eat on paper plates, and they got a whole nine yards.

Pat: Me and my sister, we fine. They really don’t pay no attention ‘cause they don’t never hear nothing about I’m sick or I don’t feel well.

Corky: All my brothers are dead. My mother’s dead. My father’s dead. My stepfather’s dead. All I got is my three sisters. I asked them to help me while I was sick, and it turned out to be a disaster. My sister, my older sister, ended up taking my medicine, $200 out of my account, and constantly trying to keep me under dictation, and it was just ridiculous.

Helen: When my mother first found out I had HIV, she was like, all of a sudden she started getting standoffish, but then she came back and told me, “Well, I am trying to read information on it.” Here, lately, my mom has been—she’s been cool. My mom has been cool, man. She calls and checks on me. She calls me every night: “How you doin’ today? What did you do today? Did you go to school? How’s your health? Well, you know, you gotta listen to what them doctors tell you now. You can’t be missin’ takin’ your meds.”

Arline: We can talk about my health, but we don’t say AIDS. I only talk about good health. We don’t talk about threatening health.

Wanda: My family was, you know, devastated. “When’s you gonna die?” And I had to explain certain things to them. But other than that, they accepted it, especially my oldest child. I’m just—you know, your child always love you, no matter what.

Gwen: You know, my brother was gay. He died in 1985 from full blown AIDS. And so, you know, my dad, I told him about my gay life. He just act like it’s nothing. He act like he just don’t hear me. When I’m speaking to him about AIDS—I speak to him about HIV and about homosexuality, he don’t hear me. Not his kids. He just doesn’t hear me.
Family reactions to being lesbian or bisexual

"I feel like you’re a puzzle and you can fit all the pieces except my piece is left out in my family"

Helen: I love my mom. I love her to death. But [laughs] jeez, sometimes I have to love her from a distance. She really don’t, don’t like my sexual preference, you know. She’s always on my case about how I should dress. Yeah, “Why you wearing that shit? Got on these pants. Why don’t you put a dress?” I had to tell my mom “I’m your daughter. I love you. I always will. But I’m gay. And this is my life, and this is what I choose, and either you accept it or you don’t.” So she ain’t accepting it, so, oh well.

Valerie: It sounds to me like it’s easier for your mom to deal with your HIV—

Helen: [Jumping in] than it is my gay, me being gay, yeah. Yeah. It is.

Valerie: Isn’t that interesting. Is that interesting to you?

Helen: It is. It’s very interesting.

Valerie: What do you think about that? How do you make sense of that?

Helen: You know [laughs], I don’t know. I can’t quite answer that one [laughing]. I’m still trying to figure that one out. But, um, I’m kinda amazed by that too ‘cause it’s like, damn, she accept bein’ HIV then she would accept me bein’ gay. You know?

Deborah: My mom, she love me dearly and everything, but when it comes to my sexuality, it’s like, I don’t fit anywhere. I feel like you’re like a puzzle and you can fit all the pieces except my piece is left out in my family. I’ve had my cousins tell me, my men cousins in my family. “Oh, just let me get it one time. I’ll show you what a man can do for you. And I’ll make you really love a man.” I say, “You can’t make me love a man ‘cause I’ve been this way all my life. I probably was born like this,” yeah. And my mother say, “Oh, no, you weren’t. You didn’t come out of me like that.” It’s crazy, crazy.

Irene: Yeah, one time my brother tried to make love to my woman. See, I have to worry about—lesbians have to worry about men wanting their other half. Lesbians—I have to protect myself from men when I’m with a woman. When two women are together, men will come in like flies. Girl, I’m very protective, very possessive with my woman. I don’t want a man bothering her, touching her, or speaking to her too much. I’m very protective.
Valerie: Arline, how is it with your mom?

Arlene: She knows that I’m gay, but we don’t talk about that. We don’t talk about gay.

Pat: My mom invites us over for dinner.

Valerie: Has she always been open like that about your being gay?

Pat: Yeah. I started bringing women home when I was 21.

Valerie: And how was she?

Pat: She was cool. As long as I was cool, she was cool.

Beverly: My mother didn’t talk to me for a whole year and sent me to a psychiatrist. My dad died; it’ll be three years now. He was there for me through thick and thin. He was there for me whether I was gay, he didn’t even care if I had a black girlfriend. He was there no matter what, he said even if I was HIV positive. My stepmother would leave the house [laughs] when I came in. I needed a place to be, and he just took me right in. And he said, “You stay here as long as you want until you can get into, you know, your next drug rehab.” He didn’t care about anything. That man loved me wit’ all his heart and soul. And I miss him so much.

Jolene: My father had a problem with it at first. You know? But like, as time went on, after about six years of me not changing and still seeing that that was it, and that was what I wanted, he eventually started to come around and visit. At first he wouldn’t even come to my house, for about five years. Yeah. He wouldn’t come to my house. And he didn’t want me to bring her to his. And after he seen that it was still going on, and that we was still just as close as we was from the time that he didn’t accept it, gradually he started to accept it. He didn’t live much longer after that, though. But it was good to know that he did before he died. I was happy about that.

Corky: I told my mother I was gay when I was 15. Well, my mom was a call girl. But my mom was my best friend. And when I told her, “Don’t tell nobody,” she says, “I already know.” And my stepfather sent me away to Hawaii. It’s like if you got pregnant, nobody say nothing, send them away. So they sent me away for a while.

Josephine: When I had to tell my family I was bisexual, it was like “Uh! God! Not my daughter! Not you!” You know, my mother didn’t, my mother really didn’t like it. And neither did my brothers ’cause I’m the only girl. I’m the oldest. I don’t know. I finally just told them. ’Cause I would find myself with them, and I would say, “Gosh, she’s fine,” and they would look at me like, you know. And so I just got tired of it. My brothers are heterosexuals. Well, that’s okay. That’s them. But I also like women, and I also like men. And they say “That’s very confused.” I said, “No, I’m not confused. I know what I like.”
Valerie: What happened?

Josephine: Well, I stopped communicating with them as much. But as the years went by, they’re okay. They don’t like it. But they’re okay with it.

Valerie: What do you think helped them adjust?

Josephine: Reality.

Valerie: It sounds like they had the hardest time with your sexuality.

Josephine: Of course. Yeah. That they really had a hard time with.

Valerie: How does that make sense to you?

Josephine: It doesn’t [laughs]. But then that’s they owns garbage, not mine, because I’m really close with my family.

Wanda: Whatever momma wants, that’s basically my oldest one, that’s her. And my sister that’s older than me, she ain’t never questioned nothing I’ve ever did. She’s a Christian, but she had never tried to stuff that down my throat, I guess, because I’ve always been so independent all my life, and she knows this.

Dates, partners, lovers, wives:
discordant couples, reactions to HIV infection, safer sex, and love

“She’s kind of been my family, my everything”

Valerie: So how was it for you with your partner, talking with her about your having HIV?

Deborah: I said, “Oh, no, how am I gonna tell her? She’s gonna leave me,” and I started crying, and I said, “I’ve got something to tell you.” And so I thought she was gonna leave me. She said, “Girl, that ain’t nothing but a virus! We can get around that. We can use Saran Wrap on it, we can do—” I said [laughing], “You know more about it than I do.”
Beverly: I found out I was positive, and my girlfriend accused me of knowing all along I was positive, and she left me. So I had nobody. And it was just, oh, it was so tragic, and I was just poor me, poor me for that whole entire year.

Gwen: The last female relationship I had was with this Italian girl, Jackie. I was really in love with her. I told her, “Well, you know I’m HIV positive.” She told me she didn’t care. It seem like everybody I tell about my HIV it doesn’t bother ’em. They don’t care. Like I told Jackie, and she didn’t care either. Then they don’t want to use condoms. What’s up with that?

Valerie: What is up with that?

Gwen: I don’t know. They don’t want to use condoms. They tell me, “Well, I love you, and so if I can go out there and play with drugs in my life out there to get loaded, then I can jeopardize my life with you.” I don’t know, it makes me feel bad at times.

Wanda: In prison they talk about giving the woman oral sex when she’s on her monthly, it’s called “you got wings.” I haven’t experienced that part yet because I didn’t want ever to do that. But at the same time, it’s called “getting your wings and stripes,” ‘cause you know how to do it without obtaining her blood or whatever in your mouth.

Beverly: I was dating women. I was having safer sex. But I wasn’t telling them I was positive, but I was having safer sex. Then gradually I told them I was positive. The first time I did was after sex, and she cried, and she said, “Promise you won’t tell anyone you had sex with me.” She didn’t want to be, like, black-balled in the community, that she slept with a positive woman. So I said, you know, well I’m gonna have to start giving these women choices. Nobody was getting me information; nobody knew. My first lover was the director of the Gay and Lesbian Health Center down in LA, and she had no barrier. She said, “I can’t get it from you. You can’t give it to me, it’s impossible.” And she still isn’t positive today. And she refused to have sex wit’ me wit’ a barrier. And she is still not positive. She never got it from me. So I don’t even know what to say about it.

Gwen: I don’t believe in doing nothing and stuff without people knowing. I just don’t believe in it. Whether it’s kiss or whatever, I don’t believe in it, because you don’t know what a person thinks about it.

Josephine: My partner is not HIV positive, but I’ve been with this person five years. She’s been clean 14 years, and I know if I don’t get it together, it’s gonna be over, because she’s been dealing with me for five years with this. And I’ve never had anyone that good to me in my life, you know? Accept me for me. So I want to keep the relationship with her. I want to be faithful to her. This is the first relationship I’ve ever been in that I’ve been faithful to her. But, um, I told her, I did turn dates, though, when I was out there using. But being sober I never cheated on her. I just want to keep her in my life, ‘cause she’s a good person. And I know she’s not gonna take my crap anymore, so— [chuckles]. Yeah, I have to get it together. But I’m going to get it together for myself.
Irene: A lot of people disagree with my relationship, but I'm like this: they're not living with me, and they're not doing anything for me, but they're commenting on the fact that I'm going backwards by going back to my old love, my wife. That's my wife. I want somebody to be in my life, and I choose to have her because she's the only one that really warmed my heart.

Deborah: That's my rock there. Without Lizzy I would, I'd probably be dead.

Pat: We've been together two months. I met her through my bisexual daughter. It was her friend. My daughter's 18. She's, 19; she'll be 20 in March. I left my domestic partner to be with her. So now I'm filing for, I guess, it's a divorce or whatever it is, but I'm filing for one. We had been together for nine months, and we've been domestic partners for two. I started messing with her during the domestic partners phase. My wife, this one here, I call her my wife, 'cause she's not like a girlfriend; she's more like a wife. Basically, me and her talk about everything. Good or bad, we talk about it. And basically, we don't argue, 'cause I tell her that's stress to me. And stress ain't good for me, so we don't—my domestic partner likes to argue, and she likes to, we had our domestic violence, so in this we don't have that, and I think that's why I'm so happy with it.

Jolene: I have different lesbian groups that I go to since I broke up in this relationship, you know, just to kinda help me get through it. Because after being with a young lady for so long a time and then being apart from her, you know; she's kind of been my family, my everything. But I still think about her a lot because of the length of time that it was and the strength of the relationship that we did have. I don't think I could really handle it if I hadn't been in recovery, so that has made it kind of easy, to where I don't know what would have happened if I hadn't been.

Irene: My old lady's really to the point where she doesn't want to use—she wasn't scared; she didn't want to use any protection. So I stopped, you know, becoming intimate more that time, at that particular time when we were together. I could not have sex with her without protecting her.

