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Old lesbians' experiences with the health care system : ten case studies

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OLD LESBIANS' EXPERIENCES
WITH THE HEALTH CARE SYSTEM:
TEN CASE STUDIES

A Thesis
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In Partial Fulfillment
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Master of Arts in Interdisciplinary Studies–Gerontology

by

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ABSTRACT

OLD LESBIANS' EXPERIENCES WITH THE HEALTH CARE SYSTEM: TEN CASE STUDIES

by Nancy Gail Hugman

This qualitative study of 10 open-ended interviews with lesbians ages 61-101 described how old lesbians view their past, present, and projected interactions with the health care system. Maximum variety sampling allowed for ethnic, religious, socioeconomic, educational, and ability diversity. Nine of 10 subjects considered active or passive suicide a means of personal control and a possible alternative to nursing home placement, mental or physical deterioration, or becoming a burden to loved ones. Most eschewed heterosexually-oriented programs and institutions. Only one spoke of having received formal counseling. They viewed coming out as lesbians to their providers or to family as irrelevant, natural, risky, unnecessary, or freeing. All valued independence or interdependence and respect. In their definitions of family, all included fictive kin such as partners or unrelated friends to whom they turn for support Recommendations were made for supportive health care environments for old lesbians and for further research.

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This thesis is dedicated to my parents, Mary Ellen Hugman and John Horace Hugman. You taught me to just be myself, and you have shown me that old age is well worth the wait.

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INTRODUCTION

The aging of the US population has focused attention on the health care needs of elder consumers, yet very little is known about old lesbians and their points of view as health care consumers. Although societal attitudes toward homosexuals are improving, aging and old lesbians will increasingly require services from the very institutions that have historically shown lesbians apathy, if not hostility (Brotman, Ryan, & Cormier, 2003; Cook-Daniels, 1997; Deevy, 1990; Quam, 1992; Wojciechowski, 1998).

Purpose

The purpose of this qualitative study was to describe how old lesbians view their past, present, and projected interactions with the health care system. The data consist of 10 open-ended one-on-one interviews of lesbians between the ages of 61 and 101. This information adds to our limited knowledge base about lesbian elders.

Rationale

Both social and individual factors influence quality and quantity of health care. Points of view from individual consumers, providers, administrators, and politicians merge with external forces to influence social policy. Legal codes that restrict marriage to a man and a woman can leave old lesbians without spousal health insurance, social security benefits, and inheritance rights (National Center for Lesbian Rights, 2003). In addition, health care and social service policies continue to be adapted to reflect the aging of the American population and the cutbacks in health care delivery (Jeglin-Stoddard & de Natale, 1999). Policymakers, under pressure from constituents or interest-specific groups, can choose to fund one group over another (Binstock, 1993).

Competing groups may include lesbians vs. heterosexual women, well elderly vs. frail elderly, and children vs. elders (Huber, 1995).

The predisposing factors affecting an individual's decision to use the health care system include familial or cultural norms, financial resources, and ease of access to health care facilities. An individual's past experiences can also influence personal health care decisions.

Individual health care providers also bring their beliefs to the table. Ageist, sexist, racist, and heterosexist attitudes can influence the provider's choices about whom to treat aggressively and whom to treat conservatively, whom to refer to specialists and whom to advise to learn to live with the problems (Rankow & Tessaro, 1998; Saulnier & Wheeler, 2000). Therefore, old lesbians, shunned and devalued by mainstream society because of sexual orientation, age, sex, and sometimes race, might be expected to receive inferior and less frequent health care (Cook-Daniels, 1997; Deevey, 1990; Mays, Yancey, & Cochran, 2002; Schoonmaker, 1993; Wheeler, 2003).

In recent years, society's attitudes toward homosexuality have improved markedly. However, it would be naive to assume that the old lesbians are well integrated into the health care system. Historically, the health care system was the central institution charged with curing lesbianism through medication, surgery, and/or psychiatry (Eliason, 1996).

In order to successfully provide for the particular needs of old lesbians, individuals and institutions must understand lesbians' health care needs in the full context of their histories (Rosenfeld, 1999). Raphael and Meyer (1988) looked back at Meyer's 1977 study of old lesbians:

> The original study showed some of the areas of an older lesbian's life that are inescapably affected by her lesbianism. These include her kinship relationships, friendships with gay and straight people, love relationships, support systems, sexuality, the organizations she will join, the places she will frequent, the professionals whose services she will use and the nature and amount of discrimination she will encounter. Additionally, attitudes toward aging, plans for old age, and participation in senior citizens' groups and activities are also affected. (p. 69)

Therefore, one might surmise that a lesbian's interactions with the health care system are inextricably linked to the fact of her lesbianism (Brotman et al., 2003). A closer look at old lesbians' perceptions of these interactions may reveal these women's health care priorities and the actions they take to meet their perceived health care needs.

Significance

Considering that old lesbians probably make up between 1% and 10% of the total old female population, depending upon definitions and methodology, public health journals have sorely neglected the issue of old lesbian health care (Abraham, 2003; Black, Gates, & Sanders, 2000; Reinisch & Beasley, 1990; Smith, 2003; Solarz, 1999). No current review quantifies the percentage of published articles dealing with old lesbians' health. However, Boehmer's (2002) search of MEDLINE articles between 1980 and 1999 revealed that 0.1% of the published articles dealt with lesbians, gays, bisexuals, and transgender persons (LGBT, alternately GLBT). Most of these articles were aimed at or heavily weighted toward gay men. Lesbians only dominated in research about LGBT families.

Findings about young lesbians' health care perspectives cannot be generalized to old lesbian cohorts. Old lesbian's health care attitudes are informed by having lived through an era in which it was not uncommon for homosexuals to be incarcerated or institutionalized (Faderman, 1991). Citing numerous sources, Stevens (1992) documents that treatment for homosexuality included “psychiatric confinement, electroshock treatment, genital mutilation, aversive therapy, psychosurgery, hormonal injection, psychoanalysis, and psychotropic chemotherapy” (pp. 91-92). Understandably, old lesbians do not easily avail themselves of health care research. Therefore, clearly defined variables and random samplings of old lesbians are difficult, if not impossible, to produce.

The goal of this qualitative study was not to create statistics but to strengthen the understanding of the individual subjects’ health care experiences. These interviews took place in a unique setting, at a specific time, and were guided by the flow of conversation between investigator and subject. Rather than hindering the validity of the study, the natural settings and interactions increased the likelihood that the derived information is valid. The open-ended interview technique allowed unexpected issues to rise and allowed old lesbians to prioritize the information they relayed. In contrast, quantitative researchers often meet subjects in unnatural settings, asking them to respond to unnatural questions that the subject cannot qualify with explanation (Bailey, 1997).

In theory, the underlying thoughts and feelings associated with these women’s experiences will be thoughts and feelings that other persons may attribute to other circumstances. In other words, one may seek to understand the human experience through the study of individuals’ experiences (van Manen, 1990).

This study adds to our limited knowledge of old lesbians. Lacking information about lesbian elders, health care workers may erroneously presume the heterosexuality of their clients (Cook-Daniels, 1997; Brotman et al., 2003; Eliason, 1996; Faria, 1997;

Jacobson & Samdahl, 1998; Saulnier, 2002; Saulnier & Wheeler, 2000). This study can increase awareness among health care workers and help them to create old-friendly and lesbian-friendly environments. Health care providers and organizational managers may use the information as a steppingstone to understanding their dynamic relationships with elder lesbian consumers. A closer look at old lesbians' perceptions of their health care interactions can help to identify some priorities and the actions they can take to meet their perceived health care needs. Kin and fictive kin (unrelated persons who function as kin) can gain insight into the varied and complex factors that may affect their elder lesbian relatives' health care decisions.

Theoretical Perspectives and Assumptions

One of the intriguing aspects of research is that the investigator is to acknowledge her or his assumptions and then set them aside to the extent possible. Only then can the investigator be open to understanding their subjects' messages. While this researcher adheres to feminist, continuity, and personal risking theories, she designed her study in such a way as to diminish her perspectives' influences on the outcomes.

Feminist theory postulates that each woman possesses an innate potential. Personal, political, and cultural oppressions too often interact to stymie women's self-actualization (Doress-Worters & Siegal, 1994). Regarding research, Erwin (1993) pointed out that psychological theories of lesbianism have been historically informed by sexist research. Theorists assumed lesbian psychological distress to be comparable to gay male psychological distress.

Lesbian feminist theory complicates the understanding of lesbian oppression by pointing out the impact of both patriarchal control and heterosexism, the presumptive superiority of heterosexuality. In their introduction to *Feminist Frameworks*, Jaggar and Rothenberg (1993) explained that a single feminist framework cannot adequately account for women's subordination or for "the conditions under which women will be able to exercise significantly free choice about our own future positions in society" (p. xvii). For example, Erwin (1993) underscored the fact that lesbian women of color do not experience separate oppressions based on sex, race, gender identity, sexual orientation, and class. Rather, they experience the multiplication of these factors interacting upon one another. One reason is that each of these identity groups has a unique social history (Cook-Daniels, 1997; Mays et al., 2002; Wheeler, 2003). For this reason, subjects for the study were chosen for their range of ethnicities, ages, socioeconomic backgrounds, and degrees of disabilities. Also, the semistructured format interview guide allowed for exploring these identities as they relate to health care.

Atchley (1989) explained the *continuity theory* of aging:

> A central premise of Continuity Theory is that, in making adaptive choices, middle-aged and older adults attempt to preserve and maintain existing internal and external structures . . . by using continuity (i.e. applying familiar strategies in familiar arenas of life). . . . External continuity is thus the persistence of the structure of relationships and overt behaviors. . . . Internal continuity acts as a foundation for effective day-to-day decision-making because internal continuity is an important part of individual mastery and competence. (pp. 183, 185)

In a health care system that generally presumes heterosexuality (Boehmer, 2002; Brotman et al., 2003; Faria, 1997; Saulnier, 2002; Saulnier & Wheeler, 2000), old lesbians must attempt to adapt to environments that they may perceive as uncertain or potentially threatening. Their adaptive choices may be based on their personal histories or their awareness of the experiences of other old lesbians. Yet, society has grown more tolerant of lesbians. Continuity theory would suggest that despite diminished risks of coming out (living openly), old lesbians who have mastered the art of living dual lives would choose to remain closeted, that is, they would hide their sexual orientation. Atchley (1989) suggested, "Consistency and linkage amid change over time are necessary conditions for concluding that one's life has integrity" (p. 185). Continuity theory would suggest that a thread of consistency may run through past, present, and future interactions with the health care system.

Hitchcock and Wilson (1992) developed the *personal risking theory* to explain the process a lesbian may go through in preparation for her interaction with health care providers. The theory supposes that before interacting with the health care system, a lesbian will anticipate what might occur if she purposely or inadvertently discloses her sexual orientation. While interacting with her provider, she will actively or passively conceal or reveal her orientation, depending on her anticipated outcomes. Ultimately, she will attempt to increase the positive and decrease the negative affects of the experience. Responses to those interview queries relating to coming out to health care providers may shed light on the personal risking theory.

Definitions

Health Care System. For purposes of this study, the health care system is defined as institutions and individuals who offer professional services related to a person's physical, mental, and/or emotional wellbeing. This may include, but is not limited to, medical clinics and hospitals; rehabilitation units; home care services; skilled nursing facilities and nursing homes; senior centers; retirement communities; alternative healers; religious institutions; health-related support and advocacy groups; government programs, policies, and procedures; life and health insurance agencies; educational institutions and researchers; pharmaceutical companies; and societal attitudes and beliefs which serve to reinforce or alter the status quo in health care.

It is not within the scope of this study to examine in detail the relationships of old lesbians to each of these services. However, the broad base permits interviewees to discuss the areas of the health care system that are most pertinent to their experiences.

Lesbian. A lesbian is a woman whose deepest sexual, erotic, and/or intimacy needs are best fulfilled in relationship with another woman (Solarz, 1999). This definition includes women who have never acted out sexually with another woman and those women who may have lived together as intimate companions, sometimes for many decades. While they may never have allowed themselves the conscious awareness of a sexual orientation toward each other, they turn to each other for profound intimacy (Faderman, 1991).

The lesbian might or might not use the word *lesbian* to identify her sexual orientation. For the purposes of this study, the definition does not include transsexuals who are attracted to other women.

Old. For the purposes of this study, old is defined as 60 years old or older. Many LGBT groups prefer the term *old* to *older* because the later term infers a comparative norm outside of which the old person stands (Nystrom & Jones, 2003). The former term reinforces the concept that one earns the title *old* in one's own right, without the need for validation through comparison to the young.

LITERATURE REVIEW

While no one knows how many old lesbians there are, several sources have estimated the general lesbian and gay population. The new Kinsey Institute report suggested that 3 to 10% of the US population of 275 million (US Census Bureau, 2000a) is primarily homosexual (Reinisch & Beasley, 1990). Black and colleagues (2000) conservatively approximated that lesbians constitute 1.1% of the female population while Cook-Daniels (1997) cites 5-10% as the most common estimates. Extrapolating, if only three to five percent of the 146 million US female population (US Census Bureau, 2000a) is lesbian, their numbers can be estimated at between 4.4 and 7.3 million.

The same percentages applied to the estimated 35.8 million women presently over age 55 (US Census Bureau, 2000a) yields between 1.1 million and more than 1.8 million old lesbians today and 2 million to 3.3 million by 2045 (US Census Bureau, 2000b). Even so, a review of the literature on old lesbians reveals a paucity of information about their relationships with the health care system.

This study's definition of the health care system is purposely broad-based to encompass those entities and attitudes that influence old lesbians' physical, mental, and/or emotional wellbeing. A review of the literature reveals minimal information regarding old lesbians' physical wellbeing, although more is written about younger lesbians' physical health. Most of the literature about old lesbians' social support needs and psychological needs includes gay men and sometimes transgender persons. Such articles tend to hold a strong reporting bias toward gay men.

Methodological Challenges

Definitions and methods of recruitment can dramatically influence data. Because of a history of oppression, old lesbians tend to protect themselves from discrimination or stigmatization through invisibility, social selectivity, and/or passing as heterosexual (Jacobson & Samdahl, 1998; Nystrom & Jones, 2003). Accessing these women for research purposes poses particular difficulties. Some may avoid participating in research if nonhomosexual persons are involved (Brotman et al., 2003). Others remain hidden due to the stigma imposed on them as members of a *triple minority*: aged, female, and lesbian (Deevey, 1990). *Multiple-jeopardy* refers to the above factors plus minority racial or gender identities (Cook-Daniels, 1997).

The typical elder lesbian sample consists predominantly of young-old, European-American, educated lesbians. Because samples tend to be derived from gay or lesbian organizations within urban populations; they may not represent characteristics of rural or isolated lesbians (Brotman et al., 2003; Hamburger, 1997; Herdt, Beeler, & Rawls, 1997; Nystrom & Jones, 2003; Quam, 1996; Woolf, 2001). These methodological problems have led most researchers to depend on nonrandom snowball sampling. While subsequent data cannot be generalized to the larger population, a well-planned sample can decrease the bias toward young-old, urban, White, highly educated, professional lesbians.