Josephine: And we have protection. But sometime we don't, you know. But I read a lot about me transmitting it to her. And it's like, it's really not that great that I'll give it to her because of the body fluids. And she gets checked every six months anyway, period. And by the grace of God she hasn't got it, but we use protection sometimes, sometime we don't. I would never want her to get it, but it's like she knows that I am positive. And she's okay with that. You know? But then, on the other hand, I always say, "Well, God, if she had got it, what would I do? How would I feel?" So then, you know, it's like it's weighing, both parts is weighin' me. So sometime when I say use protection, she doesn't want to. If I say don't use protection, she wants to. So it baffles me sometime, but most of the time we do use it. But by me taking care of myself and not using and my T-cells are high, it's real rare that she'll get it, because I know it's so much easier for a man to give it to me than for me to give it to a man. She hasn't gotten it so far, and so far, so good.
Beverly: They measured my vaginal fluids, and they saw that I had HIV in my vaginal fluids, and my T-cells fell down, to the 200 level, you know, and so I decided, you know what? I am never gonna have unsafe sex with Lisa; I love her too much. I would never want her to have the pain that I have suffered from this disease. I, I don’t wish it on my worst enemy. So we practice safer sex, and I think that’s the way we probably will, because I don’t think they’re ever gonna have a clinical trial where a woman has to give her orgasm, I mean the fluids from her orgasm, and let them be studied, like men do. You know what I mean? I don’t think that’ll ever happen, so we’ll never ever know. And I’m not willing to take a chance. I wish, I would love not to have safer sex wit’ Lisa, but I’m so afraid of infectin’ her, I could scream. I’m so frustrated and angry about it.

Communities and Support:
support groups, retreats, speaking out, race, religion, HIV, men, and other lesbians

“We’re all praying for the same cause”

“There’s a lot of places where I don’t fit”

Deborah: It’s not many lesbian support groups, it’s mostly for gay men, and the few support groups that I had been to for lesbian women, it’s not many Afro-American lesbian women in there. I don’t know, because I went to like a gay pride thing they had in Oakland, the first one they had. It’s a lot of sisters and girls out there, I mean a lot! They were hugging, and I mean, I had a lot a fun. But you don’t see them at any support groups anywhere, and I find that hard to get support right now. I have to go into like a straight group and try to play straight. And I, I can’t—I’m not comfortable there, you know? Because they’re talking about issues about their maan and all this. So it’s, it’s, it’s kinda hard to fit in the community. Like I thought I was comin’ out of the closet, but I feel like since I’ve been positive that I’m going back in the closet, because it’s no support out there for me, being gay, you know?

Helen: I would like to see support groups with lesbians. I’m getting tired of being around just regular women talking about the mens and they husbands and bla bla, bla bla, you know? I want to hear something that I can relate to, you know? I’m treated with respect, but I’d just like to hear how lesbians, how their life is, and things that I could relate to.
Arlene: There’s a lot of places where I don’t fit. There’s racial. There’s the lesbian thing. There’s the gay white man thing, with the HIV. It just makes me feel less than, you know? This is where my mind goes with that. I’m just this little black girl; you know what I’m saying? Dope fiend, bad girl, you know? And I just take whatever I can get because I ain’t got shit coming in the first place.

Valerie: Can you make any comments about any kind of racial issues within the HIV community?

Beverly: We’re all sticking together as equals. We are all sisters.

Helen: For a while, I felt really, as far as like, around my medical issues, I felt like if I asked questions they would think I’m dumb, and I was, I couldn’t say anything to my nurse practitioner. And I felt like she was rushing me in and rushing me out. She wasn’t really checking me, you know? Like I had some kind of disease or something. You know what I’m saying?

Valerie: And it felt like it was a racial thing?

Helen: Yeah. I sure did.

Arlene: You feel when you’re not a part of something. When everybody’s talking and you talk and nobody answers; it’s sorta like, you know, you really don’t belong there.

Deborah: Yeah, it’s not comfortable; it’s like, when you talk, it’s like, they give that look, like “I don’t want to hear it” or the body language, you know.

Arlene: And that’s the case a lotta times with gay white women and gay women of color. What else could it be? We’re in the same boat sexually, and there’s just an avoidance sometime or there’s just—they pretend not to notice you. So I don’t go. I don’t go to their groups ‘cause I ain’t into that. But I would most certainly make room for something like that if we had, you know, a group where lesbians, white and women of color, would get together on it, with a combination of the HIV and lesbian thing and actually get together and feel like you belong to something. It just don’t work that way.

Jolene: You know, I’ve never had any trouble with racism. It’s kind of tripped me when people tell me that, that there’s this or that, because I haven’t experienced it. And I’m 42 years old.
Irene: In the Black community we’re not as accepted. If I went to San Francisco, I can hang loose, everything cool. Coming to Oakland, I have to be reserved a little bit more about my sexuality. It’s more hidden in the black community. And being accepted is—it’s like this: you have to have an attitude: “Well, fuck you then, if you don’t want to be around me. Go somewhere else. I was kicking with my partners.” You know, that’s how you have to kinda like live: harder, tougher. Whereas you go into San Francisco and you can walk around on your tiptoes, skip down the street, and nobody’s going to say anything to you. You can do what you want. That’s true. It’s harder in our community. That’s why I like variety. I don’t particularly like groups, black African or black American.

Deborah: In Berkeley you can walk around and hold hands and kiss and stuff, and people ain’t gonna trip. You come to Oakland and try to walk around holding hands, and, “You butch. You bitch,” you know? So you have to kinda keep that quiet. But I love going to Berkeley ‘cause I love seeing women hug each other and kiss each other. I can’t believe I can go to one city and be cool and come to Oakland and it’s like taboo.

Arlene: I feel out of place with women of color as it pertains to HIV. Recovery, fine, but add HIV stuff in there—see, culturally there’s a real fear of things that you can’t see, of diseases and shit, among black women. I go over to the Park Club over in Oakland. There’s a lot of sisters there. But then again, I don’t know that I belong there. This is where I like to have a good time. But even if I wasn’t in a relationship, I would probably shy away from, like from going home with anybody or getting’ close to anybody there because of the HIV issue. But I’m getting better at talking to people. I figure I’d just rather be safe and not tell them shit. We dance, flirt, whatever. And we’ll see ya.

Deborah: You have to be very careful who you disclose to, so I mean my lover know and maybe one or two of our friends; other than that, no.

Corky: Some things are better left unsaid, you know? I don’t just let everybody know. They automatically judge me just by my appearance, and that’s sad, you know? People call you dyke. I hate that word. “Here comes this dyke broad,” you know, stuff like that.

Jolene: I haven’t really experienced no rude treatment, you know. Since I found out I was positive, that was one of my fears. I thought I would lose my relationship and that I wouldn’t have any friends and that I would be by myself. But it hasn’t happened. It hasn’t happened. And, like, I’m pretty quick to tell somebody that I am positive, I guess to see if they’re gonna to turn away, you know, before I get close to them. But so far I haven’t had to deal with any rude people in that area. So that’s been really surprising to me, because I really, really thought that I would be an outcast.
Helen: I used to trip on people. I used to be a people pleaser too. What people thought about me, I just, it used to matter. But now, the hell with what people think. Like a dude told me one day, "I get tired of seeing you in pants. You need to put a—" I said, "Well, why don't you buy me one, and while you're at it, why don't you put it on?"

Pat: Some people that I know kinda backed away from me, some gave me more support. Some, like, you know, "If you ever need me, just call me," you know and all that kind of stuff. Basically, I was the one that did the backing off. Because I had to come to grips with it. It wasn't about what nobody else thought about it; It was what I thought about it.

Valerie: I was wondering about how it's been for you as a lesbian with HIV, like, with other lesbians who aren't HIV positive?

Helen: You know what? I went to a club one night, and I had a conversation with this one girl I was kinda interested in 'cause she danced with me. And it kinda made me uncomfortable because there was like, "oooh," you know, "You're a lesbian, you ain't got no business messing around with guys." So they kinda look down on you about that. And then she had the nerve to tell the bartender to serve me a drink, and I had just told this woman I'm in recovery!

Valerie: Really!

Helen: But she was on full. And my friend was signaling; are you going to take her home with you? No. I think not. I think not.

Corky: I've never been disrespected or nothing like that.

Beverly: I have been looked down upon. If they can't see me, they can't realize it's hittin' their community. I was in Michigan, and I looked for a positive women's tent. There was none. Positive women's workshop: there was none. Kinsey six, you know? You're not a real lesbian if you're sleepin' with men or sharing needles, you know? It's incredible, you know? And I was raped, but I get treated like some kinda low-life.

Irene: There's a— you know, that if you mess with a woman who messes with a man that you're not really a lesbian. These little stereotypes. And then if you do, it's like you've committed some type of error.

Beverly: People that don't know me are afraid of me, that are lesbian. And Carol Jacks, for example, I asked her to be on our board of directors. And she looked at me, and she said, "Well, Bev, I just don't travel in those circles. If it wasn't for these parties, you're the only lesbian I know with HIV." I said, "Carol, would you at least read the information that I sent you?" I expected some kind of a donation. She's a millionaireess. She didn't give a penny. Nothing. And we are hurtin' so bad for money right now.

Jolene: I haven't experienced no problems with other lesbians.
Valerie: Irene, how do they respond to you?

Irene: They’re curious, curious. “What do I do?” They ask questions: “Irene, what do I do? To be safe, to be safe.” “You get reality, some dams and gloves,” and I go digging in my closet to come up with packages. I have condom packages in there. In fact, they are very supportive, yeah, HIV negative people. I think that people are being more educated now and they’re more accepting.

Pat: I don’t let it be a big issue. I was in a drug program, and it was for HIV positive women, you know, HIV women, and drug problems, and it was a year program. I left the program ‘cause all they focused on was HIV.

Valerie: How is it for you, Josephine, in your residential program?

Josephine: It’s like, I’m the only one in here that is positive. I might be tired more than others. I’m really energetic, but there’s sometimes I’m tired. And they would say something like, “Well, you have to go to group,” and it was like, you know, “No, I’m not going, and I mean I’m not going.” I do my share around here. I know I’m not lazy. You know, I do too much, to me. And it’s like, when I tell you I’m tired, I’m tired. And I want to lay down. Simple as that. And then I went to the director that runs the place, and I told her, “Look, sometime I am tireder than others. And sometime I might need to lay down.” And she said she didn’t have a problem with it. That’s why I said I’ll stay, you know, ‘cause she didn’t have a problem with me laying down or anything. So, that’s what I do.

Jolene: I have some friends from NA that set up a group. We talk about, like, being a lesbian with HIV or just being a lesbian, you know? And it’s good, just being able to talk to somebody who understands. All of them are beautiful ladies. They’re in recovery; some have way more recovery than I have, but they’ve been real supportive to me, you know.

Beverly: I am so sick and tired of getting’ no support in these support groups, ‘cause all the women come to me. I am the encyclopedia of what to do if you’re a woman wit’ HIV in San Francisco. It’s very lonely for me.

Corky: And see, us older women, it’s like there’s really nothing out there for us.

Valerie: So what about Karen’s group, which is for older women?

Corky: It was just a support group.

Valerie: Right.

Corky: But it was like the same thing every week, so I just stopped going.

Valerie: What are you looking for that it wasn’t?
Corky: Somewhere where we can work things out and maybe accomplish something. You know, not just to keep going and talking. We’re not accomplishing anything. You know, to have some inspiration from somewhere, some kind of hope. I’d like to see more organizations, more agencies, focusing more on women. They’re just now coming out of data with, well, now we’re finding out that this doesn’t work for the women, and this is for the men, and da-da da-da da-da. Look how long it’s been! And how many friends I’ve lost! You know? And, it’s like, how much longer do we have to wait as women? You know, it seems like we always get put on the back burner. And I think it’s time for them to start looking at things a lot more, as far as women and where they progress and what’s happening and what can we do for them, you know? There’s a lot of us that are just by ourselves, handling this by ourselves. And it’s not easy.

Josephine: The part of the community I feel involved with is WORLD. I’ve been to Hawaii, Atlanta, Georgia, Washington, D.C. As an advocate for women with HIV. They have conferences, and we go. They pay for you to go.

Helen: I do a lot around the HIV community. I just came from a trip; I went to L.A. to a women’s conference, and I met 9,000 women from all over the world. The next one that’s coming up in the millennium that’s gonna be in Africa. I don’t think I could do Africa. Africa is, it’s too, they too dangerous over there.

Jolene: Right now I’m waiting to see if I can go to Washington with a group of ladies that are moms.

Josephine: The last one we went to, we were in Pasadena. And, you know, the doctors with all these big words, and the lady didn’t want us to speak. So I just—me and my big mouth—I just, “Well, can you break it down, so those, like people like us— “ because I don’t understand it in medical words that they be saying, you know, and they all back and forth. Well, damn, what are we here for?

Beverly: I’m pretty much part of all the communities of HIV [laughs]. I’m part of the Women’s AIDS Network. I’ve been lobbyin’ when we were doin’ the Clintons’ health reform. I’m a big part of WORLD, Women Organized to Respond to Life-threatening Diseases. And I volunteer at the WORLD retreats. And I’m gonna be on the Foundation board of directors, helping the women, you know, get in there.

Irene: I got this apartment and I got a job at the same time, as a peer advocate. In the medical marijuana community, I’m established. We just went to a demonstration yesterday in Sonoma. Another community that I’m involved in is the homeless community. I’m very well respected in that community.
Helen: We’re going on a WORLD retreat in November. And I have been on that thing, this should be my seventh trip. And I really enjoy it, ‘cause I get a chance to get away. I get a chance to relax. If I want to go up there and just sleep through three days, I can do that. But if I want to attend workshops, I can do that. I don’t know if I have time to get rest ‘cause I’m so busy with other women and stuff, and, you know, it’s cool, man. The onliest thing I don’t like is that when we go in the summer time and them damn cows and them big ass flies and them big— I swear to God, even when I was little, I didn’t remember seeing no big ass bugs and shit.

Josephine: I am so tired of going to, uh, Healdsburgh till I’m just blue in the face. Yeah, I’m tired. I must have been there eight, nine times.

Arlene: One of the things that WORLD does, when we first arrive on site, is we do a circle, the opening circle, and I think during this time they ask for the person who’s had this the longest. It turns it, you know, it’s an honorable thing to be a long-term survivor amongst women suffering from AIDS. I remember when it first happened. It was so strange. I was like, you know, these people here is proud of this shit. “What?” And then the next one I went to, I was like, well, “1987. I’m still here.” I really, really have a lot of respect for the WORLD organization. And it’s a very, very, very healing thing to go to. I ain’t never done no shit. A retreat? I’m like, what the fuck is a retreat? Retreat! That’s the kind of shit that the army did. [Yells] “Retreeeat!” That’s when you run, ain’t it? What y’all running from? You’re gonna come back down from that mountain and still have this shit. That was my attitude. You go up on a mountain with the shit, and you come back down with the same shit! [Laughs.]

Corky: Yeah, they come over here one time, and I was supposed to go on a retreat, but I guess it was too crowded. But that’s the first time I ever met WORLD, was here, you know? And I haven’t seen them since.

Valerie: Do you get the newsletter?

Corky: No. We don’t get anything here.

Deborah: I do speeches for an HIV program in San Francisco. I go into high schools and stuff like that and talk to kids.

Wanda: I was on a panel with people, and I give them presentations to junior colleges, state universities, to boys’ centers, the girls’ centers, you know, trying to let youth on all levels know about high risk. That’s what I want to wind up doing, is be a peer counselor advocate for HIV, and with WORLD’s University of HIV; I hope to go to that when I get out of this program.
**Beverly:** I am co-chair of the Network of Positive People, and I have a lot of male friends that are still saying at our meetings that straight people, now African Americans, want to take all the money away from us. So the gay men are still crying. I looked at him, and I said, “Come on! It’s everybody’s money. We have to share the money. AIDS is everybody’s disease. You know? It’s not a gay man’s disease anymore. It’s everybody’s disease.” I fight for women, you know, and I let people know I do.

**Irene:** I never did like to go to a group with men. You never got your point over.

**Corky:** Women, women just don’t have enough support. Doctors and research, as far as medical research, they’re not doing enough. Ever since I’ve been diagnosed in ’96 all I’ve seen is men, men, men, men, men. Even at the Foundation. They discouraged me to go there, as a matter of fact.

**Jolene:** I get a lot of support from gay men, straight men, you know? I guess it’s the changing of the time. We’re all praying for the same cause.

**Irene:** Lesbians need to be more visible.

**Valerie:** Why aren’t we?

**Irene:** I don’t know. I know I’m visible enough. Can’t nobo cy miss me. And I hold my head up proud; I’m proud of what I am. I’m not proud of some of the things I’ve done in my life, but I’m proud still of who I am.

**Wanda:** I’m bisexual. But at the same time, for a long time I was just straight lesbian. Since I got into recovery this last year, I’m trying to get into the principle and the spirituality side, and that’s when the guilt things come through and where the thing of women not supposed to do it with women and men not supposed to be with men.

**Deborah:** ‘Cause a lotta preachers preach that, about gays and, you know, men and women being with each other is a sin. So, oh God, don’t let them get them to preaching on that one! ‘Cause my aunts, they’ll come up to my mother’s house on Sunday after church. I don’t go near there: “Whoah, here come the sinner! Oh, Lord, let’s pray for her, let’s lay haaands on her, Lord Jesus.” No, I’m serious.

**Valerie:** Do they know that you go to your own church?

**Deborah:** Yeah, but that’s a faggot church over there. That’s for them gay people. Everybody in there’s gonna be going to hell.

**Irene:** We’re both very religious. I’m not a monk or anything like that; I go to church. Community church. I’m not as active as I used to be when I was in the foster home, when I was in the choir, teaching Sunday School, reading the Bible all the time. But I keep my spirituality; I keep God first.
Valerie: And how are, do they know that you have a woman partner and you have HIV?

Irene: It’s okay. It’s not accepted, but it’s okay. They accept me, love me, but I don’t bring it into the church. I don’t bring it in front of them because, remember, they’re old, older black community, but they still accept me and love me.

Valerie: Do they spend energy trying to get you to—

Irene: [Jumping in] change? At one time they tried to, but it didn’t work. They got me to a point where they got me in a dress, almost a dress. They did get me in a dress. But I did not feel comfortable. So now, you know, I go to church, and— anyway, my pastor, his sister gay, so— [laughs]. She drive a 18-wheeler truck [laughs].

Jolene: A lot of people don’t realize how hard it is being lesbian with HIV. And they can say, “It’s a sin that you’re messing with another woman. That’s not how God meant for it to be.” And they can make you feel guilty in that area, you know? But you can’t change who you are. If God hadn’t meant for me to be like this, I mean, I wouldn’t be this way, you know? Even if I say, okay, I’ll just be with a man, that’s not where my satisfaction is. So, I mean, that would be like being a hypocrite.

Valerie: What’s the HIV part about?

Jolene: People have the tendency to make you feel really, really uncomfortable. They’re saying if I hadn’t been with a woman, maybe I wouldn’t have HIV.

Valerie: Oh! It’s like God’s punishment stuff?

Jolene: Yes, yes. God punish you, and that’s why that happened. That’s why you have that, you know? My punishment was getting a HIV [long pause]. And they don’t realize how sick they sound by saying these things.

Deborah: The way my family, when I told my family, how they treated me, you know, like, my sisters: “Yeah, well see, if you wasn’t sucking them pussies, then you wouldn’t have had it.” And I said, “What?” “Oh, yeah, you was with women anyway, so it was God punishing you.” At first I believed them. But now I know better.

Corky: That’s how I looked at getting this virus, going through the things that I’ve been through, being who I am, it’s all a punishment. I used to think that. Until recently, until I finally turned myself around. Nobody’s punishing me. But there’s a lot of people who do think that way, that God is punishing all the people now. If that’s the case I think it would be more prominent than this [laughs].
I thought lesbians didn’t get AIDS

“What the hell did you do?”

Valerie: They used to say, if AIDS is God’s punishment to gay men, then lesbians are the chosen people.

Arlene: That’s great [laughs]. I’ll have to remember that one.

Valerie: So how did it feel to you to have—

Beverly: [Jumping in] Terrible. Terrible. I felt like I let my community down. I felt shame. I felt guilty. I felt like I, I wasn’t good enough. You know, it wasn’t supposed to happen to me. After all, I’m a lesbian. How could this happen to me? And it was like, for a year all I did was cry about it. I just walked around crying and saying, you know, why get sober if I’m gonna die? And without my own people, the respect of my own people, how would I get through the world, you know, bein’ so alone? How could I have love without bein’ touched? And it just, it brought me to my knees. I wept all the time. I did. It was a very, very hard time for me. [Laughs] I was the sorriest thing you ever wanted to see.

Irene: I was devastated! It was devastating. It was like, I can’t have that shit, man. It was like, “God, noooo.” I went into a lot of denial. I stayed in denial for a year and a half. Then I got retested. And sure enough, it was okay. It was not okay, but it said the same thing. And it’s like, damn. How the hell did I get this shit?

Beverly: If you are a quote-quote lesbian then you can’t get AIDS. Like what about me? I was raped. And I got HIV.

Jolene: There’s still people that believe the lesbians don’t get HIV. There’s still people that believe that, you know? I just look at it as ignorance and try to just explain that it does happen. That’s basically mostly all I can do, is just try to express that it does happen, and I’m a living witness to it, you know?

Corky: Women are women, and we’re only human. Everybody makes mistakes, and we’re gonna to do that, regardless. So there’s nobody that’s going to be pinpointed out, that’s gonna be sacred, the savior, and not catch anything [laughs]. No. It don’t work like that.

Helen: There’s still people out there that’s not educated.
Pat: Yeah, you get that dumb look, and that's when I have to break it down to how I got it. I wanted kids. I get pissed off sometimes 'cause they don't pay attention, and they don't read, and they don't listen to the news.

Valerie: And how does that impact your life?

Pat: I just keep on; I shake it off and keep going.

Josephine: To be honest, I never really even tripped on it.

Beverly: They look at me as, you know, oh my God, I thought lesbians didn't get AIDS. What the hell did you do? [Laughs.]

Irene: I thought I was immune. I thought I couldn't get HIV. I never did have safe sex from the time that they had given the word that AIDS is out. Then they called it GRID. I don't have a dick! How am I gonna get it? No man ain't gonna give it to me. No woman can, you know? It's passed by semen and stuff, blood and things. I just be careful about women. So, you know, I'm not gonna get it. But I did. And I believe it's through a woman because, as I told you, I only had, in the fifteen years here, one relationship, and that was with a woman. That's how come I'm almost positive, because my sexual relationship was with her and her only. But she has some devious ways of entertaining herself, and me too, because we were both fucked up at the time with drugs and things.