In seeking lesbian participants, researchers varyingly have chosen self-identified lesbians (Aaron, Markovic, & Danielson, 2001; Herdt et al., 1997; Jacobson & Samdahl, 1998; Mays et al., 2002; Nystrom & Jones, 2003; Rankow & Tessaro, 1998; Rosenfeld, 1999), women who have had more same-sex than opposite sex partners since age 18 (Black et al., 2000), women who have had one or more same-sex sexual relationships (Rankow & Tessaro, 1998), women-who-love-women (Saulnier, 2002), women who consciously choose to develop intimate relationships with other women (Wegesin, 2001), or women who attend lesbian conferences or are on mailing lists for lesbian community newsletters (White & Dull, 1997). In assessing data from the Women's Health Initiative, Valanis and colleagues (2000) defined five sexual orientations of women based on reported sexual histories: heterosexual, bisexual, lifetime lesbian, adult lesbian (exclusively same-sex relationships after age 45), and those who have never had sex. The study considered members of the second, third, and fourth categories to be *sexual minorities.* These inconsistent definitions make it difficult to effectively compare the findings among studies.

Likewise, researchers' inconsistent definitions of "old" make it difficult to draw conclusions from combined research data. Valanis and colleagues (2000) sampled 93,311 women ages 50-79 who were postmenopausal. On the other hand, the needs assessment by Herdt and colleagues (1997) of old gays and lesbians (70% men) sampled persons age 45-91 with a focus on those over 50, resulting in a median age of 51. In the GALAXY study of the need for *nonheterosexual* elder housing, Hamburger (1997) specified that the 18 respondents ranged in age from younger than 45 through 74. Rosenfeld's (1999) research on elder gay and lesbian identity included 37 persons ages 65-89, with an average age of 72.5 and 40% of the sample age 75 or older. Jacobson and Samdahl (1998) interviewed eight lesbians age 60 or over. Median age was 70 with a range of 60 to 78 years. No age parameters were identified in the investigation by Brotman and colleagues (2003) of health and social service needs for old Canadian lesbians and gays and in the article by Cook-Daniels (1997) on LGBT elder abuse issues.

Methodological Problems

Aside from the difficulty in sampling the hidden population of old lesbians, many of the studies have suffered from flawed research methodology. For instance, identifying and eliciting the cooperation of old lesbians from racial/ethnic minorities and those of low socioeconomic status can be problematic. Herdt and colleagues (1997) claimed to have specifically focused their needs assessment on diversity because the old lesbian and gay community is often erroneously considered homogeneous. However, their sampling methodology worked in cross purposes to their stated goal. They distributed 5,000 copies of their survey questionnaire via the mailing list of Horizon Community Services, Inc., a large Chicago-based gay and lesbian social service agency. They also solicited participation in "natural settings such as bars and local organizations" (p. 237). From these sources, they conducted face-to-face interviews with willing subjects and "key informant interviews with a variety of gay and lesbian community leaders" (p. 238).

Herdt and colleagues (1997) worked contrary to their stated goals by limiting their outreach to community-connected individuals and by assuming that bars and local organizations are natural settings for elder lesbians and gays of color and of low income. Their final tally of 160 questionnaires revealed respondents who were between the ages of 45 and 90, but with a mean age of only 51. Ninety-four percent were Caucasian, 70% male, 31% recipients of bachelors degrees, and 58% recipients of professional or graduate degrees. While Herdt and colleagues acknowledged the narrowness of their sample, they did not acknowledge the probable connection between sampling results and sampling settings. Likewise, their two focus groups consisted solely of men "because, despite extensive efforts, we were unable to solicit enough women participants to conduct a series of groups" (p. 239). However, in their summary of focus group findings, they inferred that the focus group content can be applied to lesbians. "Both of these groups suggest that having been heterosexually married and/or having children significantly differentiate them from other older gay men and lesbians" (p. 240).

Unfortunately, much of the recent research involving old lesbians was similarly flawed. Although well-written in many respects, investigation of Brotman and colleagues (2003) into the social service needs of old lesbians and gays in Canada derived its four focus groups (N=32) from snowball sampling of lesbian and gay directories, senior groups, and activists, as well as sampling mainstream policymakers, public health key informants, and publicly supportive heterosexuals. They set no age parameters. While these contacts might have indeed offered information about the social service needs of old lesbians and gays, a sampling of lesbians and gays who were not well-connected to gay and lesbian organizations would have gone far in improving the validity of the research.

Likewise, Hamburger (1997), wishing to know the housing needs of San Francisco's nonheterosexual seniors, solicited 18 questionnaire respondents from former and present board members of Gay and Lesbian Accommodations for the Experience in Years Retirement, Inc. (GALAXY) and from nonheterosexual senior service and housing advocates, 16% of whom were below age 45 and none of whom was older than 74. Additionally, of 15 to 20 persons who attended two workshops about becoming involved in nonheterosexual shared housing, only seven completed the part of the questionnaire regarding various housing services.

Hamburger's (1997) study results would hold more validity had she gone outside of the GALAXY organization to query old lesbians and gays from varying socioeconomic backgrounds. Respondents who attended a shared housing workshop would presumably be biased toward the need for shared housing. Likewise, gay and lesbian former and current GALAXY board members might have been biased toward the services their organization offered. Hamburger's sample demographics revealed that a full 71% owned their residences in the expensive San Francisco area. Unfortunately, Hamburger painstakingly analyzed the quantitative data from this tiny, biased sample as if the outcomes held significant applicability to the many thousands of nonheterosexual San Franciscans.

Most of the scarce research that has included elder lesbians has acknowledged the inaccuracy of convenience sampling because it has usually resulted in homogeneous samples (Brotman et al., 2003; Deevey, 1990; Jacobson & Samdahl, 1998; Nystrom & Jones, 2003; Quam, 1996; Rosenfeld, 1999; Valanis et al., 2000). Currently, old lesbian data cannot be generalized to the larger population. Nevertheless, a well-planned sample can decrease the bias toward White, highly educated, professional, and, in the case of combined gay and lesbian studies, predominantly male participants. Fortunately, researchers are beginning to have access to large databases that include gay and lesbian populations. However, these databases do not specifically include old lesbian populations (Black et al., 2000).

In designing her study of old lesbians' experiences with the health care system, this researcher employed maximum variety sampling, pursuing leads toward those lesbians who are underrepresented in the literature. She was especially cognizant of the need to search for old lesbians who were not leaders in LGBT or elder care organizations.

Old Lesbians' Physical Health

A pioneering study by Deevey (1990) found that "potential health problems for older lesbian women . . . included infrequent breast self-examination, high alcohol consumption, extra weight, and skepticism toward both traditional health care and health promotion" (p. 36-37). Brogan (1997), White and Dull (1997), and Johnson and Palermo (1984), who studied young and old lesbians, reported similar results.

Deevey (1990) analyzed 78 mail surveys, which included questions on life experiences and on health behaviors. Forty-five of the respondents were in their 50s, 24 in their 60s, and 8 in their 70s. The oldest was 82. All respondents were White except for one Hispanic woman. While two-thirds lived in California or Ohio, the remainder hailed from 16 other states. The sample population was more educated than their age cohorts in the general population.

A large majority (80%) of participants in Deevey's (1990) study held positive or somewhat positive attitudes toward their own aging, and the majority were sexually active. Eighty percent of these old lesbians had experienced discrimination based on their sexual orientation, including arrest, blackmail, physical abuse, family disapproval, verbal abuse, and fear of discovery. Two-thirds believed that their lesbianism was not detectable by the general population. Only 10% were exclusively closeted and 9% were exclusively out as lesbians.

Deevey's (1990) article, aimed at nurses, recommended that nurses ask open-ended questions about patients' informal support networks rather than closed-end questions about marital status. She also recommended that phrasing of sexual questions demonstrate the providers' comfort with minority sexualities.

Lacking other old lesbians' physical health studies, a brief review of general lesbian health can suggest future trends for old lesbians' health. Roberts, Dibble, Scanlon, Paul, and Davids (1998) investigated risk factors for breast cancer among poor lesbians and heterosexual women in San Francisco. The investigators found the heterosexual women were more likely to be current smokers. The lesbian subjects were more likely to have had breast biopsies and to have higher body mass indexes (BMI), but neither group was overweight on average. The researchers did not find significant differences between the two groups in the areas of current or past alcohol use or abuse, family and personal breast cancer histories, age at menarche or menopause, hormone replacement therapy use, ever having received a mammogram, and age at most recent mammogram.

More recently, in another study of behavioral risk factors among lesbians, Aaron and colleagues (2001) compared the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System (BRFSS) data on the adult female population with data from 1,158 demographically weighted anonymous lesbian surveys. Sampled lesbians were more likely to exercise vigorously, use tobacco, drink heavily, and be overweight. They were less apt to have had Papanicolaou testing (Pap tests) in the previous two years. The two groups were equally as likely to have ever had Pap tests. Lesbians over 40 were more apt to have had a mammogram, but lesbians over 50 were less likely to have had a mammogram within the previous two years.

Rankow and Tessaro's (1998) North Carolina questionnaire-based study of 576 lesbian and bisexual women as well as 44 focus group participants indicated a higher than normal smoking rate and lower probability of having ever had Pap tests and of having had Pap tests in the previous year and three years. Having insurance and positive attitudes toward their providers and not having experienced discrimination from their providers significantly increased the likelihood that these lesbian and bisexual women would have an annual Pap test. These findings concurred with the American Medical

Association Council on Scientific Affairs (1996) report that lesbians wait up to three times longer than heterosexual women to receive Pap tests.

A Los Angeles area study by Mays and colleagues (2002) suggested that Hispanic and African American lesbians and bisexual women are more likely than their heterosexual counterparts to be overweight or obese, to use tobacco and drink heavily, and to lack access to regular health care, which corresponds to lower rates of preventative care. No significant differences were found between the Asian American groups.

Old Lesbians' Psychosocial Health

For fear of reprisal, Schoonmaker (1993) published her autobiographical essay under a pseudonym, although she had retired as an internist and psychiatrist. She described the life-long shame she and many lesbians of her late 1920s age cohort felt for being who they were: females, lesbians, and, eventually, aged. She differentiated shame from guilt in that guilt pertains to an act that "violates one's values" (p.23) but can be forgiven. Shame is an emotional response to being innately less than one should be. It cannot be changed and cannot be forgiven. All of life's accomplishments and accolades cannot tip the scales in the direction of self-worth.

Schoonmaker (1993) described a social climate in which young women were expected to marry and put their husbands' careers ahead of their own. A woman's value lay in her ability to satisfy her husband emotionally and sexually and to bear and raise offspring. Women in medical school robbed men of their rightful opportunities. Anti-sexual harassment laws were nonexistent. Female health care workers and patients did not consider filing complaints because they did not view the pervasive misogynous treatment as abusive. Old women patients were called *crocks* and *complainers* and were routinely ignored or humiliated. Whether aimed at the state of being lesbian, woman, or old, negative stereotyping, according to Schoonmaker, felt "hurtful, patronizing, demeaning, objectifying, dehumanizing, and cruel" (p. 24).

Well-conceived qualitative research by Rosenfeld (1999) explored old lesbians' and gay men's senses of identity. She balanced her Los Angeles area snowball sample with 20 lesbians and 17 gay men. The ages averaged 72.5 years, with a minimum age of 65, and 40% were 75 years old or older. While recruiting interviewees from lesbian and gay social groups, senior programs, and events, she also pursued extensions of these community-connected contacts. Her sample included three African Americans, three Latino/as, and four immigrants. Also, annual incomes ranged from below $10,000 to $100,000. This sample was probably not representative of the greater gay and lesbian community, but it was more heterogeneous than most.

Rosenfeld (1999) identified *identity cohorts*, "members of the same generation who were 'born' as homosexual during distinct periods of the homosexual subculture' s history" (Conclusion section, ¶ 1). That is, groups of gay and lesbian elders differ markedly, not based on their chronological ages but based on how the predominant culture interacted with the homosexual subculture at the time they came out. The 1969 Stonewall rebellion, which many consider the advent of the gay/lesbian rights movement, serves as a bold line of demarcation between identity cohorts. In Rosenfeld's study, elders who came out before Stonewall tended to adopt a *homosexuality-as-stigma* identity whereas those who came out after Stonewall tended to adopt a *homosexuality-as-status* identity. Of course, cohorts are dynamic. The cohort experience helps to inform an individual's identity, and individuals together help to define the cohort experience.

> Elderly members of stigmatized groups in particular have witnesses–and been implicated in–a number of reformulations of their stigma and their subcultures, and thus have access to an especially complex set of ideological resources through which to construct their identities (Abstract section, ¶ 3).

The homosexuality-as-stigma cohort, whose members came out when society and the medical/psychiatric professions considered homosexuality a sickness, a sin, and a crime, tended to view the fact of homosexuality as an aspect of one's life to be managed privately. Competent management strategies included passing as heterosexual and adapting to the larger heterosexual society's norms and mores. This cohort believed that discrimination was justifiable for incompetent lesbians and gays who did not or could not adapt. Likewise, those members who did not adapt discredited themselves because of their failures, accepting the penalty of being marginalized from their identity cohorts as well as from society at large (Rosenfeld, 1999).

On the other hand, the homosexuality-as-status cohort came out between 1970 and the present after society and the medical/psychiatric community began to reassess their perceptions of homosexuality. No longer was homosexuality considered a mental illnesses. Antigay laws were being repealed, and some churches began welcoming lesbians and gays. The years after Stonewall brought dramatic social and conceptual change to the gay and lesbian community:

> Gay liberation publicly distinguished itself from the stigmatizing discourse, constructing homosexuality not as a discrete aspect of self that can be managed, but as a positive, political, essential, totalizing self that is inherently unmanageable. Adopting the slogan "out of the closets and into the streets," it called for gays and lesbians to celebrate and proclaim their lesbian and gay identity. (Rosenfeld, 1999, Homosexuality as Status section, ¶ 1)

The homosexuality-as-status cohort considered the previous stigmatization illegitimate. The competent homosexual became one who came out to those persons who deserved or would have benefited from the knowledge. Coming out was viewed by this cohort as a matter of personal and moral integrity. They believed that homosexual incompetence was displayed by persons who resisted coming out to themselves or to others and by those who hid relevant, normal information about themselves because it relates to their lives as homosexuals. These incompetents blamed themselves for their cowardliness and felt they deserved ostracism from those members of their cohort who were not inclined to hide their own public lesbian/gay personae for the benefit of the closeted member (Rosenfeld, 1999).