Corky: Nobody's invincible. We're only human. But I believe that this virus in itself was put here by men. [Laughs] Here we go again. By men. Men brought this virus here and infected us.

Josephine: I don't know how I got the disease. It could either have been through tricks or sharing the needle with someone. I don't even know.

Arline: Well see, I got mine shooting dope. I know how, you know what I'm sayin'. Because I wasn't fucking men. I didn't get into that, to ho-ing until later. Not that I never ho-ed.

Pat: Everybody basically knows that I got it through my baby's father. I have a 12-year-old son. His father infected me, while I was pregnant with him, with my baby. And I didn't find out until my son's father died that he was, that he had it. Then my drug addiction just went sky high.

Deborah: When I found out, the lady say, "Well, how did you catch it?" I said, "I don't know." She say, "You gotta know." But I don't know how I got it myself, so I couldn't tell them how I got it.

Jolene: My partner was negative, you know, and I was positive, but she was negative. See, I was an intravenous drug user, and she wasn't.
Corky: The person that I got the virus from is dead. I caught it from my girlfriend, intravenously. She used my outfit. She died nine months after she told me.

Grief and loss

"It's like a part of my heart just left"

Valerie: You've had a lot of loss.

Corky: Yeah. So that's why I feel like, you know, I'll deal with this by myself.

Valerie: What about friends?

Corky: Nah. I kinda left the drug scene, so [laughs], what you thought was friends—. I don't have any friends. You get real lonely, but you get over it. [Chuckles] As old as I am and as long as I've been alone, you just get through it. I just found out last week that this girl Annie died. And I found out today the funeral's today. She went on a binge, and going out on that binge took her life. And the thing about it is that that child was never sick. She never got sick. All of us were sick in the hospital, but she never got sick. She was going to City College; she was doing good. And I don't know what happened. And it just tripped me out. You know, somebody that was doing as well as they were, to go out and just all of a sudden get back into the drugs and stuff, and then die? I mean, God, that's a little too close to home.

Beverly: At AIDS, Medicine and Miracles we get to grieve over our friends that we lost. Oh, and you cry and you wail and you scream their names, and you hug each other, and talk to each other like it's them, the person that you lost. You know? And you're just so exhausted the next day, but what a release! What a needed, needed thing! And so every year now AIDS, Medicine, and Miracles is going to be by Santa Cruz, where we had it this past year. I'm gonna see if I can be a volunteer there. I would love to do it. I'll see. If not, I'll just be there, you know, and take it all in. It'll be real good for me, 'cause I'm always losin' somebody. [Very quietly] You know, the fight's not over yet. [Louder] Not by far.

Helen: I read an article about Bunny Knuckles. Oh, baby, I miss Bunny. I miss her. I still miss her. Sometimes I feel like she's watching over me, like, "Okay, Helen, you doin' okay, continue doin' it." She brought a lot of joy to people. It's like a part of my heart just left.
Josephine: Oh my, when she died, oh my goodness gracious! I've been knowing her for over ten years. Great friend. Good advocate, too. I went to the wake. I couldn't go to the funeral. It was too much for me; I just couldn't go. I try not to dwell, but I miss her a lot. Oh God, yes. I looked up to her, you know? A lotta people did.

Wanda: Oh, it was sad for everybody. And I've been there when women have died with it in prison.

Gwen: Because of the death of somebody I cared a lot about, I got all stuck on sleeping outside on the streets. It really affected me, so I've just been back for about a week. I never lost my bed, but I was just running the streets like crazy because I didn't know how to deal with the death. I lost myself, and I was doing a lot of damage to myself. I was up there every day to see him. It was terrible. I was watching him die right there in front of me. I'm still trying to get over that right now. I had a brother pass the same way. From AIDS.

Helen: I had this one particular friend. And she really made me proud; she was always going to school. And she died recently, she died recently. Shortly after Bunny Knuckles died, she died. And I lost so many, I swear, over the course of two years, I've lost a lot of friends.

Violence

"I had gotten to where I couldn't even separate it from my daily activity"

Jolene: I was on Methadone, and I was going to a group, and I had started talking about being molested when I was six years old. And I had gotten to where I couldn't even separate it from my daily activity. I'd be doing something, and it'd just come up, and I couldn't control the thoughts about it, you know? I was staying on the hotline, calling somebody on the phone because I started having nightmares, and I mean, it was just like terrible, you know? It was just so many things at one time. I didn't know what I was going to do or what to do, you know? And finally I just, like, made up my mind, well I can't keep using because it wasn't making anything any better or any lighter, you know? It just made it harder each time that I had to think about it. So finally I made up my mind to be in recovery. I've tried to commit suicide twice. And that was when I first started dealing with the thing about being molested. At one point it had affected me really bad. But now, like, I'm more under control, you know, than before. But I sent myself through a lot of changes because of, you know, like, I
felt like it was my fault. I went through all that. It took a while to get through it. I finally got through it. Being molested, I think, is one of the reasons that I ended up with a woman. Because when I was molested, I was really hurt. I can’t have kids behind it. And I was only six years old. I was damaged to the point that I can’t ever have children. So, yeah, I never wanted another man in my life, you know? It was like a long time before I would even have my father touch me. And I know he would have killed my uncle if I had told him at the time. But I wouldn’t tell because he had me believing that he was doing it because, that he was helping my mother to live by doing this to me, you know? And I believed it.

Deborah: When we were kids and we were growing up, my stepfather started molesting me, you know. And then it was like he molested every, all, all my sisters, and then when we told my mom, he beat my mom up and put her in a coma and had to take her spleen out; she had fractured ribs. Ooh, girl, I mean, you know, we didn’t think she was gonna live, you know. And back then, that was like in the Sixties, they didn’t do nothing to him, nothing. And so when my mom got out of the hospital, she went right back to him again. She, she didn’t have nowhere else to go. That came up when I found out I was positive, this, like, over-flooding. Usually I cry at this point, but I’m tryin’ to hold it back. It just overflowed me, you know, when I found out I was positive. The memories of it. It’s, it’s like replaying in my head, like he was doing it right then and there, and like I was still seven years old, and, yeah, it was real, real deep. And, so after going through that experience, I knew I never wanted to be with a man again because he forced sexual, you know, intercourse on us and stuff. But then I did try it one time, and I said, “Oooo no,” because it brought back the memories of my stepfather. And then I met a few women, and they know how to treat you sexually gentle, and know how to touch you right, and, you know, embrace you right and kiss you right, and, you know, you feel that loveliness and that closeness, you do. Yeah you do. And so, it, it felt right for me. My first sexual experience with a woman, she was way older than I was, it felt right.

Helen: My mom’s still married to my stepfather, the guy that raped me when I was 15, and I, I really have a problem with him, you know, still being married to her. But, you know, that’s her life. I’m, it’s like, I’m accepting her and her shit and her faults and whatever. And I, I went so far one time, I pulled the, uh, a meat cleaver out the drawer, ‘cause him and her had got into a fight or somethin’. And she had called, and she didn’t sound right on the phone. And, see, when my mom don’t sound right, I don’t give a fuck where I’m at, I could be in Timbuktu, I’m catching the first thing smokin’, coming back to see my mom. And I, I pulled a meat cleaver out the drawer, and I told him, “If you ever put your hands on my mother, I’m gonna, I’ll take your ass out.” And then on top of that, “If you put your hands on me,” I said, “—yeah, I was, I was young and you took advantage of me,” I said, “but now, I’m not.” And I say, “I’m gonna chop your dick off with this meat cleaver.” And my mother, she was like, “Damn, my daughter said that?” And she said, “Look, I appreciate your defendin’ me, but don’t ever cuss like that.” It’s like all that shit just came out, you know, all my feelings and everything just came out. She, she appreciated me being, defending her, but she just didn’t like the cussin’. That’s my mama.
Irene: My father worked real hard for us. He was a good provider, although he was an abuser; I hate to say. I used to see my father beat my mother unmercifully. I mean he would just hit on people, you know? He hit me, and I left. I took my stuff and went to live with my brother, and from that point on, from the age of about 17, I'm on my own. I was on my own at 14 really, when he gave me to my foster parents. And, you know, I just here recently, being of age enough to talk to him about it and not feel that I'm gonna get my head knocked down off the ground somewhere, and be looking all funny, I was able to talk to him and ask him why did he do these things. I told him, I said, "You know, you really fucked me up" [laughs]. You know, why did you? And he was always, he was blaming.

Helen: Shoo, I've been in relationships where I was just, you know, I was beat up. "Get your ass out there and make me some money." And I remember I had to fight back. He took me over his relatives' house, right? And he was showing out in front of his relatives, you know, slapping me around and shit, and I got tired of that shit. I just was like I had all this anger and shit just held up, just, and when I finally exploded, I took off my heel and I commenced to beating him. We started from inside the house, worked our way outside in the yard. And people came out, and they was just like, "Kick that ass!" And he was running around, hollering, holding his head, blood, and, it's like, that stopped me.

Arlene: I had been in and out of sobriety. And I remember I went to a counselor, and I told her, I said, "I know about a murder. They didn't put it in the paper, and nobody—the police ain't doing shit about it. I know that a murder was committed, and I know who did it." And it was an insane murder. It was an insane murder. The dude was talking about how he was going to do this, and I thought, no, he just, he's high; he ain't—he's talking that bullshit like he's some kinda gangster or something, he ain't shit [laughs]. And, girl, the next day, I think it was like a couple days later; I couldn't even tell you because I never slept. But he said he was going to hang this girl up; he was going to break her back and hang her ass on a hook. And somebody died like that. A prostitute died like that. And I, and I thought then, you know, it just made me realize how much danger I was around. You know? It affected me severely because, because I have issues with woman beating and shit. When I grew up, my daddy beat my mama up, and I ain't talking about just knocking down and shit. I'm talking about this motherfucker was crazy. He was sick, and he was crazy. And so, and that happened; it hit a nerve. It hit a nerve. My brother, he's gay, he was really abused for his femininity. My dad used to bust him in his mouth: the way he held his fork wasn't right, you know what I'm sayin'? My father hated him, and he was violent.

Corky: I come from an abusive family. My family were alcoholics, and my brothers were morphine junkies. And I used to deal a lot before I started using. I was making a lot of money. And I started experimenting at the age of 19, and when my mother killed herself, I became my best customer, because I gave up, I gave up everything. I lost two homes, three cars. I just lost everything I had accomplished getting, and totally dedicated myself to using heroin. The more people I lost in my family, the worse it got.
Irene: It’s not safe to say you’re lesbian sometimes, you know? People don’t, it’s like, fear. It’s like, “You’re lesbian”: pow! That’s why I fight good. You know?

Valerie: Have you gotten jumped on for being lesbian?

Irene: Hell, yeah. Heck, yeah. Raped. I’ve been raped on two different occasions.

Valerie: For being a lesbian.

Irene: Yes. Yes. And my old lady was too. Separately.

Beverly: I got raped on the job.

Gwen: You know, I was raped—this is probably one of the reasons why it’s so easy for me to be with a woman, you know, as far as finding comfort and companionship. I find it more with a woman than I do a man, because when I was eleven, my mom used to let men have sex with me and stuff. I was only eleven years old. And I had syphilis real bad when I was eleven years old. That can be a lot of mental damage, you know? I was locked up most of the time, from eleven to fourteen. I was locked up because my mom says I was incorrigible. What it was is, my mom didn’t have time for me. She was too busy. I used to come home and find her trying to hang herself and everything. That hindered my growth a lot too.

Addiction, relapse, recovery

“I’m gonna get it right this time”

Arlene: The issue that threatens me is my addiction and this AIDS shit. I have had, and still have, so much to do to maintain my sobriety.

Josephine: I’ve been an addict for about fifteen years. I started smoking marijuana, snorting heroin and cocaine, and then I kinda graduated. I started smoking the crack and then shooting the drugs intravenously. I’ll be clean a year or so and come back, but this time it was like every four or five months or two or three months I was going and going.
Gwen: I’m coming back. Slowly, but I’m comin’. Yeah, I went through a lot on this last trip. Did thirty days in the streets, pushing buggies, smoking crack, going crazy. I lost myself, and I was doing a lot of damage to myself. I couldn’t see anything in front of me. I couldn’t see any dreams, any kind of—nothing. Usually I wanted to go to Academy of Arts or do something. I couldn’t see me doing anything. I was just stuck in a time warp or somethin’. I was really messed up. But I’m finding my way back. I’m tired and I’m stressed out.

Corky: I’ve gotten sick enough to know, from using drugs and ending up in a hospital, just how bad it is. And I just don’t want to get there anymore, you know? It’s really nothing out there I want, not even a high. All of that was an escape, from my mother’s death, from different losses.

Arlene: The flip side of it is that I got some serenity today, and I would not have had that if I hadn’t gone through the shit that I went through to get help and to deal with my pain in another way beside medicatin’. I’m really grateful for the insight that I have, and I’ve got some kind of self-love. It’s still not really easy to look in the mirror and say I love you. That was assigned to me one time when I was in Morgan House. Look in the mirror, every day you get up, and you look in the mirror, and you tell yourself you love yourself. And I tripped, because I thought, “You must be out your mind! Yeah, right, I’ll do it,” you know? I thought, well, I’ll try it, ‘cause I can tell them anything, I’ll try it. And when I did it, I just broke down. I was like, yeah, you know, I really don’t, I have no self-love. You know what I’m saying? I got a good act. I got a good act.

Pat: The staff here gave me more tough love, man! That’s why they all tickled to see one year coming next month. Next month I have a year clean off of heroin and crack.

Wanda: That other program, I don’t know if it exists now, because people was, at that time, was getting all kinds of them programs, but, anyhow, they wound up closing it, and I didn’t get past the 30 day thing there. They was doing drugs in the house. The director wind up being doing drugs. So I didn’t, for a long time, I didn’t have trust with programs.

Irene: It’s been so hard to struggle to break my behaviors, you know? I find myself sometimes preparing to go out and cop. You know, it’s just an automatic thing that just pops—put the clothes on, get ready, then my stomach starts turning, and I’m ready: I got a little money in my pocket, and I get ready to go out, and I have to stop myself. I have to sit myself down and take a time out, you know and let that pass. You know, it hurts sometimes, even now today, how many people I haven’t had in my life because of my addiction. And it’s been kinda lonely.

Arlene: The addiction made me separate from my family, because I was doing wrong, and I was so ashamed that I didn’t call nobody for years.
**Helen:** I stayed out for about a whole week; Didn't go home! I'm right there in my neighborhood, at my house, by my house, for a whole fuckin' week but didn't go home because I was scared I was gonna miss somethin' out there, you know? For drugs, I'm out there panhandling, tossing up, doing everything: Here I am, giving head or something for five dollars, you know? That's sick shit. You know, now that I look back on it, it's really sick. It's sad.

**Arlene:** And it's like so all you can think about is more. I need some more crack. It ain't about making love or watching a movie. It ain't about nothing. It's about committin' crimes and doing whatever it takes to get you a little more money to maintain that rush, and it just never happens. It is an insane, insane drug. I used to smoke and think, why, why did I do this? [Laughs.] It's an absurd high. Whoever made that shit, man, they must be the third anti-Christ, because it infects whole families of people. I think that's the first thing that had me runnin' to recovery, because crack has made people so crazy. I'm talkin' about beating on people, murder! I know this dude, he murdered this girl. When that happened, now, that was close to when I had to get up out of there.

**Gwen:** One day I was sleeping over there by the Examiner and I thought somebody had stolen my shoes one morning, and I thought I would have to walk down the street barefoot, and I just started crying and going "this is not me, this is not me." And I found my shoes about ten minutes later, but I thought somebody took off my shoes, and I couldn't see myself walking down the street with no shoes on. That's the bottom of the barrel right there.

**Josephine:** I like to drive, just driving, delivery jobs, driving. And I've always liked it, you know? And then I got to being real complacent with myself: "Oh, I don't need no meeting." And then I would drive, loaded, and pulling over, going to the bathroom, taking a hit, get back on the bus, drive. Oh, people got tired of that. I was waiting for it, you know? And then I was stealing the mail because of my using. Just awful things.

**Arlene:** When this crack stuff hit the streets, it just made it worse. It's the most horrendous drug I have ever encountered. And that's when I started going in and out of jails and selling my shit, losing my houses, and, oh, man! On heroin, it was like a maintenance kind of thing.

**Wanda:** Being back and forth in prison from selling dope and using dope and making money with dope, and having a home, losing a home, all these things, back in the prison system, you know, three more years, and here we go again . . .

**Helen:** I remember one time when a guy sold me a macadamia nut [laughs]. It was a macadamia nut! That was some crazy shit.
Jolene: When first I was diagnosed I just like went really, really, really deep down into drugs, you know? And the following year’s when my family died in the fire, so it’s just like, I’m surprised I’m not dead. I’m surprised I’m not dead, because I would like, just use, take pills, all type of using; you know what I mean? I would try to get myself just too intoxicated that I didn’t know what was going on from one minute to the next, you know? I’m just surprised I’m alive. I sent my body through some changes. I would use so many different pills till, you know, I’m just surprised that some, taking some wouldn’t kill me. And my lover, she tried to hang in there with me, but I had became so mean and brutal, you know, that it wasn’t really much you could do with me. She tried to, she tried to stick with me through it, you know, to be there for me, but I just wouldn’t allow nobody to be there. I didn’t want nobody around, so there wasn’t anything she could do. It was devastating, those two things so close together.

Irene: . I went and got tests. Came out positive. Dude was sitting on the back of the car, telling me I’m positive, and I didn’t know what the hell he was saying. I was in a good home, you know, a good place, then my sobriety got messed up, and here we go again, you know. I went to self-destruction. I went on self-destruction.

Corky: There’s people out here, like a lot of people I know in the drug situation, they start talking about people: “Oh no, that other broad, she’s got HIV.” It’s ridiculous, and they’re selling you drugs [laughs] you know? Complete assholes. I learned a lot out there contending with that.

Wanda: That TL, I don’t want to be there no more. It’s just too ugly. I mean, you know, the kids don’t have no respect. They don’t have the honor. And, believe it or not, we had all that when we was in the TL, way back in the seventies, okay. Everybody know what everybody do. You’re bisexual, gay, whatever, nobody didn’t really trip because everybody was too busy hustling and selling or using or whatever. And if the speedsters, if they was doing crank and selling crank, if I didn’t have money, I could go get that from them and go and sell it, you know, and get myself well and then go back and give them something, you know? But it’s not like that today. These kids, the way they sell dope, they don’t respect each other customers. Now it’s ugly because they’s too busy trying to out-do each other, and in prison it’s like that too a lot, with the competition.

Josephine: When I was HIV positive, I didn’t want anyone to know, because I didn’t think they would like me. And once I really started talking about it, it was like, I had all the support in the world. And it only became, when I got in recovery, to be honest. I have more support from people that’s in recovery, way more.
Beverly: I just started a group at Old Oak, and it was very surprising to me because it was for long-term sobriety, I have nine years. And I walked into the room, right away I said I was HIV positive, this and that, you know, I was tellin’ them, you know, this is what’s happenin’, and I just got finished with surgery, and I just had an accident with my car, and well and well, and this and that, and they said, “Well, you know, you’re just another alcoholic to us” [Laughs]. And I was accepted, you know, at my AA. So to me, you know, that felt like, wow; it was great.

Valerie: Jolene, what about the recovery groups you were involved with?

Jolene: Some women there, like “I can’t understand what you, what one person sees in a woman, being the same sex,” you know. I get a lot of that. “How could a woman be—for two women to be together,” that kind of stuff. I get that a lot, you know?

Arlene: They say “you’re only as emotionally mature as you was when you started using drugs.” I’m thirteen years fuckin’ old, and I can be thirteen a lot of the time. It’s true. You know, each time that I come into recovery, I’ve learned something else. And they say that relapse is a part of recovery, and it’s really a sad thing, but it is [laughs]. For those who that’s not true for, fine, but it’s certainly been true for me. But I’ll be clean for about two and a half years now, almost two and a half years.

Irene: One day I just stopped. I just said, “Now, wait a minute, what do I want, to die fast or die slow?” I had to make a decision.

Corky: You just have to make up your mind. And it’s not easy. You go through the ups and downs of it, but eventually you get tired of it, or you get devastated with a diagnosis like this. So. And there’s so many people that I’ve been watching die behind it. I just don’t want to go that way.

Josephine: As long as I don’t use, I’ll be okay. And that’s my biggest fear. I sabotage it. I don’t know why; I’m trying to get a grip on it. I don’t want to kill myself. And I don’t want to die. Just ‘cause I have it, don’t mean I have to die with it; I can die with something else. It don’t have to be HIV. And I’m really honestly tired of programs, programs, programs. So I’m gonna get it right this time, no matter what, you know? And I have choices. I don’t have to pick up, no matter what happens. And that’s the hard part. The easy part is just to pick the drug up and use it. But the hard part is dealing with whatever’s going on with me.

Wanda: Yes. I’m trying to stay in my recovery, yes, trying to stay in my recovery, because, like I say, this is a matter of life and death.
Arlene: I'm still growing a lot. I'm 43 years old; I'll be 44. And I'm still developing my emotional self. But I know how to get some help. And when I feel like I gotta run, I know where to run. It ain't to the TL no more. It ain't to the bathroom with a needle full of shit. It ain't to the streets. It's to somebody that I know can give me some kind of guidance. And if I walk outta there without having anything resolved, what I did get was some serenity; I would calm down. I get into a place where I can look at things intellectually and walk myself through a series of steps to do something about the way I'm feeling. And that, that support system is everything. It's everything.

Case workers and counselors

"Thank God I had my case manager"

Wanda: I went through Morgan House detox. You do your basic own footwork. You know, you get your ID. They'll loan you the money or give you the money to get the six dollar ID. They set you up with GA. They help you get on Medi-Cal or ADAP, you know, for your HIV med coverage.

Helen: I've been in and out of programs before, you know? But this time I, I think I really got it. But, like I said, I had case managers that didn't give up. They worked with me, and they helped me, and then I eventually got into a program. But I had relapsed, and I was in the relationship with this girl, and I tried t' change her and make her into something, and it didn't work. I was tryin', I was helping her get into a program. I found myself, you know, takin' the focus off of me and focusin' on her, and the next thing I know I'm neglectin' myself, and then, you know, but I made the choice. I, I chose to use. You know, she didn't twist my arm and put a gun to my head and say, "I'll shoot you if you don't smoke this, if you don't take this here." Thank God I had my case manager that worked at Brewer.