Even among same age groups, these two coming out cohorts might experience tension when interacting. Participants in Rosenfeld's (1999) study who belonged to the homosexuality-as-status cohort considered the homosexuality-as-stigma perspective to be obsolete. In theory, as the former stigmatized the latter, the homosexuality-as-stigma cohort members grew increasingly isolated from their generational cohort of lesbians and gays. Consequently, their opportunities for passing on their subculture's history and for serving as role models for younger lesbians and gays became limited. Currently, lesbian and gay elder organizations generally promote the post-Stonewall liberationist perspective.

On the other hand, Rosenfeld's (1999) homosexuality-as-stigma cohort members explained that they preferred not to become associated with obvious homosexuality-as-status persons so as not be looked down upon by the larger heterosexual culture. According to the homosexuality-as-stigma members, telling someone that one is gay or asking a person if she or he is gay was akin to admitting one's inability to naturally and intuitively know one' s own. Also, being openly gay was seen as self-destructive and incompetent because open persons apparently did not understand the potentially negative ramifications of their behaviors.

Rosenfeld (1999) theorized that cohort identity is fluid among the subcultures as well as among individuals because identity changes with the ebb and flow of external and internal forces. Both cohorts emerged from their places in history, and new cohorts will form as history progresses.

Dorfman and colleagues (1995) surveyed 108 old homosexual and heterosexual women and men from urban settings in Central and Southern California. The team of researchers wanted to test the social assumption that old lesbians and gay man are isolated and depressed because of the social stigma surrounding homosexuality. The investigators used non-probability sampling in a wide variety of settings such as gay and lesbian elder organizations, lesbian and gay events, mainstream senior centers, and churches. Because lesbian elders were difficult to locate, the researchers extended their geographical area from Southern California into Central California. The final samples of both homosexuals and heterosexuals but less representative of the general population in terms of race, income level, education, and health. Comparing the heterosexual and homosexual groups, the lesbian/gay groups were significantly less likely to be living with a spouse or partner and were significantly more educated.

The survey consisted of the Geriatric Depression Scale (GDS), which assesses elder depression, and the Lubben Social Network Scale (LSNS), which assesses quality and quantity of social support (Dorfman et al., 1995). Results showed that 15% of the entire sample was depressed, consistent with other elder studies. After controlling for education, sex, and partner status, the researchers found no significant differences in depression between the homosexual and heterosexual samples. Also, social support was found to be a primary indicator for decreased depression in both samples. Analysis of results showed differing quantities of family support, from greatest to least, among the study's heterosexual women, heterosexual men, lesbians, and gay men. While there was no significant difference in friend support among the four groups, the trend indicated that lesbians have more friend support than the other three groups.

The researchers referred to Kimmel's hypothesis that the painful coming out process serves to strengthen lesbians' and gays' coping skills, thus helping them to cope more easily with the changes brought on by aging. They also suggested that the losses and role changes of aging are less traumatic for gays and lesbians because their gender roles are more malleable. Lastly, the investigators theorized that the experience of being homosexual in a heterosexual culture may "strengthen bonds between gay individuals, thus enriching their friendship networks" (Dorfman et al., 1995, p. 40).

Some organizations have sought to strengthen lesbian and gay elder social support. The fate of Seattle's Elder Initiative illustrates the results of setting nebulous old age parameters when designing social support programs for old lesbians. In hopes of building a community responsive to the needs of old lesbians, Elder Initiative facilitators plastered posters in general public areas such as grocery stores, doctors' offices, and shopping centers. The notices invited aging (ages 45-59) and old (age 60 and above) lesbians to a meeting to discuss their needs. Thirty-six respondents, ages 45-72, mean age 59, filled out skills and needs assessments. At a subsequent meeting, participation grew to 67 women, including representatives from the Area Agency on Aging and the state legislature. Participants identified needs for a tool bank and an active list of old lesbians willing to share their skills in minor home repairs and improvements. Also, committees were formed to address grief support, health issues, and social support (Nystrom & Jones, 2003).

Hoping to spur even more excitement, organizers dropped the lower age limit to 40 and met a third time with 125 participants. These members decided to delete the term *elder* from the Elder Initiative because it did not accurately represent those involved. The group set the goal of organizing the first gay and lesbian community center and retirement complex in the United States. In its third year, the organization consisted of 550 lesbians with a mean age of 47. The group decided to redirect its goals towards health and wellness and socialization opportunities, which were more in line with the interests of the middle-aged lesbians. At this point, the disenfranchised old lesbians dropped out. No alternative Seattle community outlet was available for these old lesbians (Nystrom & Jones, 2003).

The aforementioned research summary offers a picture of the physical and psychosocial health concerns that can affect old lesbians. However, questionnaires and interviews can still limit our understanding of the underlying meanings of health care for this population. A broader perspective considers lesbian cohort effects and individual and social histories that help to form older lesbians' individual worldviews (Rosenfeld, 1999). Faderman's (1991) well-researched book *Odd Girls and Twilight Lovers: A History of Lesbian Life in Twentieth Century America* delineates influential events and attitudes which marked each decade of the twentieth century. For instance, today's 70 year-old lesbians came of age in the 1950s, a time during which psychiatrists considered homosexuality a psychosis characterized by "cannibalistic fantasies" (p. 132). It was not uncommon for homosexuals to be incarcerated or institutionalized. During this era, Sen. Joseph McCarthy led the efforts to identify and remove all homosexuals from government jobs.

Stevens (1992) concurred with this historical perspective, noting that treatment for homosexuality included "psychiatric confinement, electroshock treatment, genital mutilation, aversive therapy, psychosurgery, hormonal injection, psychoanalysis, and psychotropic chemotherapy" (p. 94). Not until 1973 did the American Psychiatric Association remove the diagnosis of homosexuality from its *Diagnostic and Statistical Manual* (Brotman et al., 2003; Woolf, 2001). Understandably, today's old lesbians may feel vulnerable in their associations with psychiatrists, physicians, and/or government-sponsored elder service agencies. Improved knowledge about lesbian health care presently and in the past will pave the way for more accessible and sensitive health care in the future.

Summary

Presently, the US population might include between 1.1 and 1.8 million lesbians over age 55. These numbers will presumably increase as American's population ages (Black et al., 2000; Cook-Daniels, 1997; US Census Bureau, 2000a; Reinisch & Beasley, 1990). In large part, one can only surmise about old lesbians' health care issues by combining knowledge about old women's health, possible trends from younger lesbian research, and fragmented information from old lesbian health studies. The size and nature of the hidden and stigmatized lesbian elder population is indeterminate because of the inherent inability to randomly sample large numbers of these women (Brotman et al., 2003; Cook-Daniels, 1997; Deevy, 1990; Quam, 1996; Rosenfeld, 1999; Wojciechowski, 1998).

In addition, faulty research designs call into question the results of many of the studies. Design flaws include the tendency for investigators to recruit urban subjects who are White, well-heeled, well-educated, and well-connected to lesbian organizations. Also, studies that include lesbians, gay men, bisexuals, and transgendered persons are often heavily weighted toward gay men (Brotman et al., 2003; Hamburger, 1997; Herdt et al., 1997; Nystrom & Jones, 2003; Quam, 1996; Woolf, 2001). Other investigators can mistakenly assume that findings about gay men can be generalized to lesbians or that findings from nonrandom studies can be generalized to the invisible segments of the population that could not or would not participate (Deevey, 1990; Herdt et al, 1997).

Therefore, the literature suggests, but in no way proves, that all lesbians, and thereby old lesbians, may be at risk for higher than average rates of breast cancer, cervical cancer, alcoholism, obesity, and tobacco use. They may also delay or neglect medical care (Brogan, 1997; Deevey, 1990; Johnson & Palermo, 1984; Rankow & Tessaro, 1998; White & Dull, 1997). On the other hand, other studies suggest they may be less likely to use tobacco (Roberts et al., 1998) and more likely to exercise vigorously (Aaron et al., 2001).

The psychosocial health of old lesbians is similarly sketchy. Old lesbian patients and old lesbian health care providers may find themselves patronized, ridiculed, or ignored when seeking help within heterosexist institutions (Eliason, 1996; Schoonmaker, 1993). Likewise, old lesbian friendly institutions which function from a gay liberationist perspective may unwittingly ostracize many of the old lesbians who adhere to the dignity of the closet (Rosenfeld, 1999). Intragenerational conflicts can occur between closeted old lesbians and old lesbians who are out. Also, intergenerational conflicts can occur between young, middle-aged, and old lesbians because of differing psychosocial and social service priorities (Nystrom and Jones, 2003; Rosenfeld, 1999).

Regarding mental health, studies have indicated that old lesbians may be no more likely than old heterosexual women to be depressed. Old lesbians might be slightly more likely to have friendship-based support networks. They might have less family support than heterosexuals but more family support than old gay men. It is possible that the psychological adaptation necessary for successfully negotiating lesbian life in a heterosexual world better equips old lesbians to adjust to aging changes (Dorfman et al., 1995). An understanding of the personal, subcultural, and cultural histories of old lesbians can offer insight into understanding this population (Faderman, 1991; Poor, 1982; Rosenfeld, 1999).

If Rosenfeld (1999) was correct, the cohort of lesbians who came out before the 1969 Stonewall rebellion believe that remaining unidentifiable is a sign of successful lesbian aging. If so, researchers will not soon obtain their coveted random sample. Therefore, well-designed research must employ nonrandom sampling in a way that maximizes the potential for relevant findings.

This review of the current literature highlights the need for much more research on old lesbian health. No investigations were found that encompassed the past, present, and perceived future health care experiences of old lesbians.

METHODOLOGY

The use of narratives for qualitative researched has gained acceptance in the past several decades in academic fields such as sociology, gerontology, anthropology, history, education, and psychotherapy. Such research adds to our knowledge base by examining complex human lives in context rather than simplifying the human experience to fit neatly into the unnatural settings and rigidly defined variables required by quantitative analysis (Clark, Carlson, & Polkinhorne, 1997). Moreover, while quantitative research might work well for easily accessible populations, hidden, oppressed, and stigmatized populations do not lend themselves to the random sampling that is necessary to validate quantitative research.

This study used *maximum variety sampling* to achieve a small yet highly diverse nonrandom sample. In this way, the commonalities among these 10 old lesbians were more conspicuous than if the sample had been homogeneous.

Research Query

How do old lesbians view their past, present, and projected interactions with the health care system?

Research Design

Between March 1998 and May 2000, this researcher conducted 10 face-to-face interviews with lesbians over the age of 60. The tape-recorded one-on-one interviews ranged in length from approximately one and one-half hours to three and one half hours. The length of each interview varied according to the subject's physical endurance and her interest in elaborating upon the topics. Each interview was accomplished in one session except for one interview that was conducted over a two-day period.

At the onset of each interview, the researcher read aloud the study's definition of the health care system, instructing the subject to elaborate on the health care areas of her choice. She also reviewed the purpose of the study and reiterated the main points of the informed consent, including the right to withdraw from the study.

The open-ended, semistructured guidelines (see Appendix L) allowed for the transformation of the interview guide as the subjects revealed better ways of approaching the research question. At each interview's conclusion, the subject granted permission to be contacted again if areas required elucidation or if the direction of subsequent interviews were to take an unexpected turn. However, at least two subjects have died since the interviews. Also, because several years have passed between the collection and the interpretation of the data, revisiting the subjects to ask for elaboration would risk the subjects superimposing their present points-of-view upon their past perspectives (Mahaffy, 1996).

The interview guide questions were designed broadly enough to encompass both formal and informal support systems as well as physical, psychological, and spiritual health. Also, questions used the term *health care provider* instead of *physician* or *doctor* in order to allow the subjects to expound upon those experiences most pertinent to them.

All audiotapes were transcribed and converted to computer files and hard copies. The transcriber signed a confidentiality agreement.

Subjects

Interviewees for this study ranged in age from 61 through 101. The average age was 72 and the mean was 68 years old. Setting the minimum age limit at 60 held several advantages. The bulk of subjects in lesbian aging studies have tended to lean toward the younger end of the researcher's predetermined age range (Deevey, 1990; Hamburger, 1997; Herdt et al., 1997; Nystrom & Jones, 2003; Valanis et al., 2000). To restrict the lower limit to 60 years helped to insure that the subjects' median age was higher than if the lower limit had been set at 50 years-old.

Aging issues are different in one's 40s and 50s than after age 60 (Nystrom & Jones, 2003). For instance, in 1990, 55.3% of US women between the ages of 55 and 59 participated in the workforce, but only 35.5% of women between ages 60 and 64 worked outside the home. The percentages continue to drop rapidly thereafter (Rappaport & Schieber, 1993). Secondly, lifestyle and financial changes often inherent in leaving, considering leaving, or choosing to remain in the workforce can influence the world views of people over the age 60 (Stein, Doress-Worters, & Filmore, 1994). Also, the cohorts of lesbians who were over 60 years old at the time of the interviews reached adulthood more than a decade prior to the Stonewall riots of 1969, considered to be the advent of the gay liberation movement in the United States (Rosenfeld, 1999). Lastly, the incidence of chronic illness increases with age, potentially increasing the frequency and nature of interactions with the health care system (Doress-Worters & Siegal, 1994).

Gay men were excluded from the study for several reasons. Gay men's health care needs are different from those of lesbians, especially in regard to the ways in which AIDS has impacted their lives. Because society views men differently than women, gay men's perceptions of and experiences with social institutions and providers might be expected to differ from those of lesbians. Likewise, the nature of gay men's relationships and support networks, the overt ageism and emphasis on youth and sexual attractiveness that is pervasive in the gay male community, and the cultural stigma of being gay vs. lesbian sets gay men apart from lesbians. Finally, men enjoy economic and cultural advantages that may influence their worldviews (Cook-Daniels, 1997; Harper & Schneider, 2003; Herdt et al., 1997; Rosenfeld, 1999; Woolf, 2001).

Transgendered persons, regardless of sexual orientation, were excluded from the study because of the potentially divergent complexities of their physical and mental health care experiences. If gay men, transgendered persons, or heterosexual women had been included in the study, the resulting framework would have been so broad and flat as to offer no noteworthy similarities among the sample (Hamburger, 1997; Herdt et al., 1997).

In order to identify common health care concerns among a small sample of 10 subjects, the researcher sought diversity within the identity group. Subjects varied in racial and ethnic backgrounds, religions, economic status, education, health status, and life experiences. However, their common status as old lesbians offered a limiting framework on which to build understanding.

Sampling

Because old lesbians cannot effectively be identified through random sampling, and non-random sampling cannot be generalized to the larger community, this researcher purposely employed maximum variety sampling. That is, she attempted to obtain a diverse sample in order to explore "both unique and shared experiences" (Jacobson & Samdahl, 1998, p. 236.) among old lesbians. The investigator purposefully pursued leads toward those lesbians who have been underrepresented in the literature: the older old; ethnic, racial, and religious minorities; immigrants; and those without direct connections to LGBT organizations. Pursued to a lesser extent were those with low incomes and high degrees of disability. Subjects also hailed from a variety of community sizes and settings.