Corky: Janine and Billie are working together right now, trying to get me into Brewer's Place. They're great. Billie and them got me talked into coming into Lotus Center. That's how I got in the Dawn program, trying to find out about housing. They got me into everything at the same time [laughs]. They pulled that one on me. I go to a group on Tuesday. I go to a therapist once a week, da-da da-da da-da, in order to get this housing.

Valerie: They got you to do that.
Corky: Yeah.

Valerie: You didn’t want to do it.

Corky: No.

Valerie: Because you like to just deal with your stuff on your own.

Corky: Right. So I mean, in a sense, I asked them for help, but, I mean, I asked them for help with housing, and I had to end up doing all these other things in order to get that. So they pulled it on me. They got me taking a little bit of everything [laughs].

Beverly: I was at this group, and I was askin’ people to help me and, you know, when Janet Shane was running it, and it was like, Janet Shane said to me, “You’re my client now. I can’t help you out as a client.” Now, I wonder, now that Stephanie’s my facilitator, if she’s gonna be a support to me or not. I hope I didn’t lose a friend over that.

Helen: We have this facilitator, and she is so sweet. She invited us all to her house one time, and we ate over; and we talked, had girl talk, and we just had a ball.

Jolene: I have a case worker. She’s really good. She, I can talk to her about anything. She’s more than a case worker; she’s a friend also.

Arlene: I had a problem with Rye Hospital, and my doctor had went somewhere, and the other doctors didn’t want to prescribe the medicine that she done had me on for how long, for years. That’s that morphine shit. And I, well, here I am, I’m sitting up in here, fiending, kicking. And finally I asked my counselor that’s over this house, I said, “Listen. I’m goin’ crazy. I’m afraid, ‘cause I’m sitting up in here kicking. You know what I’m sayin’? I, I want some dope right now, you know?” And she said, “Well, you know what? I’m happy that you was able to reach out, and we’re gonna help you.” And she called up there and got the ball rolling a little better.

Helen: Karen Weiss is my case manager, and Karen is sweet. I feel like I could ask questions, and if I get stuck with something, she’ll help me out. And she say, “Helen, don’t be afraid to ask, if it don’t sound right, you know, ask, ‘cause how else you gonna learn if you don’t,” you know?
Doctors, nurses, and hospitals

"I've been humiliated in hospitals"    "Never had a hospital like it in my life. Excellent."

Helen: I think I have the best darn doctor there is. Her name is May Simione; she's at Hilltop.

Josephine: I have Bluberg. I go to Hilltop. I think it's the best. Never had a hospital like it in my life. Excellent. I wouldn't trade it for the world. I was at County at first, when I first started, and I didn't like it at all. So I transferred to Hilltop. They take care of everything. Even my addiction, when I went up there, I think she let me sleep in a room for maybe ten, eleven, twelve hours.

Valerie: What do they do that's so key?

Josephine: Well they have, she have time to talk. They don't just brush you off.

Arlene: I've been humiliated in hospitals. For being a dope fiend. You know, you done stuck yourself twenty-five thousand times. And I'm saying, "no, hell, no, wait a minute," you know? 'Cause I don't like getting stuck. You ain't putting nothing in there that's gonna make you forget about it; you know what I'm saying? And if you don't know what you're doing, you got to go, you know? I used to be in a place where I just let them do whatever. Pap smears that hurt and shit, you know what I'm saying, and bite the bullet, and thank them. "Thank you." you know? And I never exercised the right to have a different doctor.

Beverly: I've been misdiagnosed for ten years with peripheral neuropathy, when alls I had was tendinitis. I was a fifteen-year technician. If they woulda just asked me what I did for a livin', they woulda sent me to a neurologist, and I wouldn'ta suffered for ten years. I am so furious, but I love my doctors.

Irene: I felt that the medical system or the clinical world really treated me somewhat blasé. You know, I'm on Medi-Cal. And, you know, the health field don't really give you that much respect. You know, when I give you a card, that's only worth seven dollars to them.

Valerie: Where do you go now?

Irene: New Bay AIDS Clinic. Wonderful. I think there's been a growth in care, and I think, on my part, I'm seeking people who are more concerned about people that are HIV, besides just concerned about getting that seven dollars.
Deborah: At Bluelake Hospital, the clinic I go to, everybody know I'm gay there. So, you know, the nurses be looking at me all funny, and I feel uncomfortable going there. I get that stand-offish, like, like other people, they hand them their stuff, "Oh, good, come back, you're doing well. How nice to see you again." I don't get that. I've been seeing them hug other people. Where's my hug at? I don't get no hugs or no pats. Or when they hand people their prescriptions or their, or their card back, it's like they put it in their hand. But with me it's like it's sitting on the table, like, "Here, Deborah, here's your next appointment," or "Here's your prescription." And it makes me not really want to go there. And some, some of the nurses there are Afro-American, and I guess that's how they were raised, that you're supposed to be with a man, and if you ain't with a man, then you're a freak. You know, you don't belong. And that's how I feel when I go there; I feel like a freak, or I don't belong. And that's very hard.

Corky: I go to County. My doctor is an AIDS specialist. He's a very compassionate doctor. He really doesn't put any discrepancies. He's good. He's overwhelmed, but he's good.

Bev: I'm gonna have knee surgery. If they only coulda operated three years ago without giving me these cortisone shots, I would be already fixed. Now I'm 44 years old; I'm getting on. I'm ten years infected now, and they're finally gonna operate on my knee. I just wish they would have done it three years ago and not make me wait so long. Damned cortisone. Robert Wilson looked at me, and he said, "You have Jenny Walters; I'm gonna talk to that woman. You need to have surgery on your knee." And I went in, I saw her; boom, I got surgery. Doctors are afraid of people with HIV, I'm beginning to think. That's why she didn't operate sooner. But Wilson pushed her, and now she's gonna do it. She was resistant to do it all these years. But seeing how well I healed and everything, now she's not so afraid.

Wanda: I do my primary care at County. I have a nurse practitioner, a very good one. Her name is Davis. But she listens, you know, to what I have to say. She, you know, helped me to learn more than I had already learned in prison.

Corky: They corral us in certain areas, you know.

Valerie: Say more about that.

Corky: Well, for instance, I was going to the Compass Clinic when I lived over in Hunters Point, and what they did is start telling me to go to County, 'cause my doctor works out of there too. And what I found out is that all HIV and AIDS patients go to County, so they corral us, you know? You cannot just go to a regular place. Because they don't want us to intervene with the population.
Pat: I had one in Bluelake, where she was getting ready—I had gotten assaulted, and my face and stuff was bleeding—and she was getting ready to touch me without gloves on, and I told her, I said, "I'm HIV positive; you need to put some gloves on." And then when I said that, her nose kinda went up in the air, and she took her time coming back, and that's when I left the hospital, and I went home and cleaned up, because that nurse made me feel bad.

Arlene: I'm in this room. I'm falling asleep, and this Indian guy comes in, and he's sticking me, trying to get a vein, and I'm sleeping. I wake up and I'm like "What the fuck are, you, what? What are you doing?" I was like, "Heey, heey, somebody get this motherfucker outta here because he's sticking me in my sleep! Get him outta here!" And he's like, well, you know "You're just dope fiend. You already stick yourself." And I said, "Look, check this out. Get the fuck away from me;" you know what I'm saying? "Get the fuck away. You do not stick people while they're sleeping." I was pissed off. Fortunately, another nurse came in and she said, "Well, let me do it. Let me do it." And she puts the IV in and by this time I ain't feeling good, so I fall back asleep, and all of a sudden I wake up. This motherfucker put Narcan in my IV, which is what they give people when they OD, and it makes you ill. It's a sickening, scary—you know, I woke up and I was like [gasping], my heart was pounding, and I'm like, this is a fuckin' nightmare, right? And he says, "You just, you had a little Narcan," 'cause he thought that I was OD-ing, although I been in there sleeping for hours. You go to sleep and you breathing, you fine. So I wake up like this. At that point, I shit all over myself. That's what it does to you, okay? I'm all tied up, and I'm laying there. I said, "Well, you know, can somebody come and clean me up?" I tried to get a bedpan, but as soon as I woke up, it started coming out. And they know that; they know that. And they let me lay in my shit all night. And this lady came and shut the door to my room. I thought, now this is a bottom. This is a bottom. And I will never, ever, ever come here again, not ever, okay? Laid in my shit. When they rolled up, up outta the room, the guy that tooks the ties off, we in another room, in the hallway actually, and I get up, and he goes, "Oh, goddam!" You know what I'm saying? I said, "Yeah, well, I was tied up. What the fuck you want from me?" You know what I'm saying? But it still made me feel like a dog. Laying in my shit and somebody saying, "Oh, you nasty." Yeah, this was my entry into this sobriety period, Okay? Laying in my shit was a bomb.

Gwen: Lately I've been having problems with my doctor, Ann Reiter, 'cause she's been wanting to give me medication. She wanted to give me, you know, one of these medications that I don't want to take, because it was the reason one of my friends died, time release pain medication. You know, and I feel like my hands were tied. What do I need to do? You know, I either have to go around in pain, or do I have to take this medication? And I didn't think it was too cool, and especially when it was one of them meds that helped kill my friend,
Bev: Betty Jacobs, she had judgement. Andi Anderson had judgement. They treated me poorly. They looked down at me. They were very fast and very abrupt with me. They treated me like trash, some kinda trash beneath them. I was, I felt humiliated bein’ around either one of ‘em. I had fights with these doctors, you know? I can’t believe how they wanna treat me. I won’t allow it. I can’t. And I’ve found Veronica Karr and Louise Ponti that treat me with dignity. They’re private doctors. They take my Medi-Cal and my Medicare, and they treat me with dignity and respect, and they treat me as a, as a partner. We’re partners in this. We’re gonna do this together.

Hopes, goals, and inspirations

“A voice was talkin’ to me, and a voice told me, ‘Helen, it’s not your time yet’”

Beverly: The numbers are looking better and better [laughing], so maybe I may survive this whole epidemic; I don’t know. Wouldn’t that be something?

Josephine: I look at it now, maybe it happened for a reason. ‘Cause, to be honest, if I never found out I got HIV, I would still be using. I’d still be using if I hadn’t found out I was HIV positive, because I know the drugs would kill me quicker with this disease, and I just felt it was a warning from God. Well, He didn’t give to you, you did it to yourself. I’m not blaming anybody. That’s what really helps me stay clean, though, honestly, the disease, to be honest. It was just a wakeup call, you know? I had to really get my life together.

Gwen: I like to draw. I want to go back to school. I’m a dreamer, you know; I’m a dreamer. I’m thinking about going back, going to the Academy of Arts. I want to take commercial designing, commercial designs, you know, like do slogans or album covers or something like that.

Pat: I’m gonna move to Oakland. We’re going to stay in a hotel, till we get our money saved. She’s good with computers. She likes to go on the Internet and surfing and looking for studios and stuff like that. We’re going to move into an apartment. In two years we’re going to try to have a kid. She told me, if I wanted to, instead of going back to work, I can go to school and get my GED, and she would help me with the work with that to get my GED.
Deborah: I’m just, I feel like I’m just existing, I’m not living, okay? I’m just here, I’m existing. I’m not living my life, like I wanna live it; you know what I’m saying? I feel like, you know, like I want to give too, in the relationship, I just don’t want to be taking money, money. I mean we give as far as feelings and stuff like that. I can give that, you know; I love her a lot, you know. I can give that and show my feelings sexual-wise and stuff like that, but as far as financially, I mean, you know, that’s, that’s the hard thing to deal with also. You know, it’s like, putting a strain on our relationship, ‘cause it seem like I just fuss and bicker about every bit of little, tiny thing, which doesn’t matter. And, you know, I get mad about things, and it’s all become the money issue, you know, not being able to do the things that I want to do for her, buy her a dozen of roses. I mean, if I do, then it mean that I can’t buy no food for a week or, you know, or stuff like that, so that’s a big issue for me.

Wanda: I want to be a HIV peer counselor. Yeah, because it’s so much needed for young kids to know about it. I got to get to somewhere knowing a little more about myself and what’s happening with me, and then in the end, one, like I say, one thing I know I’m wantin’ to do is get back with my family, after I get myself some recovery, and I want to be a peer counselor. Those are my two long-range goals. Other than that, in the meantime, I just have to keep taking my medication, keep going to meetings.

Arline: Maintain some self-love, you know, figure out what it is I’m wanna do, there’s so fuckin’ much to do.

Corky: I didn’t look at it that way until now—I have a lot to contend with. But I’m still here, so it must be for a reason [laughs].

Valerie: Do you have an idea of what the reason is?

Corky: No. I tried to figure it out. I stopped, ‘cause He’s got a purpose for everybody. I just thank him for every day that I can get up and still walk, be alive.

Jolene: I want to go into Zami House, because I’ll be still dealing with a lot of recovery while I’m waiting for my housing to come up, you know? And I want to continue to do, you know, a little more structure than if I went into satellite. It wouldn’t be that much structure there, and I still want to deal with the structure for a while.

Irene: I may go back to school. I think that’s what I’ll probably do in the near future. It’s been a good life though. I haven’t been any happier than I could possibly be right now. You know, I have good spirituality; my old lady has good spirituality. I’m glad that I have someone that loves me. All I want her to do is live with me. I want her to be living with me, you know, like we used to. And we’d get up in the morning, and we’d both smell each other’s bad breath and whatever, and cooking and eating and together and going shopping and, you know, going on little trips. And now we’re older. You know, I really would.
**Helen:** I was sitting out on the crate, I done been up for days and days, just smokin' and just, you know, doing all kinda, selling my body, tossin' up, you know, for one hit of crack, you know? Doin' things that I wouldn't normally do, said I would never do? I was, you know, into drugs and trying to destroy my, trying, trying to kill myself, until one day this, a voice talked to me. A voice was talkin' to me, and a voice told me, "Helen, it's not your time yet. I put you here for a reason, and it's time for you to turn your life around." I mean, this voice is talking, and I thought I was hallucinating off the drugs. Get the fuck away from me! You know? But then my mind said, "Well, I think you'd better listen to this voice." And I believe it was God talking to me. It's like I'm just blessed, you know? I guess I was put here for a reason.

**Valerie:** What is it?

**Helen:** The reason is to help other people and educate and make my mark on the world before I leave. That's what I'm doing. Get educated, so I can better teach other people, you know?

**Beverly:** I feel like, you know, I have to give back to get. And if I want to live a certain life, you know, and be well, then I have to give back to the world, so that the world can give back to me. And to be able to do that and have such pleasure doin' it, I mean, what could be better than that, you know, to help the women, to be there, to be where it's happening, you know, and to be part of it all? Yeah, I feel good about who I am today. Probably wouldn't have done half the things I've done today if I wasn't infected, to tell you the truth [laughs].

**Valerie:** It's ironic.

**Beverly:** Isn't it? Isn't it, so? It's forced me t', you know, go above and beyond. Who knows?
Conclusions

Despite its breadth, these relatively few pages cannot possibly accommodate enough information to fully capture these women’s lives. Some of the important aspects of their lives which were spoken of in the interviews, but could not be thoroughly addressed, include: the African American community; attitudes regarding transgendered people; children; class; family configurations and relations; health, illness, and medications; jail and prison; money; prostitution; and relationships with men. Moreover, there are certainly additional elements of their lives that were not mentioned during the interviews.

Although I have immersed myself in the examination and analysis of these women’s experiences, many lingering questions remain. I explore but a few here.

Many women described experiences with physicians, nurses, and hospitals that were both extremely positive and extremely negative. I found myself comparing these experiences with their expressions of overwhelming satisfaction with their case workers and counselors. Additionally, many times it was the care-giver that went “beyond the call of duty” and bent the rules that left a lasting impression on a woman. For example: one social worker informed a woman of a “secret” way to receive methadone from the hospital; another social worker arranged to keep a woman in the program, even though she had relapsed; and we heard Josephine’s story of a physician and her hospital clinic that allowed her to sleep all day in an exam room while she was struggling with addiction: “Even my addiction, when I went up there, I think she let me sleep in a room for maybe ten, eleven, twelve hours.” From these stories, what can we
learn about the needs of clients and the adequacies as well as the limitations of our health care and social service systems?

Are women really at risk of infecting each other with HIV? An exciting new study began this year of HIV positive women who have had sex with women. Among other concerns, the researchers are interested in woman to woman transmission\textsuperscript{14}. Beverly said: "I don’t think they’re ever gonna have a clinical trial where a woman has to give her orgasm, I mean the fluids from her orgasm, and let them be studied, like men do." Will this new study, or others, undertake an examination of the fluids not just regularly found in a woman’s vagina but the fluids of a woman’s orgasm, as Beverly asks? Will we ever have a definitive answer regarding woman-to-woman risk?

Why aren’t lesbians with HIV more united? The women reported a variety of reasons, including racial divides, competition among these women, and their numbers being too few. How can closeness among this group be fostered? Should it be fostered? What purpose would that serve?

This ultimate question is important because these women displayed a remarkable wealth of community involvement and support, despite the challenges they encountered. In the light of many of these women’s histories, they are often viewed by our society as bereft, destitute, and without resources. Indeed, there is no doubt that each one has faced desperate times, yet most of these women have communities that are important to them and that sustain them. At the same time, these women have hit rock bottom in their lifetimes. Although support services for those who have “hit bottom” are strong, why is

\textsuperscript{14} Called “Fem to Fem” in San Francisco and “WOW” in New York and Washington, D.C. San Francisco phone numbers are (415) 597-4653 or (888) 609-5367.
there a gap in the social services available that leaves people to drop a long, long way before they encounter the “safety net?”

I did not initiate questions in the interviews about violence. Yet eight of the eleven women volunteered histories of violence, and six of these eight recounted experiences of sexual violence. This begs us to look at the interplay of violence, addiction, and HIV infection. We are accustomed to speaking of HIV risk factors in terms of contact with blood and body fluids. Are histories of violence, sexual abuse, or addiction important risk factors for HIV infection?

Many of these women have been sexually involved with men. How do we understand this for lesbian identified women? In their study of HIV risk in lesbians and other women who have sex with women, Mays and colleagues write: “we are most likely to view [lesbian-identified women having sex with men] as volitional and based on desire rather than as utilitarian sex that is employed for the sake of earning money, in the interest of shelter or to avoid the stigma some experience in being a lesbian” (Mays, Cochran, Pies, Chu, and Ehrhardt, 1996, p. 131). What insight will we gain by understanding the myriad of motivations for lesbians’ engagement in sexual relationships with men?

Intertwined with the violence and homophobia encountered by these women is substance abuse. bell hooks says, “psychic pain is most often relieved by some form of substance abuse” (hooks, 1994, p. 169). Arline gave us the same analysis of her own experiences with addiction: “I got some serenity today, and I would not have had that if I hadn’t gone through the shit that I went through to get help and to deal with my pain in another way beside medicatin’.” This problem begs an enormous and vital question: how do we eliminate these causes
of psychic pain? How do we eliminate violence, homophobia, and all other forms of hatred in our society?

Finally, what can we do for these women on a practical, everyday basis? As a guide, we have available to us not only the reflections of these eleven women, but a statement of twelve ways in which we can improve the situation of women living with HIV, created in 1992 by HIV positive women worldwide. Despite the intervening years, many of their goals have yet to be met. You will find this list on the following pages.

I have been captivated by the notion that these women could speak not only to me, but to you, the reader, as well. And in so doing, they, not I, would be the final arbiters of meaning. In the end, my hope is that in hearing their varying voices, you will draw your own conclusions. But more than deciding what it means, I urge you to become more curious and open to wondering about and listening to the stories of these women’s and of everyone’s lives. The importance of this is best expressed by Wanda:

Valerie: You said you go see a doctor or a—

Wanda: A nurse practitioner. She’s a very good person.

Valerie: So she treats you very well.

Wanda: Yeah, she listens. She’s a good listener, and that’s what you need sometime. Then she’ll say, “Okay, what have you been doing? What has happened?” And she listens. And then she’ll give her opinion.
What do HIV-positive women need?

The following statement was created by the International Community of Women Living with HIV and AIDS (ICW)* before the 1992 International AIDS Conference in Amsterdam. The list is important because it represents a united view of HIV-infected women from all over the world who came together to identify their needs. These are critical issues women want support organizations to address and include in their objectives.

To improve the situation of women living with HIV and AIDS throughout the world:

1. WE NEED encouragement, support and funding for the development of self-help groups, and local and international networks of women living with HIV/AIDS.

2. WE NEED the media to realistically portray us, not to stigmatize us.

3. WE NEED equitable, accessible and affordable treatments, and research into how the virus affects women, including psychosocial and medical aspects, and both conventional and parallel treatments.

4. WE NEED funding for services and support for women living with HIV/AIDS, to lessen our isolation and meet our basic needs. All funding directed to us (HIV+ women) needs to be supervised to be sure that we get it.

5. WE NEED the right to make our own choices about reproduction and to be respected and supported in those choices. This includes the right to have children and the right not to have children.

6. WE NEED recognition of the right of our children and orphans to be cared for and of the importance of our role as parents.

7. WE NEED education and training of health care providers and the community at large about women's risk and our needs. Up-to-date, accurate information concerning all issues about women living with HIV/AIDS should be easily and freely available.

8. WE NEED recognition of the fundamental rights of all women living with HIV/AIDS, with special consideration for women in prisons, drug users and sex workers. These fundamental rights should also include the right to housing, employment, and travel without restrictions.
9. WE NEED research into woman-to-woman transmission, with recognition of and support for lesbians living with HIV/AIDS.

10. WE NEED decision-making power and consultation on all levels of policy and programmes affecting us.

11. WE NEED economic support for women living with HIV/AIDS in developing countries to help them to be self-sufficient and independent.

12. WE NEED any definition of AIDS to include symptoms and clinical manifestations specific to women.

*To contact the ICW, write to: ICW, 2nd floor, Livingstone House, 11 Carteret St., London, United Kingdom SW1H9DL. Tel: (44171) 222-1333 Fax: (44171) 222-1242

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risk in the absence of information: HIV risk among women injection-drug users
Appendix A

ARE YOU A LESBIAN LIVING WITH HIV?

My name is Valerie, and I am a graduate student and medical student at the University of California at Berkeley in the department of Health and Medical Sciences and at UC San Francisco.

I am doing a research study of lesbians with HIV from all types of backgrounds, over age 18, about experiences with HIV in relation to the lesbian communities, the HIV communities, and the health care communities.

If you are interested or if you have any questions please call Valerie at (415) 255-8694. Thank you for considering this request.

(Along the bottom there were tear-off tags with my name and phone number)
Appendix B

Interview Questions

I am trying to understand experiences of community among HIV positive lesbians. Do you consider yourself part of any particular communities?