To recruit volunteers, flyers were distributed in lesbian-friendly gathering places, as well as in mainstream senior centers and housing complexes, women's bookstores, mainstream bookstores, and coffee shops. Ads appeared in LGBT, lesbian, feminist, and mainstream newspapers and newsletters. The investigator visited support and social groups frequented by old lesbians. Via phone, e-mail, or mail, she contacted social welfare and health care organizations which might serve elder lesbians, organizations which might include old lesbians or persons who know old lesbians, ethnic minority lesbian and gay support groups, churches, synagogues, and religious groups known to be open and welcoming to lesbians and gays, on-line lesbian chat rooms and on-line lesbian support groups. She also queried ethnic minority women, visited Internet websites, and followed word-of-mouth leads.

To increase the possibility of reaching closeted lesbians and women of lower socio-economic status, information was posted or distributed at low-income senior housing complexes, and notices were submitted to mainstream aging newsletters. Both flyers and ads used the term *women who love women* in order to open the door to those who did not identify with the term *lesbian*. To establish trust and allow parties to verify the authenticity of the study, they were given business cards with the researcher's personal contact information and contact information for the Director of the SJSU Gerontology Program. This information also appeared on the flyers.

Wheeler (2003) postulated three reasons for lack of research participation among LGBT African Americans: social stigma, researchers do not consider the population important, and investigators have not done the work to gain trust and access to the community. Because this researcher is a White, middle-aged lesbian, she met with an African American lesbian educator who is active in her community. The stamp of approval from this woman opened doors that would otherwise have remained closed. Wherever possible, the researcher established rapport with persons who might have had contacts with hard-to-identify old lesbians. While trust building requires more time than snowball sampling, it can yield fruitful results.

Unfortunately, no old Asian American lesbians were identified. One Asian American clergyman, who was speaking about meeting elders' needs, responded to a question about serving the spiritual needs of old lesbians and gays, "We are Asians. We do not air our dirty laundry in public" (personal communication, San Jose, CA, 1996).

Confidentiality

Flyers and ads emphasized confidentiality. In order to insure confidentiality, numbers, dates, and initials were coded on the audiotape labels to prevent visual identification of the subjects' names. Likewise, each subject and all relevant persons named in the transcripts were assigned pseudonyms. Geographic locations were identified in vague terms, e.g. "a small town outside of the San Francisco Bay Area" or given pseudonyms. Specific professions were altered in those instances in which the job might identify the speaker. Care was taken to maintain the pertinent information and tone of the interviews while protecting each participant's privacy.

The audiotape transcriber signed a confidentiality agreement. Audiotapes, digital data, and hard copies were secured to prevent access from unauthorized persons. Each subject received a copy of the consent form, signed by both the subject and the investigator, which included assurances of confidentiality.

Setting

Interviews were conducted at locations convenient to the participants and conducive to confidentiality and emotional safety. All except two interviews took place and the subjects residences. One was conducted in the subject's daughter's home because of its convenient location. Because one subject preferred a neutral, yet private, location, the researcher rented a church meeting room in the subject's neighborhood.

Interpretation of Data

In interpreting case study data, one must first set aside, to the extent possible, theoretical perspectives and assumptions about which conclusions can be drawn from the data. The investigator reviewed the data, recalling the details of the experiences as they were related to her. She summarized each case, identifying common elements within each case and among the cases. She expanded on her analysis, citing current literature to broaden the discussion of the predominant topics. Lastly, she made recommendations based on her findings (Bailey, 1997).

Limitations and Advantages of the Study

The study of old lesbians offers many methodological challenges, which are summarized above. Also, participants might tend to self-report that which works against stereotypes and stigma (Bailey, 1997). Elder lesbian research is limited by problems in accessing those old lesbians who choose not to reveal their lesbian orientations or who do not identify with the terms *lesbian*, *women who love women*, or similar terms.

The study's small, nonrandom sample and the difficulty in quantifying information gleaned from open-ended interviews do not allow for generalizing the study's findings to the entire old lesbian population. On the other hand, qualitative research methodologies offer deeper understanding or insight into the statistics produced by quantitative researchers. In some ways, qualitative studies speak more truthfully than quantitative ones (Bailey, 1997) because the former open windows into the shared humanity of their subjects. Therefore, when viewed in context with other qualitative and quantitative studies of elder lesbians' health care issues, this study elucidates some of the factors that can influence old lesbians' interactions with the health care system.

FINDINGS AND DISCUSSION

When viewed holistically, many aspects of a lesbian's life affect her experiences with the health care system. This study's working definition of the health care system focused on institutions and individuals who offer professional services that relate to a person's physical, mental, and/or emotional well-being. Also, societal attitudes and beliefs that serve to reinforce or alter the health care status quo were examined through personal histories lived within the influences of ever-shifting cultural and subcultural contexts.

The following examination of the data compares and contrasts predominant health care experiences while drawing on current literature to illuminate the findings. In order to protect participant confidentiality, this discussion uses those pseudonyms assigned to the interview summaries.

Participant Demographics

As previously noted, this study employed maximum variety sampling in order to learn from diverse individuals whose commonalities were old age and lesbianism. The sums within several demographic categories equal greater than 10 because several participants identified more than one variable per category. For example, Kim K. identified her ethnicity as Black, Irish, and Native American. In reporting the sample's diversity, it is important to note the different terminologies the subjects used to describe themselves. These varying terminologies remind the reader that each life experience, including each health care experience, is informed by a particular time and location intersecting with the unique interactions of age, race, gender, sexual orientation, socioeconomic status, and degree of disability (Cook-Daniels, 1997; Erwin, 1993; Mays et al., 2002; Wheeler, 2003).

Ages. This study's lower age limit was set at 60 years old. The 10 study participants ranged in age from 61 to 101 years old with an average age of 72 and a mean of 68.

Lesbian terminology. The following examples demonstrate that the terminology lesbians use for self-identification can vary by geography, age cohort, degree to which a person is out, and/or the subculture with which one identifies. Shared jargon can be seen as psychosocial short hand for a sense of belonging to one's peer group(s).

The term *lesbian* was preferred by 8 women to describe their sexual orientation. Two used the word *gay*, and 5 employed the following alternative terms: *dyke*, *in the life*, *the "L" word*, *bull dagger*, *being as such*, and *lesbian-feminist*. While Gloria G., a West Coast 66-year-old, used the term *lesbian*, she disliked its "ugly connotation," and she was disgruntled that lesbians are "stuck with the big ol' scientific" word while gay men "have such a neat little ha-ha-happy term." On the other hand, Kim K., a closeted 77-year-old who grew up in the Midwest and on the East Coast, preferred *dyke* or *in the life*. Frieda F., age 66, used *lesbian* on the West Coast and *bull dagger* in her native urban Northeast community. The latter is a term of derision which Frieda's social support circle had reclaimed so as to take the sting out of the insult.

Just as terminology varies among lesbians, research on lesbians is hampered by inconsistencies in conceptual definitions of the terms used to identify this population. Some studies depend on the subjects to self-identify as lesbians, leaving the definition open to interpretation (Aaron et al., 2001; Herdt et al., 1997; Jacobson & Samdahl, 1998; Mays et al., 2002; Nystrom & Jones, 2003; Rankow & Tessaro, 1998; Rosenfeld, 1999; Wegesin, 2001). Old lesbian-rights pioneers Del Martin and Phyllis Lyon (1985) define a lesbian as "a woman who prefers another woman as a sexual partner; a woman who is drawn erotically to women rather than to men" (p. 51) whether or not she has ever acted on her preferences.

To use Martin and Lyon's (1985) either/or definition would have excluded those women who were involved in sexual relationships with other women but did not consider themselves lesbian because of the horrific connotation the word has had in their histories (Faderman, 1991). To disqualify a participant from the study because she did not identify with a particular word would have risked the loss of information vital to the understanding of these women.

Also, this study did not attempt to differentiate between lesbians and bisexual women. Sexual orientation can be fluid throughout the lifespan (Plumb, 2001) and is frequently defined on a continuum. The Kinsey Scale of Sexual Orientation rates sexual orientation on a 7-point scale with 0 meaning exclusively heterosexual behavior and attraction and 6 meaning exclusively homosexual behavior and attraction. The scale does not separate behavior and attraction (Solarz, 1999).

The sexual arena is not the only area that unifies lesbians. A woman's lesbianism permeates nearly every aspect of her life (Solarz, 1999). Therefore, the criterion for participation in this study was only that the women currently conform to the study's definition of a lesbian: a woman whose deepest sexual, erotic, and/or intimacy needs are best fulfilled in relationship with another woman.

Races/ethnicities. All participants were born in the United States except Esther E., who emigrated from Austria as a child and spent much of her adult life overseas. While 6 participants identified only one heritage each, the other 4 listed several racial/ethnic identifications. Therefore, totals were reported by continent and the terms in parentheses represent the participants' own terminology. Four interviewees were of African descent (2 Afro Americans, 1 African American, and 1 Black); 4 claimed European descent (1 English, 1 Anglo, 1 Irish, 1 Scottish, 1 Austrian, 1 Italian, and 1 Spanish); 4 identified North American ancestry (2 American, 2 Native American, 1 American Indian, and 1 Mexican), and 1 identified herself as Jewish but did not specify her ancestral country. Race/ethnicity can influence health care experiences. For instance, although she cared for her mother and sister for many years after her father died, Frieda F. felt guilty about placing her mother in a nursing home. "The Black population . . . has a thing about putting your mother in a home."

Race and ethnicity can also influence the prevalence of certain diseases among old women. For instance, Richardson (1996) reported that African Amercians are at high risk for obesity, diabetes mellitus, hypertension, glaucoma, and cataracts. Also, old Hispanics are at higher than average risk for diabetes, hypertension, and cardiovascular disease (Villa, Cuellar, Gamel, & Yeo, 1993). The most prevalent causes of death among Native Americans are heart disease, malignant neoplasms, and cerebrovascular disease (McCabe & Cuellar, 1994). Unfortunately, those who study health issues among racial minorities might neglect lesbians because of a misconception that homosexuality is less prevalent among racial minorities (Mays et al., 2002).

Mexican American Gloria G. sometimes felt she must use "50-cent" words to prove her intelligence to those who mistook her for a laborer. Likewise, as an African American with a master's degree, Hillary H. felt she must display her intelligence before others would take her seriously.

> Doctors have a habit, still: They talk down to you because you're a woman, and they talk down to you because you're a minority. And sometimes, I get so mad I just want to spit. So, I have to hurry up and tell them what I do for a living. "Well, how come you know so much?" "I know so much because I can read, for one thing." . . . Fortunately, I've got an interesting group of doctors. . . They're pretty patient, so I ask questions for myself. But before, I didn't ask very many questions.

In addition, race is relevant to the study of these old lesbians' health because racial segregation, with its associated health care limitations, played a part in some of the subjects' early health care experiences. When Hillary H. was 17, her mother contracted duodenal cancer. After postponing treatment because of a strong work ethic and lack of health insurance, her mother's African American doctor, who worked in the Black hospital, referred the woman to the better White hospital for treatment. The patient was welcome, but the doctor was not. Hillary's father never forgave the African American doctor for allowing his wife to die.

Religions. The 10 participants in this study included 2 Catholics, 2 Buddhists, 2 Unitarians, 1 Jew, 1 United Methodist, and 1 atheist. One participant with a Metropolitan Community Church background did not label her expressed faith in God. Another had recently severed her affiliation with the Congregational Church, but it appeared that her core spiritual beliefs were still intact.

Josephine J., 101, could walk to the United Methodist Church for worship and to the senior center located in its building. However, she quit worshipping there when she found that the people were friendly during service, but they never greeted her during the social hour. At the time of the interview, she walked to the Catholic Church, which also ran a senior program. There, "everybody treats me lovely. . . . I came up in church and told 'em I was a lesbian."

In contrast, Allison A., 66 ½, expressed strong cognitive dissonance regarding her religion. While dedicated to her Roman Catholic faith, "a religion of love," but she did not respect the church institution. "It's very repressive for women," and "some of those people would be the first to stone me if they knew my life." To complicate matters, her livelihood depended on her Catholic customers. "Basically, I'm selling to the enemy." Although Allison's parish priest had reached out to gay members, she would not respond. Her way of coping with her cognitive dissonance was to occasionally attend a church far away from her parish. She was much more inclined to seek support from lesbian organizations than from a church.

Educational levels. Many of the participants stressed the importance of education as a means of improving personal opportunities and the socioeconomic situations in which they were reared. For instance, Josephine J. believed that both parents were born into slavery. Although her mother could not write, her father was self-taught, and he urged his children to become educated.

One participant who attended high school and 1 who attended college did not specify if they had graduated. Of the others, the highest educational levels achieved were high school graduate (1), some college (3), BA degree (2), MA degree (1), and two MA degrees (1).

In comparing large samples of gay and lesbian adults with data about heterosexuals, Black and colleagues (2000) suggested that lesbians are more educated across all age groups than heterosexual women. "Among lesbian women, 13.9% have post-college education [sic] and 25.0% have college education [sic]; comparable rates for married women are 6.1% and 16.0%" (p. 116). However, uneducated lesbians might have been disinclined to identify themselves to survey takers.

Esther E. planned to leave all of her estate to benefit women's educations.

> [So that] they don't have to go through the same shit that I and my generation had to go through [such as] the suppression and the professional limitations. I mean, my particular generation was aided by the war, if you wanted to take advantage of it, because there weren't any men around. And, this is how I got my chance and climbed up the executive ladder, but then . . . when the guys came back, . . . many of [the women] wanted to be homemakers. Well, bully for them. I'm all for choice. . . . And, I grabbed mine with all fours.

Residences. Half the subjects owned their homes, and half rented apartments. One homeowner and 1 apartment dweller resided within retirement communities. Of the 8 lesbians who lived on the West Coast, 4 lived in urban areas, 3 in the suburbs, and 1 lived in a semirural area. Of the two interviewees who reside in the North Central US, 1 lived in an urban downtown and the other lived in the semirural outskirts of a midsized industrial town. Of the 8 West Coast residents, 3 were reared in the area, 2 came from the Midwest, 1 from the North Central US, 1 from the Northeast, and 1 from Austria and the Northeastern United States. Of the 2 North Central US residents, 1 was native to the area and 1 grew up in the Northeast.

Data comparisons (Black et al., 2000) revealed that the partnered lesbians and gays were less likely than married couples to own homes, but the lesbians bought slightly more expensive homes when they did buy. Also, partnered lesbians were not as concentrated in large cities as partnered gays.

While subjects from many studies have tended to be concentrated in large urban areas (Aaron et al., 2001; Black et al., 2000; Matthews, Hughes, & Johnson, 2002; Matthews, Brandenburg, Johnson, & Hughes, 2004; Nystrom & Jones, 2003), this study's subjects hailed from semirural areas to urban downtown. Ideally, this study would have included rural old lesbians as well, but none were identified.

Limited health care access and few choices can be a challenge for rural lesbians. Bernie B. and her partner Beth planned to move to a small town when they retired. Bernie was concerned that the small hospital might not have quality doctors, or it might lack up-to-date equipment. Because she believed that one person can make more of an impact in a small town than a large one, she planned to advocate for changes that might be necessary in the local health care delivery system. As for their lesbianism, Bernie and Beth plan to "melt into the landscape."

Professions and socioeconomic statuses. Professions varied widely among study participants as well as throughout their lifespans. Half of the old lesbians owned or had owned businesses, and 2 were retired teachers. Other professions included factory worker, soldier, investment banker, cashier, trade specialist, computer operator, and human resources specialist. A subjective assessment of current socioeconomic status placed 1 at a high income level, 1 at upper income, 4 at middle income, 2 at low income, and 2 at or below poverty level. Four participants still worked at the time of the interviews, 5 had chosen to retire, and 1 had recently lost her job due to layoffs and her disabilities.

Woolf (2001) suggested that successful aging for lesbians and gays includes "good health, social class advantage (influenced by wealth and education), and an alliance with a significant other" (Gay and Lesbian Aging section, ¶6) as well as learning to avoid stressors rather than having to cope with them.

Bernie B. listed three criteria necessary for living to be 100: having "enough money to live that long," not deciding prior to 100 that one's "debilitations make it unworthwhile to keep living, [and having] someone that you're living with [as a] synergistic kind of thing [to] keep each other going." She pointed to her parents. They often fought when they were younger, but they grew "much more loving with each other" as they aged and had to depend on each other.

Gloria G. had health insurance through the teacher's retirement system and was not yet eligible for Medicare. She was concerned about efforts by the radical religious right to prevent lesbians and gays from teaching. She felt that such discrimination would put her at risk of losing her teachers' retirement benefits.

Although both Hillary H.'s parents worked, they did not have health insurance when Hillary's mother died from cancer. When she was a young schoolteacher, Hillary's district did not offer health insurance for several years. Hillary stated that when her district got health insurance benefits, she paid extra for the best policy. "I was so thrilled . . . because I was so afraid that [my kids] would get sick, and I wouldn't have enough money to take care of them." She would not have been eligible for public assistance because she was employed. "If you aren't below the poverty line, you don't get any help. You just suffer it, tough it out."

Old lesbians who are independent business owners must also be concerned with health care coverage. For example, as a new divorcée and small business owner, Allison A. had difficulty acquiring affordable health insurance. Her medigap prescription insurance gave her peace of mind for the future even though she did not need prescriptions at the time of the interview. She and her partner wanted the tax and medical benefits they would have if they were allowed to marry.

Children and heterosexual marriages. Half of the women had reared or helped to rear a total of 10 children. The participants were the birth mothers of all but two of the children. One child was a partner's daughter and the other a partner's distant relative. The latter subject and her partner were rearing a grandson at the time of the interview. Five of the participants had been married heterosexually. All the marriages, ranging in duration from 6 weeks to 37 years, ended in annulment or divorce. Three of the old lesbians have survived a partner's death. Duration of these relationships was 7 years, 38 years, and 39 years.

Both Esther E. and Ilene I. had been married to men for short periods. They credited World War II with instigating the changes that gave women financial and social choices. Ilene felt strongly that compulsory marriage "brought a lot of kids into the world that they really didn't want, and then you wonder why so many kids are in the street."

Although Josephine J. did not have children, she and her partner were fictive kin to many African American young adults, mentoring them and helping some through college. Jo believed kindness rewards kindness, but she felt many of these younger people forgot about her when she grew old.

Kim K., 77 years old and disabled, was facing her future alone because Dee, her partner of 44 years was leaving her for a younger woman. Kim believed the crux of the breakup was that Dee, the healthier of the two, did not want to care for Kim in her old age. Also, Dee had recently experienced heart problems and wanted a younger woman to take care of her. Kim did not have the legal benefits and protections that an old married woman would have in her situation. Laws protecting a spouse's rights to the other's social security, community property, and retirement income did not apply. Luckily, Kim had excellent retirement health benefits.

Suicide

The option of suicide was one of the most surprising topics which participants broached. A literature search did not reveal research on suicide among old lesbian elders. In 1999, Surgeon General David Satcher reported suicide to be the eighth leading cause of death in the United States. The article stated that old men were the most likely to kill themselves, but American Indians and gay and lesbian youth were also at high risk (Meckler, 1999).

After the first several participants initiated the topic, the researcher wondered if planning to control end-of-life events was common among old lesbian elders. The researcher never led the participants into a discussion of suicide. Instead, she made a point to ask what they would do if their relatives or fictive kin could not take care of them.

"If we are lucky, we die quickly." Allison replied.

> I'd like to be in control until the end, and if we don't get a rational health care system that allows physician-assisted suicide, I would . . . probably do it myself. It's all in quality of life and how much of the burden people who love me are going to be suffering. . . . [My family doesn't] want to hear this. . . . I wouldn't involve anyone else in it.

Allison's sentiments concurred with those of Derek Humphry (1992), the executive director of the National Hemlock Society. His essay on rational suicide pointed out that elders often kill themselves quietly so as not to bother anyone.

In total, 3 participants mentioned their support for physician-assisted suicide. Gloria G. hopes that California will follow Oregon's lead in legalizing euthanasia. She believed an ideal assisted suicide law would include a clause that requires doctors to uphold "the dignity of a person, not just the life of the person." She suggested that a person with a mental illness that cannot be alleviated should be allowed to "opt out" of life. Gloria G. and Deborah D. emphasized that they wanted their estates to benefit their heirs rather than supporting their physicians' lifestyles.

Besides wanting to preserve their financial reserves, subjects listed numerous reasons they might choose to end their lives. Many stated or inferred a desire to be in control, but their concepts varied when asked to specify at what point they might consider their lives not worth living. Bernie B., age 61, expected that "a cascade of health issues," including Alzheimer's disease, terminal and painful cancer, and communication disorders, might befall her in her late 80s. On the other hand, Josephine J., age 101, suggests that one might expect to decline after 100.

Individuals who had experienced a loved one's protracted dying spoke of wanting to die before becoming a burden. Hillary H. feared she would not have the money to cover convalescent home care beyond the 100-day Medicare allotment. Kim K. did not want to feel useless, and she feared abuse and humiliation in a nursing home. Allison A. did not want to live with a poor quality of life. "I don't think any of us *want* to die, but there's also such a thing as not wanting to live either."

Richman (1992) wrote that suicide among the elderly is not rational. He listed all of the above-mentioned motives for suicide among the risk factors for stress-induced erroneous thinking. Humphry (1992) emphasized that "terminal illness causing unbearable suffering" (p. 126), not old age, is a rational motive for suicide. In the stress of her relationship breakup, Kim K. fit Richman's profile. However, most of the other interviewees were not under stress at the time of the interviews, but were contemplating methods of ensuring that their lives end with dignity and control. Humphry believed if elders who fear losing control and choices in their lives had the option of medical euthanasia, they might be less likely to kill themselves at the onset of physical and mental deterioration.

Indeed, several of the participants spoke of wanting to end their lives before they become unable to carry out their plans. Deborah D. asked her doctor to give her an overdose of medication when she reaches end stages of life. Because she spent many years outside of the United States, she was not sure of the US laws restricting her doctor's actions. Participants differed on whether or not they had talked to their relatives, fictive kin, or close friends about wanting the option to choose when and how they die. Several revealed that their loved ones did not agree with the right to suicide, or they feared criminal prosecution.

Deborah D. and Esther E. were both members of the Hemlock Society. Four months after Deborah told this investigator that she had sent away for hemlock and six months after her lymph nodes had been removed due to metastatic cancer, she was found dead in her home. Information about cause of death was not accessible.

During her interview, Josephine J. suggested that she might choose to stop eating, but would not actively kill herself. Jo died five months after the interview. Her swallowing difficulties caused progressive weight loss. According to the woman to whom Jo had assigned power of attorney, Jo simply decided to quit living.

According to Freda F., Buddhists believe that life is the greatest gift, so she also would not actively commit suicide. She believed she would be able to will herself to die. Each woman expressed the point at which she would prefer death to life. Gloria G. would accept home health care but would want to die before allowing others to bathe or toilet her. However, she acknowledged that her views could change as she ages. She also feared a failed suicide attempt would leave her in a vegetative state. Hillary H. and Kim K. said they might kill themselves before entering nursing homes, but the strength of the intent was vague. They were most concerned about potential indignity, and it was possible that simply having the choice of suicide is an effort to manage the cognitive dissonance between the need to maintain personal pride and the potential need for dependent care.

Hammer (1999) used the theory of cognitive dissonance to explain sense of home among men and women in long-term care settings.

> Individuals [seek] environments congruent with their needs. The dissonance between the [pressured outcome] and the need necessitates modifying the [pressured outcome] or taking leave of the environment. If the choice of leaving the environment is not available, stress and discomfort result. (p. 11)

For example, after declaring that she would need to commit suicide before disability pressures her into a nursing home, Hillary H. eased her dissonance with a compromise idea: "Have they got a gay one? . . . That would be a blast! We could sing and dance and change our diapers together! Who would care?" In fact, during the interviews, 4 participants expressed interest in lesbian retirement communities or nursing homes.

In contrast, Hillary explained her perception of nongay nursing homes, "I would hate to get to the point where I didn't know if I was clean or dirty . . . and damn those nurses. Why don t they change their clothes for them?"

When discussing her research on the importance of feeling at home in one's surroundings, Hammer (1999) also employed continuity theory:

> A constant tension [exists] between the unsettling forces of change and the reassurance of continuity. . . . The formation of one's sense of self . . . is subject to the influence of external forces that at times serve to threaten its integrity. The struggle to maintain continuity in older age is concerned partly with the older adults' adaptation to the space they occupy. (p. 11)

In the cases presented in this study, each of these old lesbians has coped with social ostracism by forming and protecting a sense of independence and personal identity that was outside of the heterosexual mainstream. It should not be surprising, therefore, that they would seek to maintain that continuity through a dignified, self-controlled death rather than abdicating personal identity and surrendering to the heterosexist attitudes and institutions from which they had insulated themselves.

It should also not be surprising that these women would wish to live their most vulnerable adult years within lesbian surroundings. Hammer (1999) listed seven themes associated with "being at home: privacy, respect, affection, security, autonomy, commonality, [and] significance" (p. 13) and seven themes associated with "not being at home: intrusion, disrespect, disdain, fear, dependency, discordance, [and] anonymity" (p. 13). The latter themes were common among this study's 10 old lesbians when describing their general histories as lesbians and, specifically, their histories of interacting with the health care system.

Patient-Medical Provider Relationships

Health-seeking behaviors. White and Dull's (1997) study of lesbians' health seeking behaviors and health risks identified four conditions that increase the probability that lesbians would seek medical treatment soon after onset of symptoms: (a) easy access to health care, (b) easy communication with the primary care provider, (c) comfort with discussing depression, and (d) comfort with discussing menopause. Likewise, Valanis and colleagues (2000) suggested that trust between patient and provider is necessary for gathering accurate histories and assessing health care needs.

Hillary H.'s case study illustrates these findings and suggests that both family and personal experiences might lead to delayed health care. As one who was "poverty raised," Hillary believed that health services were for important people. Her family's primary method of coping with illness was self-diagnosis, self-treatment, and hiding symptoms. Hillary's mother hid stomach cancer symptoms, telling the family she was on a diet. Treatment received too late and with little money forced teenaged Hillary to have to dress her mother's incisions. Her early experiences might have influenced her health care habits. As an adult, Hillary tended to use outside resources only during emergencies.

In addition to their hiding symptoms and delaying health care, inattentive physicians put Hillary's family at risk. After Hillary discovered that her 16-year-old daughter, Pam, was hiding lupus symptoms, she took her child to two doctors. One dismissed Pam's weight gain as junk food related; the other dismissed the symptoms as a psychosomatic response to assumed sexual intercourse. Hillary delayed searching for a competent physician until Pam nearly died. Good care and good insurance worked in tandem to save Pam's life. A medical subcontractor attempted to cover up liability when an untrained staff and faulty dialysis machines nearly killed Pam. Hillary's partner Gail advocated for both Pam and Hillary, but delayed her own health care when she found a lump in her breast.

Hillary also hid her own health problems. As a child she memorized the eye chart so that the school nurse did not detect poor eyesight. Her father treated her constant leg pain, a probable side effect of rheumatic fever.

Her mother's early death left Hillary naive about reproductive matters. Because she had been raped several times, Hillary was reticent to put her feet up in stirrups in a gynecologist' s office. Therefore, after her children were born, Hillary did not consult a gynecologist for 21 years. Consequently, she did not know that her vaginal bleeding was excessive, requiring a hysterectomy.

Even at the time of the interview, Hillary avoided gynecological examinations. Lesbians in Rankow and Tessaro's (1998) study were less likely to receive Pap tests during the previous year if they had experienced discrimination in the past. Hillary was too embarrassed to ask her doctor if her hysterectomy left her with her cervix. Even if she does have a cervix, Hillary believed the hysterectomy and not having sex with men prevented cervical cancer. However, cervical neoplasia can occur in lesbians who have never had intercourse with men (Rankow & Tessaro, 1998). Hillary was old when she received her first mammogram, and she would rather die without knowing if she carried the genetic marker for breast cancer.

Hillary's delayed health care, her belief that hysterectomy and not engaging in heterosexual sex prevents cervical cancer, and hesitancy to speak to doctors about personal matters are all high risk behaviors which researchers have identified in the lesbian population (Aaron et al., 2001; Brogan, 1997; Brotman et al., 2003; Clark, Landers, & Linde, 2001; Cochran et al., 2001; Dean et al., 2000; Diamant, Wold, Spritzer, & Gelberg, 2000; Eliason, 1996; Johnson & Palermo, 1984; Matthews et al., 2004; Mays et al., 2002; Rankow & Tessaro, 1998; Roberts et al., 1998; Stevens, 1992; Valanis et al., 2000; White & Dull, 1997; Wojciechowski, 1998; Woolf, 2001). Hillary brought to her patient-provider relationships a long list of other influences: Some doctors who would not take her seriously; her family history was one of hiding illness; her past and present poverty had led her to assume, and sometimes rightly so, that treatment was not available to her; and she had outlived her expected life span, so was not keen to prevent life-threatening diseases.

About her interactions with doctors, Hillary explained:

> Doctors have a habit, still: They talk down to you because you're a woman, and they talk down to you because you're a minority. And sometimes, I get so mad I just want to spit. So, I have to hurry up and tell them what I do for a living. . . . Fortunately, I've got an interesting group of doctors. . . They're pretty patient, so I ask questions for myself. But before, I didn't ask very many questions.

Continuity theory. The continuity theory of normal aging came into play when examining these individuals' relationships with their providers. Continuity theory surmises that an old person's way of dealing with changes will be to apply "familiar strategies in familiar arenas of life" (Atchley, 1989, p. 183), thus allowing change to occur without tremendous turmoil. In Hillary's case, she appeared to have continued her lifelong pattern of delaying or avoiding health care interactions.