Do you consider yourself part of the lesbian community?
   the HIV community?
   a religious community?
   any other community? Recovery?

Identification with the gay community vs. with the women's community.

How does it feel being an HIV+ lesbian?

In your opinion, is being a lesbian with HIV different from being a straight woman with HIV?
   In what way?
      OR
      Why not?

Have you had any experience with the wider HIV community?
   What kind?
   What has that been like?

How have your communities changed since you learned that you are HIV+?

Tell me about the people in your life.
   Family
   Friends
   Lovers
   Other HIV+ people
   Support groups
   Therapist
   Your caregiver (doctor/NP/PA)

Are you in a relationship?

Has your relationship / Have your relationships changed since becoming HIV+?

Where you in a relationship when you learned you have HIV? What happened?

Where do you go to meet people to date?
How is your partner involved in the communities?

[Intersction of biography and history. Trajectory of AIDS and individual biography.]

Experiences regarding **source of HIV infection**: Does the way you were infected relate to how you have been treated in the lesbian community?

Does the way you were infected relate to how you have been treated in the HIV community?

Does the way you were infected relate to how you have been treated in support groups?

Does the way you were infected relate to how you have been treated by health care providers?

Does the way you were infected relate to your feelings of/in community?

Are there judgements made which relate to how much you feel the community is there for you?

Are there judgements within the lesbian community?

Where do you go for **health care**?

Are you getting what you need?

What experiences have you had with health care that relate to your being a lesbian with HIV?

Are there things the health care community could do, particular to your being a lesbian, to help you cope with having HIV?

Do you feel judged by your provider or at your health care office?

What would you want your doctor to know that you haven’t said to him or her?

Do you have any general advice for health care workers about caring for lesbians with HIV?
What happened when you were diagnosed?

What’s changed since then?

Tell me about when you found out that you’re HIV+, and how you dealt with this as a lesbian.

Describe for me where you live.

How do you like it here?

Have you ever heard this in the past; maybe 5 or 10 years ago:
If AIDS is God’s punishment to gay men, then lesbians are the chosen people.

Did you believe it? If so, how did it feel to have that “safety” come apart?

[Is being chosen such a great thing? (Jews)
   You’re not as safe as you think.
   Vulnerability of today’s world. Not such a safe place.]

Is there something I’ve forgotten to ask that would help me to understand your life better?

Specific analytic questions later, at the end. Then ask openly.

Demographics:

Age
Ethnicity
Class background
Current class/Income
Place of birth
Place of growing up
How long here
Educational level
Children
Appendix C

Selection challenges

Some of the women who contacted me are not in the study for various reasons. Three or four never returned calls after their initial call. One woman did not show for our scheduled time, and then did not return subsequent calls. One called numerous times (as did I), but we never spoke on the phone and she stopped calling. One woman was disqualified on the phone.

- After approximately twenty minutes with one woman I realized that she either had no lesbian experience or possibly had a few months of experience in the past over 42 years of life. She was unable to speak to any questions concerning lesbian identity, activities, social networks, support issues, or community experiences. I explained the problem and ended the interview.

- Another woman had only learned she was HIV positive two months prior to the interview. She had told no one and, in her own words, was “in denial.” She was unable to speak to any aspects of being HIV positive regarding identity, networks, health impact, support issues, or community experiences. Although a look at this experience of “denial” would be extremely interesting, she did not speak to issues central to this study. This entire interview was completed but excluded from the project.
• One woman who scheduled with me did not show for the interview. Another participant told me that this woman was not actually a lesbian. Because of the aforementioned problems and the report of this participant, I had a discussion with the woman about whether she was lesbian or bisexual, and how it was important to be lesbian or bisexual in order to be able to answer my questions. She insisted to me that she was a lesbian, but she did not show for the interview the next day. That day, yet another participant volunteered the information that the woman was not a lesbian.

• With a fourth woman I began to believe that she too had not actually had lesbian experience. Her stories became contradictory as the interview progressed, specifically with regard to her one reported lesbian relationship. Some of what she said was so irreconcilable that I decided to not include her in the study. (As Adele Clarke said, this may show just how eager people are to tell their own stories, to be heard [personal communication, March 2000].) This entire interview was completed but excluded from the project.

• Finally, another woman interviewed was wholly uninterested in talking. She said very little, and the interview ended after twenty minutes because she had nothing left to say. It was a frustrating experience and was compounded by the other experiences that were causing me to doubt whether some of these women were actually lesbian or bisexual at all. I chose to leave out this interview as well. I had very little to go on either way, and was strongly influenced by these other experiences. If not for these difficulties, she may well have been included in the study, although I am not sure.
I understood why this might be happening. I was approaching women with very few resources and offering them $30.00 if they would talk to me. My experience was part and parcel of the socio-economic inequalities of this time and place. Nevertheless, my guard went up. The woman mentioned above, who was disqualified by phone, called after these experiences had taken place. I screened her on the phone. She said she had been in a lesbian relationship for one year, and she was in her 30’s or 40’s (I have now forgotten which). Out of energy and out of time (this was late February 2000), I chose to not interview her. While I am loathe to question another’s self-identification, lived experience was wholly relative to achieving the goals of the study.
Dear participant,

I am interviewing lesbians with the Human Immunodeficiency Virus (HIV) who are over age 18 and live in the Bay Area. I am interested in gaining a better understanding of the experiences of lesbians who are HIV positive. I am a graduate student and medical student at the University of California at Berkeley in the department of Health and Medical Sciences and at UC San Francisco.

If you agree to talk with me we would have a conversation about what it is like to be a lesbian and to be HIV positive. We would set up a time and a place to talk that would be convenient for both of us. The interview will take 1 to 2 hours. I will ask you to talk about what is important to you about living with HIV. If you agree, I would like to tape record the interview, so that I can later analyze what you think is important. Sometimes I ask for a second interview after the first.

Some people enjoy telling their stories and experiences and find it helpful to have another person hear their thoughts and feelings. On the other hand, sometimes it is difficult to discuss these experiences. You can decline to participate in the interview at any time. If you agree to the interview, you may end the interview at any time, you may choose not to answer any question or questions, and you may take a break whenever you want. You may also decline to do a second interview, even if you do the first.

Your name will not be used on any forms. Every effort will be made to protect your privacy. Any information that identifies you will be changed or omitted. When the study is done I will write about my findings and share them with other students, doctors, nurses, and other health care providers and researchers.

If you have any concerns you can reach me, Valerie Curtis, at (415) 255-8694. If you have any concerns that you do not want to talk about with me you can contact my supervisor Adele Clarke of UC San Francisco at (415) 476-0694.
Ms. Valerie Curtis
88 Webster Street
San Francisco, California 94117

Re: "Lesbians Living with HIV" – Continuation of Joint Medical Program Research – Health & Medical Sciences Program

The project referred to above was granted continuation approval in an expedited manner by the Committee for Protection of Human Subjects on Wednesday, September 29, 1999.

The number given to this project is 99-10-41. Please refer to this number in all future correspondence.

The expiration date of this approval is October 7, 2000. Approximately six weeks before the expiration date, we will send you a continuation/renewal request form. Please fill out the form and return it to the Committee, according to the instructions.

Attached is a copy of the consent materials reviewed by the Committee; the expiration date of the Committee's review of this form is noted in the upper right hand corner. Please copy and use this stamped consent form for the coming year and destroy any unsigned, out of date consent forms in your file.

Please note that even though the Committee has approved your project, you must bring promptly to our attention any changes in the design or conduct of your research that affect human subjects.

If you have any questions regarding this matter, please contact the CPHS staff at 642-7461, FAX 643-6272, e-mail: subjects@uclink4.berkeley.edu.

Sincerely,

Judith Warren Little
Professor of Education
Chair, CPHS

cc: Professor John Swartzberg
    Ms. Ronnie London

Attachment
JWL:amb
October 5, 1998

MS. VALERIE CURTIS
Health & Medical Sciences Program
MC: #1190

Re: "Lesbians Living with HIV" – Master's Research

We have received your revised consent materials relating to the protocol referred to above. They satisfy the conditions in our letter to you of September 18, 1998, and we are pleased to grant full approval.

The number of this project remains 98-10-9. Please continue to refer to this number in all future correspondence about the project.

The expiration date of this approval is October 8, 1999. Approximately six weeks before the expiration date, we will send you a continuation/renewal request form. Please fill out the form and return it to the Committee, according to the instructions.

Please note that even though the Committee has approved your project, you must bring promptly to our attention any changes or untoward events in your research affecting human subjects. If you have any questions regarding this matter, please contact the CPHS staff at 642-7461, FAX 643-6272, e-mail: subjects@uclink.berkeley.edu.

Sincerely,

Henry E. Brady
Professor of Political Science & Public Policy
Chair, CPHS

cc: Professor John Swartzberg
Graduate Assistant
Graduate Degrees #83114584

sb
From: Snerry <snerrille@uclink4.berkeley.edu>
To: reese@socrates.berkeley.edu
Cc: jes@uclink2.berkeley.edu, angora@uclink.berkeley.edu
Subject: CPHS Review--#98-10-9

September 18, 1998

reese@socrates.berkeley.edu

CPHS Review--#98-10-9

MS. VALERIE CURTIS
Health & Medical Sciences Program
MC: #1190

Re: "Lesbians Living with HIV" - Master's Research

The project referred to above was reviewed and granted CONDITIONAL approval in an expedited manner by the Committee for Protection of Human Subjects on Thursday, September 17, 1998.

We approve your request for a waiver from the requirement for obtaining the documented consent of subjects. This waiver is based on our understanding that the research poses no more than minimal risks to subjects and that the waiver will assist to minimize and lessen any possible risks to subjects.

Please note that when you respond to the conditions below, because we do not need to stamp your corrected consent form we will accept your final revisions by electronic mail.

PLEASE NOTE: ANY MATERIALS YOU REVISE AND RETURN MUST BE DISTINCTLY MARKED (HIGHLIGHTED) AS REQUESTED BELOW. IF THEY ARE NOT, YOUR MATERIALS WILL NEED TO BE RETURNED TO YOU FOR COMPLETENESS AND THIS WILL DELAY THE REVIEW OF YOUR RESPONSE.

(A) REQUIRED WRITTEN MODIFICATIONS TO PROTOCOL: None required at this time.

(B) UNDERSTANDINGS AS REQUIRED MODIFICATIONS TO PROTOCOL: None required at this time.

(C) REQUIRED WRITTEN MODIFICATIONS TO CONSENT FORM: PLEASE REVISE YOUR PROPOSED CONSENT MATERIALS AS FOLLOWS AND HIGHLIGHT THE CHANGES ON ONE COPY ONLY:

(1) The Attachment D, "Dear Participant," letter's paragraph four should be revised at the end to add the following sentence. "Again, all information shared will not include your identity."

(2) As a reminder, at the time you present your consent materials to subjects please do so on University of California at Berkeley letterhead.

When we receive TWO sets of any required modifications noted in (A) or (C) above, the Committee will notify you whether the conditions have been satisfied. Please understand that NO research involving human subjects may begin until we inform you that all conditions have been met and that CPHS fully approves the research.

The number given to this project is 98-10-9. Please refer to this number in all future correspondence. If you have any questions regarding this matter, please contact the CPHS staff at 642-7461, FAX 643-6272, e-mail: subjects@uclink.berkeley.edu.

Henry E. Brady
Professor of Political Science & Public Policy