The continuity of Hillary's health care strategy included not coming out to her health care providers, even though she believed that "our lifestyle is different, and some of the things that they're worried about and examining for are not even going to happen . . . [such as] infections and diseases." She continued a strategy of remaining closeted despite her belief that her young, "enlightened" doctors would accept her and despite a positive earlier experience. Gail and she were out to their doctor.

> That was the first time that I was comfortable with a doctor, and we did all of our appointments together. . . . 'Cause I never told a doctor that I was a lesbian. . . . I didn't have to hide anything, and I could say whatever I felt like saying.

Like Hillary H., Gloria G. did not know if her surgeon had left her cervix intact during a hysterectomy surgery in 1977. Until two years ago, doctors had performed annual Pap tests. Her doctor then told her she did not need the test because she had had a hysterectomy. Gloria did not ask if the Pap tests were previously performed on noncervical tissue or if the cervix was intact but the doctor believed the hysterectomy would prevent cervical cancer. Gloria stated that she was not good at asking doctors questions because she did not go to doctors as a child and because she wanted to finish her appointment and get on with her day. About a skin rash, Gloria G. stated that doctors "never know anything. They lay a lot to the door of stress."

As with Hillary, Gloria believed that coming out to her doctors "might change their diagnosis or their interpretation of information that I might give them if they realize that my sexual situation is not like they think it would be." As a teacher, she concealed her lesbianism to prevent loss of her career. Although she retired, she thought coming out to her provider could open "a can of worms," such as loss of her health coverage. In short, Gloria did not thoroughly trust doctors to maintain confidentiality and to know, or perhaps care, about the etiology of her symptoms. Her strategy of hiding her orientation had worked in the past and, she felt, would continue to work for her.

Lesbians in Saulnier's (2002) study disagreed about whether or not a provider should chart one's sexual orientation. Advantages would be not having to be asked irrelevant questions and insuring recognition of one's partner in health care considerations. The primary disadvantage would be the potential for confidentiality breaches. However, the study participants agreed that the patient, not the doctor, should decide if her sexual orientation should appear in the medical records. Old lesbians might be more likely than younger lesbians to remain closeted or to prefer that their orientation is not documented (Wojciechowski, 1998).

Freida demonstrated continuity between her early life experiences and her health care seeking behaviors. As a child, Frieda was responsible for making all dentist and doctor appointments for the family, as well as for driving the family to their appointments. Frieda believed in seeking health care at the first sign of a problem, then following the doctor's advice, including exercising. From her early adulthood, she underwent annual physicals. She had never directly come out to her physicians. When doctors asked, "Do you have any problems with intercourse or anything?" she simply answered, "No."

However, continuity theory "assumes evolution, not homeostasis, and this assumption allows change to be integrated into one's prior history without necessarily causing upheaval or disequilibrium" (Atchley, 1989, p.183). Several times during the interview, Frieda spoke of wanting to try new approaches to her life. She was beside her younger ex-lover, when Casey was forthright with her providers about her lesbianism. These experiences gave Frieda the courage to consider doing the same. Coming out to a provider would mean "more freedom" for Frieda.

> [It would mean] I don't have to be particularly any way, when I'm there. I don't have to think about what I'm gonna say. I just say it. But, I really don't think about it. And, I just never say I'm a lesbian, but I talk, and I act and react like a lesbian. They'll say, "Who you live with?" I say, "I have a partner, a roommate." And everybody in California knows what *partner* means, you know.
>
> [When one doctor asked me if I lived with a man or a woman,] I felt kind of glad. [I thought] this is my chance without actually saying *the L word*. . . . So, she doesn't have to worry about . . . having to ask me about certain intercourse things. . . . Let's see if I can [come out] the next time I'm interviewed . . . by this new doctor that I have.

Feminist theory. Feminist theory (Jaggar & Rothenberg, 1993; Erwin, 1993) proposes that while women are equal in value to men, women's needs, including health care needs, are not the same as men's. Likewise, while there is obvious overlap, the needs of the old are different than those of the young, and the needs of lesbians differ from the needs of heterosexual women and of gay men. Therefore, feminists believe that equal health care delivery and research would not be a situation in which all persons have equal access to the same health care, but one in which all persons have access to health care that meets their needs equally (Siegal, 1994; Saulnier & Wheeler, 2000).

One barrier to this goal is the prevalence of sexism among physicians (Schoonmaker, 1993). Hillary H. speaks of being talked down to because of her sex and race, while Bernie B.'s history of physician disrespect started as a four-year-old. Because one side of her body has always been smaller than the other side, her doctor would show her off to his peers by projecting a glaring light onto her naked body in order to cast her misshapen shadow onto a wall.

Many bad doctors hide among the good, Bernie believed. "I think that as a woman, you are treated as material for pornography with some doctors." She cited the dermatologist she consulted at age 19. In lieu of billing her, the doctor told her to strip naked. He stared at her as she turned around. Years later, a dermatologist showed off her breast rash to a colleague as if she were "some kind of nonhuman or freak." Another doctor blamed Bernie for her husband's ulcer, saying, "Behind every ulcer there's a woman."

Provider characteristics. According to Bernie, a good doctor respects her time, listens, wants to talk to her, has a broad range of experience, treats her/his patients as equals rather than "father knows best, "approaches each problem with an open mind, and is willing to search for the source of the problem. "It's personal dignity and the feeling of trust that you're getting adequate care." When necessary, Bernie changes health plans in an effort to find good primary care physicians and specialists.

Allison saw the same gynecologist for 20 years, since before her divorce. Although the gynecologist helped two of Allison's lesbian friends to conceive through insemination, Allison was reticent to come out.

> I'm moving on. And what is the point of getting into all this when my health concerns are not related to my sexual orientation? . . . I mean, a gallbladder is a gallbladder, whether you're a lesbian or a straight person. . . . She's not a good enough physician for me, so . . . why even get into this?

According to Rosenfeld (1999), Allison's response was typical of those who came out before the gay liberation era. Because she understood homosexuality-as-stigma, she compartmentalized her lesbianism into a manageable and separate segment from the rest of her life.

Although not conveniently located, Allison remained with her gynecologist.

> She's easy to talk to. . . . I know some MDs who treat patients like children. . . . She's entirely fair in her billing practices. She will speak to me on the phone and not charge me phone time, and she's a nice woman. I mean, there's a certain loyalty. I've been with her all these years, and she's now beginning to lose clients, because Medicare will no longer pay for annual physicals.

Opinions differed among the participants as to the value of a doctor's age and sex. Hillary H. believed her young doctors were more aware of new treatment techniques. She was more comfortable with young doctors because old doctors are "stiff, and they're set in their ways." She thought she could and probably should talk frankly with the young physicians, but personal issues were embarrassing for her.

Esther E.'s mother had chosen a doctor who made house calls. Esther described him as "young, brash, . . . the back-slapping kind, and he was fat and handsome and thought he was the world's blessing to old ladies. . . . I mean, she could have been his grandmother. And his entire manner: much too jovial." Esther despised the man for his cocky manner and for continuously pressuring Esther to approve life-prolonging treatment for her mother. She wanted him to respect her desire to carry out her mother's wishes to not be kept on life-support.

Despite a long history of numerous sex partners, Esther never came out to a health care provider. "I don't volunteer any information, let alone sexual information. . . . I consider it irrelevant."

Josephine J. was out as a lesbian to the man who was her doctor for 50 years, and she gave him her video about her life as an old African-American lesbian. Ilene I. and Bernie B. also liked old doctors. In general, Bernie preferred female to male doctors and old to young. She was forgiving of the old doctor whose hands trembled as he cut out a malignant mole from her face. Old doctors "have a lot of experience, and they can kind of pull out something, you know, that will work and might be old fashioned."

Ilene I. respected her old physician's opinions. "He's the kind of a doctor you can talk to easy. You know, you don't feel a strain to talk to him . . . to ask him questions that you think are kind of silly to ask." She asked him about the possibility that she might contract AIDS from having sex with a woman whose husband had AIDS. He brushed her off, albeit with humor and professionalism, telling her that she should not worry so much about AIDS at her age.

Ilene's dilemma was not uncommon among older lesbians. Lesbians often remain sexually active as they age and might experience off-time life events (Slusher, Mayer, & Dunkle, 1996) including coming out in later life after their husbands die (Poor, 1982). Yet, providers such as Ilene's might dismiss old lesbians' sexuality concerns because they do not view old people as sexual, the risk of sexually transmitted diseases

(STDs) is lower among lesbians (Aaron et al., 2001; Diamant et al., 2000; Matthews et al., 2004), or they assume an old woman will die of something else before she dies of a sexually transmitted disease.

Frieda requested that her large HMO place her with a black female primary care physician in order to vicariously live her thwarted dream of becoming a doctor. The HMO assigned her to a Chinese woman doctor instead, but Frieda was satisfied with her. She appreciated that her HMO automatically contacted her for her annual checkup appointments which included a Pap test, a complete blood count, and whatever the doctor deemed necessary for a woman her age.

Gloria G. chose her doctors by convenience rather than characteristics. She was content to accept whomever the HMO assigned to her. When Deborah D.'s partner of 39 years had stomach cancer, Deborah posed as her sister to visit her in the hospital. Because her primary care physician had retired, Deborah went to the doctors who serviced her retirement center clinic.

Personal risking theory. Hitchcock and Wilson (1992) developed the personal risking theory to address elements involved in forming these lesbian patient-provider relationships. Personal risking consists of a two-phase social process. The *anticipatory stage of personal risking* involves the imaginative strategy of *imagined scenarios*, in which the lesbian imagines what will happen if she discloses her sexual orientation. For instance, as previously mentioned, Gloria G. imagined that her HMO may breach confidentiality resulting in loss of her health care coverage (Saulnier, 2002). Frieda F. imagined that she would feel freer to speak candidly to her physician.

Cognitive strategies include *formalizing* and *scouting out*. Lesbians can formalize their relationships using powers of attorney to help to insure that their partners will have decision-making rights in case of severe illness (Hitchcock & Wilson, 1992). All of the interviewees have formalized their relationships with their partners or other fictive kin through wills, medical powers of attorney, durable powers of attorney, and/or living wills. Deborah D. included a formalized trust fund for her fictive daughter's children, and Josephine J. assigned legal guardianship to an old neighbor and power of attorney to a young lesbian friend.

A lesbian will *scout out* information about the provider, through networking or questioning the provider, thus seeking subtle clues about the provider's degree of acceptance of lesbianism (Hitchcock & Wilson, 1992). Allison A. and her partner planned to move to another town for retirement. Allison decided she would ask people from the LGBT organizations to refer them to lesbian-friendly doctors to whom they might feel comfortable coming out. Many lesbians in the Hitchcock and Wilson (1992) study reported they would not visit a provider if they lacked the opportunity to scout out the doctor. To some extent, this may explain the aforementioned significant delay or neglect of health care among lesbians.

Hitchcock and Wilson's (1992) *interactional phase of personal risking* involves four *interactional stances*. *Passive_disclosure* is the process of laying subtle hints that an alert provider might pick up on. When she became depressed because her partner was leaving her for younger woman, Kim K. employed passive disclosure in an attempt to explain her depression to her primary care physician.

> I started, in so many words, I guess, I did [tell her I'm a lesbian]. I told her I was depressed. . . . I said, "Well, I have a friend, and I lost them." Just put it like that. General explanation. And I said, "My friend has been my friend for 43 years. We're not friends anymore. And, I feel really bad about it." She was . . . trying to give me encouragement. I can't really say [if the doctor understood the nature of Dee's and my relationship]. . . . She may have misinterpreted. She may not have. . . . No follow-through to reassure me that she really understood. So, I can't really say.

Passive nondisclosure is responding in such a way as to avoid the issue of lesbianism (Hitchcock & Wilson, 1992). Esther E. avoided the subject by remaining closed off in general. "I don't volunteer any information [to my doctor], let alone sexual information."

Active disclosure occurs when a lesbian chooses to state her sexual orientation or feels coerced into revealing her orientation (Hitchcock & Wilson, 1992). Ilene I. actively disclosed issues of concern for her as a lesbian when she asked her doctor if she might be at risk for AIDS because she was having sex with a woman whose husband had AIDS. When her doctor asked directly, Deborah D. acknowledged that she lived with a woman. He replied, "I've always kind of wondered about you." Generally a closeted woman, Deborah wondered which of her traits would lead him to think she was a lesbian.

Active nondisclosure occurs when the lesbian pretends she is heterosexual or does not contradict the provider's assumption of her heterosexuality. Whenever doctors asked Frieda F. if she had any problems with intercourse or anything, she said, "No."

Frieda explained that she habitually deflected conversations that might reveal her orientation. "In Shiloh, when I was a young woman, a young lesbian, you practiced what you said, you know, because you were not out and you weren't about to be out."

The interviews with Kim K. and Deborah D. revealed a method of conversing that was so filled with ambiguous terms and phrases as to be unintelligible at times. They both used the coded pronoun 'em instead of definitive pronouns that would reveal gender or number. The following is part of Kim K.'s phrase-coded response to the question, "What term do you use to identify your sexual orientation.?"

> If we were in a group among ourselves. Then, it wouldn't have to be specifically specified what they were. Because they were there, because we all were. Had the common interest. See what I mean? That's why they were there. But if we were with the heterosexual group, mixed in, then you would say, if you were able to identify anybody that was homosexual, then it would be specified. . . . [that] I think they are *in the life*.

It is with this practiced awareness that many old lesbians enter their providers' waiting rooms. The lesbian *scans* the environment for indications of safety or risk. After disclosure or nondisclosure, she continues to use her observation skills to *monitor* the process. Regardless of her stance, her goal is to safely receive the most appropriate treatment in a manner that is not diminished by the fact of her sexual orientation (Hitchcock & Wilson, 1992).

Other studies indicate that lesbians might not be over-reacting in their application of personal risk theory. In a 1993-94 study of 186 female Canadian medical residents, 9% of the women complained of sexual orientation discrimination. The residents also reported unwanted advances, sexist jokes and learning materials, and sex discrimination (Cook et al., 1996). For these reasons, lesbian health care professionals can also employ personal risking theory. Thus, while Kim K. dropped hints that she was lesbian and wondered if her doctor might be lesbian, her doctor's apparent unresponsiveness might be because she was not lesbian or because she would not risk revealing her lesbianism to a patient.

Further research might reveal the personal risking theory can be applied to nonmedical situations in which a woman may face discrimination if her lesbianism is revealed or suspected. For instance, although their doctor knew them to be lesbians, Ilene I. posed as her partner' s sister while visiting her in the hospital, taking care of her partner's end-of-life affairs, and dealing with the customers who knew them both during their 38-year relationship. She chose this deception because "it's none of their damn concern. . . . I like that privacy, and I like that respect that goes with it."

Sympathetic gatekeepers. Gatekeepers, those professionals who help or impede access to health care, can guide the patient through bureaucratic barriers. When Allison A. learned she would have to pay $110 out of pocket for her annual pelvic exam and Pap test, her gynecologist's office worker cued her to claim a "weak bladder" so that Medicare would cover the exam.

Likewise, while skiing in the Alps on a business trip, Esther E. broke her hip. The doctor recorded the injury as a slip on the ice so that her business travel insurance would cover treatment and therapy. Also, Esther required injections to treat her enlarged spleen, but she could not imagine giving herself shots. Her nurse asked her leading questions in order to document that Esther complained of poor vision and trembling hands. In this way, her HMO would pay for a home health nurse to perform the injections. Considering the difficulty of navigating certain aspects of the U.S. health care system and the hesitance to come out that many of these participants expressed, old lesbians might fear that their providers would not be as likely to help them through the bureaucracy if their lesbianism were known.

Psychosocial Health Issues

Patient-mental health provider relationships. Not surprisingly, only 4 subjects in this study addressed the issue of formal mental health services and only 1 reported receiving professional counseling. Although indications are that young lesbians are more likely than heterosexual women to seek mental health counseling (Saulnier & Wheeler, 2000), the old women in this study were from an era in which one rarely sought formal physical health care, much less mental health care (Brotman et al., 2003; Herdt et al., 1997; Rosenfeld, 1999). Interviewees explained that personal issues were kept personal, and a person was expected to rally after a crisis without outside help. Also, mental health care insurance was not available.

Allison A. could not purchase mental health coverage because she had received many years of therapy. She did not speak of the reasons for therapy. The predominant conflict expressed during her interview was her love-hate relationship with the Roman Catholic Church, including the need to stay closeted to protect the livelihood she derived from the church.

Esther E. never received psychotherapy. She explains, "I pulled myself up by my bootstraps." When her mother was hospitalized on life supports, Esther broke down and wept for the first time in her life.

> [The social worker] more or less encouraged me to break down. . . . I needed somebody to, well, literally or whatever, pat my back. Just to listen. Just to be a support. And she did; she was great. . . . She said, "Just let go, Esther." And I did. By that time I had made my decision. . . .
>
> [Breaking down felt] peculiar. . . . It was . . . something I had never done.

> I wouldn't have done it if she hadn't invited me. She saw the need. I appreciated that. It hasn't happened since. I hope it'll never happen.

Although Hillary H. counseled college students for a living, she did not seek counseling when her lover of 7 years died from breast cancer. Besides her reticence to speak to a stranger about personal matters, "money is a very important thing that we've always been short of! In those days, your insurance didn't cover [psychotherapy], either. . . . I did all my grieving in strange and terrible ways." Because her student assistants thought Hillary an expert on psychological matters, they did not intervene or attempt to convince her to get professional help. However, they did cover her schedule for her when she was emotionally incapable of performing her duties.

Kim K., who was struggling with the breakup of her 44-year relationship, approached her primary care physician for antidepressants but found the side effects intolerable. Her doctor left it up to Kim to decide if she would like a mental health referral. Kim said that if she were to see a psychotherapist, she would reveal the nature of her relationship with Dee because "that's the only way I could get help. Somebody that's trained along that line that could tell me what I need to do." She would only see a woman therapist because "they have a better understanding. . . . unless it's a gay man. But, if it's a woman, it'd be easier for me to talk to, let her know my true feelings."

Of the participants in Saulnier's (2002) study, the great majority of lesbians preferred women counselor and about one third preferred lesbian counselors, but the women did not generally care about the race/ethnicity of their providers. Other important factors included counselors' positive attitudes about age, disabilities, size, weight, and food.

Dean and colleagues (2000) reported a 38% variance in depression rates among lesbians who were open about their lesbianism and who perceived that they had satisfying relationships and good friendships and/or family support. In comparison, Kim's relationship was dissolving, she was generally closeted, and she had developed few friendships because she had feared other lesbians might try to break up her relationship. Kim attempted to get moral support from her brother, but did not tell him that she needed him. While her fictive daughter was verbally supportive, the woman's husband was not. Her primary support came from a young lesbian couple a considerable distance away.

If Kim were to seek counseling, she would have to confront a mental health system that might not have evolved to meet her needs. Homosexuality as a mental illness was removed from the APA's *Diagnostic and Statistical Manual Of Mental Disorders* in 1973, but the diagnosis of *ego-dystonic homosexual*, a homosexual who is thought to be overly concerned about society's lack of acceptance of homosexuality, was not removed from the manual until 1986 (American Medical Association, 1996; Dean et al., 2000). Saulnier and Wheeler (2000) cited a 1991 study by Garnets and colleagues of 2,544 members of the American Psychological Association (APA):

> [The study] found that practice with lesbians and gay men was biased, inadequate, and inappropriate. This sample included practitioners who believed that homosexuality is a psychological disorder, attributed psychological problems to sexual orientation, failed to recognize that symptoms can be negatively influenced by a clinician's bias, assumed that all clients are heterosexual, inappropriately focused on sexual orientation as a therapeutic issue, and discouraged lesbian and gay orientation. It also included those who trivialized the lesbian or gay experience or orientation, transferred lesbian or gay clients to other clinicians, did not understand the development of identity in lesbians and gay men, underestimated the consequences of the disclosure of sexual orientation and the importance of lesbian and gay primary relationships, assumed that

> lesbians and gay men have poor parenting skills, underestimated the effects of prejudice and discrimination, and sometimes taught inaccurate or prejudicial information to students. (2000, p. 412)

Another barrier to mental health care for old lesbians might be the tendency of managed care to reserve individual therapy sessions for short-term crisis intervention while funneling clients into group sessions to deal with chronic problems such as depression, coping with relationship breakups, and coping with disabilities. Except in metropolitan areas with large lesbian communities, the elder lesbian is not likely to find a therapeutic support group within her community. In theory, Kim may have benefited from participation in a therapy group of newly divorced women, disabled persons, or elders going through transitions. However, Swindell and Pryce (2003) concluded that the trauma of coming out as a lesbian might intensify the trauma of other emotional stressors, such as Kim's relationship dissolution. Other barriers to elder lesbians' access to mental health care can be lack of personal or domestic partnership insurance and high insurance copayments.

Informal and formal support systems. The importance of informal support systems for social, physical, and emotional well-being was the most commonly discussed health care issue among the 10 old lesbian interviewees. While heterosexual elders tended to first turn to relatives in time of need, these lesbian elders included a significant number of fictive kin in their definitions of family. Persons who function as family regardless of legal relationships are sometimes called one's *family of choice* (Herdt et al.1997).

Commonly, former lovers remain as family of choice or as close friends (Jacobson & Samdahl, 1998; Woolf, 2001). While the literature does not address causation, this phenomenon could be attributable to a combination of several factors. A lesbian's social options within her geographical area might be more limited than those of heterosexuals. Ostracism from heterosexist society might strengthen the friendship bonds even when romance has waned. Also, if society and/or biology program women to create and protect their families and communities, a lesbian couple doubles this inclination.

Pauline was Esther E.'s only long-term relationship. The two have remained friends for many years, and they vacation together. Josephine J. and Sandy were lovers and then roommates for 30 years. When city redevelopment demolished their home, they moved to separate retirement communities.

Although her sister was alive and her mother was in a nursing home, Frieda F. considered her ex-partner Casey to be her family. They still shared an apartment together. Casey was named the proxy for Frieda's medical power of attorney. She will inherit all of Frieda's assets. Regarding her health care future, Frieda envisioned herself with Casey.

> We have no family, because we have no children, you know. . . . So, Casey is the only family I've got. And I'm the only family she's got. She's got two brothers [who are] straight, and they're all wrapped up in their families. . . . So, we're gonna take care of each other. . . . And, I think this is what lesbians do mostly.

Because old lesbians' various relationships often function outside the larger social context, vocabularies might not be available to define one's place in society and one's social support systems (Shenk & Fullmer, 1996). For instance, if Deborah D., Hillary H., and Ilene I. had been married to their partners, society would have accorded them the respect and benefits given to widows. Their relationships of 39 years, 7 years, and 38 years, respectively, were clearly more than friendships, although *friend* was the most common term these women used for their partners.

Similarly, Deborah D. and Kim K. reared girls. Within heterosexual constructs, the relationships would have been called *stepmother/stepdaughter* and *mother/daughter*, respectively. Yet, the two elders had no vocabulary for their relationships with the younger women. Deborah insisted that she had no family, although a brother was still living. She stated clearly that Kelly, her lover's daughter who lived with them from ages 11 through 20, was not her family. Deborah explained, "I don't have any family. Well, I do, but I'm a stranger, because of the situation [of Deborah and Peggy being lesbians]. Peggy's daughter, she is beneficiary to everything." She would not let Kelly's descendants call her *Grandma* "because I'm not! . . . They call me *Deb.* If I was related to 'em, it'd be different, but I'm not."

Kelly, currently 54 years old and a great-grandmother, was only told the couple were roommates. Deborah believed it was unfair to children to be raised by homosexuals because of the negative impact of societal stigma. Yet, Kelly functioned as family. She lived in her elder's other house, and although Deborah liked to work independently, Kelly helped Deborah when necessary and was named proxy for her advance directives. Kelly and her descendants inherited all of Deborah's assets.

The subject's obituary identified Kelly as her niece. Deborah had pretended to be her lover's sister when the latter lay dying in a hospital. Wojciechowski (1998) pointed out that old lesbians commonly maneuver within the health care setting as sisters or cousins because it opens doors restricted to socially sanctioned relatives and does not force the couple to come out, risking inferior care.

Although the doctor knew that Ilene I. and Shirley were partners, Ilene still posed as her sister when Shirley was hospitalized and when she took care of her after-death affairs. Ilene stated that she liked the privacy and the respect that she might have lost if they had been open about their relationship.

Kim K. and Dee reared Heather from infancy, but they never adopted her. "We took *care* of her. We took *good* care of her. We *loved* that child. Love her to this day. . . . To this day, she is my friend." The couple was also rearing Heather's son Michael. Still, society did not offered Kim terminology for these loving relationships. During the interview, Kim referred to Heather as "that child that I raised." She called Michael by name or referred to him as "that boy" or "this little boy." Yet, like Deborah D., Kim bequeathed funds to her fictive daughter for her children's educations.

The literature frequently addressed old lesbians' limited social support networks as well as the risks involved in coming out within heterosexist institutions. A nonrandom survey of Gay and Lesbian Medical Association (GLMA) members revealed that 67% of respondents believed that they had witnessed lesbians and gays receiving poor care because of their orientation (Dean et al. 2000). Thus, for many old lesbians, coming out at the heterosexually oriented doctor's office, senior citizen center, nursing home, church, or bridge club is tantamount to risking social ostracism, vulnerability to rumors, hostility; avoidance of touching; poor services, loss of access to services, or even physical assault (Brotman et al., 2003; Hitchcock & Wilson, 1992; Saulnier & Wheeler, 2000; Swindell & Pryce, 2003; White & Dull, 1997). The irony is that many lesbian elders seek to avoid these negative consequences by avoiding the heterosexist institutions. Hence, they might receive delayed health care or no health care in their efforts to avoid biased health care providers. They might avoid ostracism at senior centers by not participating in the senior programs. Some might not avail themselves of in-home care services so that they would not be vulnerable in the face of workers' prejudices.

Analysis of participants' interviews revealed a pattern of restricting informal support systems. Some did not associate with other lesbians for fear of the women coming between them and their partners. Others did not associate with obvious lesbians and gays for fear heterosexuals would assume them to be lesbians. Some believed they had nothing in common with heterosexuals, especially with men. With each chosen restriction, the old lesbian had fewer people to call upon in a crisis or to depend upon to help her in the event of chronic illness. Yet, as stated above, old lesbians have often been reticent to call upon formal support systems for fear of discrimination or because they might feel like outsiders.

For better or worse, continuity (Atchley, 1989) is at work. These women tended to use the isolation strategies that worked for them when they were younger. When as a child Esther E. asked her mother for advice, her mother told her to solve the problem herself. Thereafter, she functioned as a self-sufficient loner. As a young single woman, Esther E. felt unwelcome in her lesbian community because "lesbians come in pairs," and she was considered a predator. As an old lesbian, Esther would consider a lesbian retirement community, if available, provided she were not required to socialize.

In the emotional fallout following Deborah D.'s expulsion from nursing school for being a lesbian, she moved to the West and cut off all communication with her family. In middle adulthood, she and her partner cut themselves off from the lesbian community to insure that other women would not try to destroy their relationship. At the time of her interview, she had only limited, impersonal contact with heterosexuals, excepting for Kelly, the woman who acted as a stepdaughter. Deborah worked in the same office with her partner Peggy for 30 years. "We never went with the lesbian crowd. And we didn't really have anything in common in the workplace with people. So, [we] really didn't have a group of friends to fall back on [when Peggy got cancer]."

Although she prided herself on her independence, in an emergency Deborah would call upon Kelly, someone in her retirement community, or possibly someone from Women Over Fifty and Friends (WOFF), the lesbian social group with which she had been involved marginally for about a year. However, the people in her retirement community and WOFF were only acquaintances. Her only true friends were two gay men who lived an hour's drive away. They knew Peggy and her as a young couple. Young Kim, a "homebody," had five successive relationships with unfaithful women. She moved to the Midwest to be near her parents' home, but remained closeted. Kim and her partner, Dee, also shunned the lesbian community in order to protect their relationship. While Kim remained a homebody, her partner of 44 years began to go out at night, presumably to have an affair. "This [house] is my senior citizen's home. . . . Never have participated in anything outside of the home. If I'd of known it would come to this, I would have been more outgoing." Faced with the breakup that she sought to avoid through isolation, Kim was alone except for the emotional support of her fictive daughter and an out-of-area young lesbian couple with whom she might live.

Continuity could also be observed in the lives of those old lesbians who successfully established informal support systems. After her mother died, 12-year-old Josephine's brother helped to rear her. As adults, the home of Jo and her partner Sandy served as the social center of lesbian and gay African Americans. They helped many youngsters to get jobs or go to college.

> It comes back to you. 'Cause, see, I helped these kids when they were trying to strive to go to college. . . . We'd take them in until they could find a job. . . . We didn't have much to give them, but then, it didn't take too much.

Jo was sad that some of the young people she helped did not always show their appreciation by staying in touch with her. However, her life's continuity of intergenerational reciprocity was reinforced several years before the interview. A group of young lesbians, Jo's "girls," drew Jo into their circle and began watching after her needs. She readily accepted their gifts and assistance, and in return she regaled them with stories and offered them pieces of her 101-year-old wisdom.

The day before this interview, Jo attended a banquet in honor of elders. She offered a suggestion to Newsom's mayor: He should hold a reception before the banquet so that the generations could mingle instead of sitting at separate tables. She believed people who work with old people need to take the time to listen to their stories and find out who they are. Also, if young people would spend one or two hours per week or month with old people or "find someone you can help," the youngsters would learn invaluable life lessons that would help to keep them out of trouble. In addition, the interaction and assistance would help old people to stay healthy.

Jo's belief in intergenerational support continued beyond her death. She and her girls established the Josephine J. Center, a residential and social services center for LGBT homeless and at risk youths in Newsom. Also, Jo donated memorabilia to the new LGBT museum in Ann Arbor, Michigan.

Frieda F. credited her relationship with her younger ex-lover Casey for helping her to be more open about her lesbianism. She found social support among younger lesbians to be refreshing.

Allison A., who left a 37-year heterosexual marriage to come out, repeatedly praised her lesbian community for its support during her coming out process. She was deeply closeted because her business supplies the Catholic Church. Her interracial intergenerational committed relationship enriched her. Although not active in lesbian organizations, her personal contacts were strong. She financially supported the LGBT center and would turn to it for help rather than to her church.

Ilene I. enjoyed participating in her local LGBT community. She stated that not having a driver's license "has stymied the devil out of me!" She was unable to worship at the Metropolitan Community Church, browse the LGBT bookstore, or visit friends out of town. She read in the church bulletin that a young lesbian couple held weekly church gatherings at their house within a five-minute walk from Ilene's home. She had not gone there because "I feel out of place . . . because of age." Even though the younger women did not talk down to her, she felt self-conscious. Ilene seemed to be thinking out loud when she said, "Like, if I got to know those girls better, maybe I'd get over [myself consciousness]. But, I haven't yet. But gee, it's just a five-minute walk. It'd be a nice social meeting."

Although she generally had a "pretty good attitude," Ilene complained, "my world has gotten pretty narrow." Fear of harm was one reason Ilene hesitated to participate in a neighborhood activity that might identify her as gay.

> You read in the paper all the time, like those two [lesbian] girls that was killed in Medford and the two boys that was killed in Redding and the scrapes that they have in San Francisco. I'd just as soon just keep my mouth shut and not say one word to anybody.

Bernie understood the importance of psychosocial support in healthy aging. In order to grow old successfully, she believed one should have "someone that you're living with" as a "synergistic kind of thing" to "keep each other going. After 27 years of heterosexual marriage, Bernie came out in 1985, 16 years after the Stonewall rebellion. The post-Stonewall homosexual-as-status perspective (Rosenfeld, 1999) extended beyond Bernie to her family, to whom she was out. From the beginning, her grown daughter thought having a lesbian mother was "quirky" in the positive sense. When asked to identify her family, Bernie listed Beth, with whom she had had a commitment ceremony, and her "blood relatives," who included her children and grandchildren and her Southern Californian brother and parents. Although Bernie introduced Beth as her partner at her father's family reunion, "it's not like they got it."

While Bernie projected a positive identity as an old lesbian, she had to weigh personal risks. She was not out to her doctors. In the couple's small retirement town, she would only come out if she wanted Beth's involvement during a life-threatening situation. She believed that she and Beth would be able to "melt into the landscape" because "unless you wear a leather jacket or something, pierce your eyebrow, I think you get away with a lot as you get older. We're just these sweet old ladies, . . . not threatening."

In this respect, Bernie hailed from the prior-to-Stonewall school of thought in which competent homosexuals were those who successfully manage "information control devices" (Rosenfeld, 1999, Stigma ¶ 1) such as passing as heterosexual. In contrast, those who wore leather jackets and pierced their eyebrows were discredited as incompetent. This tension between pre- and post-Stonewall ideologies was not uncommon. Having lived through a great shifting of social attitudes, Bernie could draw upon a wide array of perspectives to help her to age successfully as an old lesbian (1999).

As Rosenfeld (1999) pointed out, old homosexuals can ostracize obvious lesbians and gays so as not implicate themselves. Outside of a strictly gay setting, Deborah D. would not associate with obvious gay people. If a masculine lesbian were walking her dog, Deborah might exchange staid pleasantries as she passed. Deborah had "no urge to flaunt it." She considered gay parades, gay marriages, and the open discussion of the subject in the media and between gays and straights (heterosexuals) as unnecessary. As straights grew informed about homosexuals, it became more likely that people would single her out as a lesbian.

Although Jo was out to her doctor, she believed that most providers could not identify a lesbian. "I don't know. I don't think they would know it, unless somebody would tell them . . . unless their dress is so extreme that they would know it. They wouldn't know it." She used to date women from church, but was not sure if other lesbians would have recognized her as such. She believed she was more obvious in her old age. "People in church are lesbians too. . . . Maybe a long time ago they wouldn't know [that I was a lesbian], because I had my hair. I didn't have short hair. But, maybe now they'd know it, because I wear mostly slacks and my hair's short." At age 101, this homosexual-as-stigma lesbian has changed her outlook to fit the times.

Some participants excluded from their social support systems those lesbians who were obvious and fellow lesbians who might have threatened their relationships. Some also excluded heterosexuals and their families of birth. Swindell and Pryce (2003) pointed out that coming out involves losing one's reference groups such as place in the birth family, church, and coworkers and losing the mutual sense of reality that was once shared with these people. Coming out also involves losing control over the way others might respond. Therefore, it is not unusual for old lesbians to never come out to their families of birth.

Despite, or perhaps because of, her excellent relationship with her birth family, Gloria never came out as a lesbian to them. As a young adult, she could not afford to go home often. When she brought girlfriends home with her, their closeness blended into a family of

> huggers. . . . I never had to share. . . . [It's a] scary thing. It's an admission that would have caused *them* consternation, not me. . . . And also, I've always adhered to the situation that if they don't ask, they don't want to know. So, why burden them?

Asked if she felt they may be waiting for her to tell them, Gloria commented, "Nope. I choose not to think that. . . . All my justifications are mine. . . . But, I never felt any less loved. . . . I don't think it would've changed anything."

Gloria supposed that her mother might have blamed herself for Gloria's orientation. Then she mused, "Actually, I've never really thought it over. Maybe it is my own denial or hiding or not. I don't know. . . . I didn't tell them because I didn't want to bother them, hurt them."

While coming out could have hurt people, Gloria also realized that her closeted life might have hurt others. For instance, when relating weekend activities to a coworker,

> I always had to change the words. . . and leave stories out. . . . I always had two lives. I had my work life and my personal life, not to say anything about my

> family life. . . . You learn. You adjust. . . . A woman's gotta do what a woman's gotta do. . . . You hope not to get too comfortable with the person so it should slip. And, I think I curtailed some of my times with straight people, too, because it was not worth the effort.

It is not uncommon for lesbians to compartmentalize their lives as Gloria did. They might form one social support system for people who know of their orientation and a separate one for people who don't know (Jacobson and Samdahl, 1998).

Five of the old lesbians mentioned a dislike for socializing with men, though some enjoyed friendships with gay men. Esther E. had a few straight men friends who were artistic and "not mainstream. . . . I find most men fairly intolerable. . . . Because they're intolerant. Because they're insecure and because I'm not into beer drinking, and I'm not into ball games."

In the face of chronic illness, Bernie would prefer a lesbian support group, but she would consider going to a "mixed" group "if there weren't too many men in it." Bernie believed she would come out to this group to test their supportiveness.

> I think it's fun to stir people up. You know, if you're sick, and everybody's sort of feeling sorry for you as well as for themselves, and then . . . people would have to think how they felt about gay people. And if your support group could not support you because they didn't approve of your lifestyle or whatever, then you wouldn't want to be in that support group.

Besides restricting interactions with individuals, old lesbians might sever ties with community institutions such as membership organizations and churches. Nine out of 10 subjects identified with one or more religions. Few were involved with the church institutions because the churches know them to be homosexuals, because the women did not want to risk being found out and rejected, or because they did not respect their churches' anti-gay positions.

Gloria G. felt she was part of the reason that her partner, Maggie, was forced to retirement after 30 years as an associate minister in their Congregational Church.

> When you look at me living with her, I don't think anybody looks at me and doesn't think "lesbian" I think I'm very obvious, always have been. [Regarding her dismissal from her church, Maggie] was very hurt and still recovering from that, I'm sure. Don't think she ever will [recover]. We may never go to an organized church again.

Asked if she would ever turn to a church for any type of assistance or support, Gloria replied,

> I think I'd go to the LGBT Center before I'd go to a church. Not because I'm antichurch, but because I'm pro-me, and I can be me at the LGBT Center. I've never come out at church. People may think what they wish, but . . . my vocalizing was only in the choir.

Frieda F. counted three women from her Buddhist temple among her fictive kin. If plans with her informal support system did not work out, and "if I was a big burden on whoever was taking care of me, . . . then I would go in [a lesbian retirement home] and get professional help." Her second choice would be a Buddhist home, but a lesbian home would be "paradise." Ultimately, she was prepared to go into a straight nursing home, but she would have done so as an out lesbian. "At that age or whenever that time is, it won't matter. . . . It might get me a room to myself! . . . Where I wouldn't have to share a room. It might work to my benefit!"

Deborah D. would prefer living in a gay and lesbian retirement community, such as one she heard about in Florida, but she would not move to Florida. "That's too far away from Kelly and the kids. Although I don't see 'em that much."

Esther E. wanted to live in a lesbian apartment complex "that leaves you alone, and you're under no compulsion to participate. But, most gay people tend to be rather social, and they also come in pairs."

When the subject of retirement centers or nursing homes was brought up in the interviews, 4 subjects mentioned that they would like the institutions to be lesbian or lesbian/gay oriented rather than having to live in a heterosexually oriented facility. However, residential LGBT facilities are extremely rare in the United States.

In summary, old lesbians' informal support systems such as fictive kin and good friends can serve as a bridge to formal support systems such as churches, retirement centers, and nursing homes. Lesbian elders can be ostracized from the institutions that are formed to meet physical, emotional, or spiritual health needs. However, old lesbians can also remove themselves from informal heterosexual and homosexual social support systems. Doing so could protect them from ostracism, disrespect, or abuse but could also lead to few options when these women experience crises or become dependent.

Elder abuse and safety. The adaptive strategies that have helped old lesbians to survive heterosexist society–independence, social selectivity or isolation, delayed health care, closely guarded privacy, coded speech–can block outside intervention in cases of elder abuse (Cook-Daniels, 1997). Domestic violence appears to be less likely among lesbians compared to heterosexual couples or gay male couples. So, when such violence does occur, women's shelter personnel, law enforcement, and health care providers might not recognize the problems or know how to intervene (Eliason, 1996).

> The equation of homosexuality exclusively with sexuality does lesbian and gay male elders a grave disservice. It erases two key components of gay life that have everything to do with how well these elders are served by aging providers in general and by adult protective services in particular: their relationships and their social, psychological, and legal environment. (Cook-Daniels, 1997)

Dee was leaving Kim K. after 44 years together. Kim suspected an affair although Dee denied it. Tensions were high. One morning, Kim overheard Dee whispering and cooing to someone on her cell phone. The two old women wrestled for the phone. Dee pushed Kim, who tumbled backward and hit her head on a dresser leg. At the time of the interview, Kim still carried traces of her black eye. Kim stated that the couple had never before resorted to physical violence.

At times Kim felt she could "wring Dee's neck," but she depended on her faith to give her control.

> I have tried to keep myself stable. . . . I am filled with rage to the point I feel like I could kill and not feel one way or the other about it. And then, there are moments I go through like a solitude. . . . My senses come to me and try to take over . . . this turmoil going on inside of me. . . . I still have a certain amount of sane thinking. It goes back to religion. It goes to God. That gives me that stabilization. . . . All my life, I've been doing the golden rule. . . .
>
> I've also thought about . . . taking my *own* life. That's the one thing you won't be forgiven for. That's a drawback. You won't be forgiven.

Kim warned Dee:

> [Your] cup runneth over. . . . When . . . I didn't hit you, I didn't let that cup run over. I still have a certain amount of control. But, I had a strong urge to hit you as hard as I could. . . . Thank God, I didn't do it. Remember that!

Although she occasionally attended the Unitarian church, Kim never mentioned church as a resource for support.

Health care providers can fail to identify domestic violence as a cause of injury between two harmless-looking old women. Most such incidents are not reported (Faria, 1997). Kim did not go to a doctor. She planned to treat the black eye with cocoa butter when she was able to go to pharmacy.

After 44 years, Kim and Dee did not have the legal and social protections of divorce court, community property laws, and family mediators who are trained in diffusing the tensions between angry spouses. Moreover, it is highly unlikely that a closeted couple like Kim and Dee would consider calling the police, hiring a mediator, or filing suit to fight for property rights. To do so would add coming out to the list of stressors already in play. In a breakup such as Kim and Dee's that has its roots in declining physical health, the stress of coming out to authorities can exacerbate physical disability (Solarz, 1999) and deconstruct the ego resources that affect how one interprets and adapts to stressful events (Swindell & Pryce, 2003).

Studies indicate that lesbians may be more prone to stress-related depression than gay men. In turn, depression can lead to inertia and self-neglect, the most prevalent form of elder abuse (Cook-Daniels, 1997). Multiple sociological stressors, such as being old, ethnic minority, lesbian, and disabled, increase the likelihood of depression (Solarz, 1999). In addition, while Dorfman and colleagues (1995) did not find significant differences in depression among heterosexuals in one and homosexuals, "17% of the change in depression can be accounted for by change in social networks; indicating, as expected, that social support was a primary factor for depression among heterosexual and homosexual elderly" (p. 35).

Cook-Daniels (1997) reported that 79% of verified elder abuse cases involved self-neglect. Old lesbians' pride of independence can work against them because they tend to resist asking for assistance. The following example demonstrates how independence can lead to self-neglect and how a social support network can intervene without bruising the elder' s pride: While being treated for spleenomegaly, Esther checked herself out of the hospital against medical advice because her provider wanted to perform an unnecessary test. A loner, Esther E. did not easily ask for help, but she was too weak to drive herself on her errands. When two women who had offered their help arrived at Esther's apartment, she could not walk, was in "excruciating pain," and her voice and hearing were significantly diminished. They conducted Esther's business by telephone, then they discreetly called the director of the local LGBT center. Esther praised the director for helping her without taking over.

> She intercepted my phone calls. . . . She called the doctor. . . . She alerted a few other women to come here, and she grabbed my laundry and did it one day. And one other woman came and cleaned the kitchen floor because [the radiation treatment had given me] uncontrollable diarrhea. . . . Everybody offered to bring me groceries, . . . Them and they helped me with transportation. . . . She was very tactful. I mean, everybody knows that independence is very important for me. But, she saw where her help was needed. She didn't interfere.

She had acquaintances around the world, but Esther considered these women "friends in the true sense." Meanwhile, hospital staff called her several times to ascertain that she had notified the proxy for her medical power of attorney. "They were scared I wouldn't survive the weekend." However, the proxy was himself hospitalized.

While every participant except Bernie B. had protected themselves with legal documents such as medical powers of attorney and living wills, the proxies for Esther E., Hillary H., and Kim K. might not have been able to speak for them in emergencies. Hillary's proxy, her partner, was severely ill and living with her sister. Kim K.'s proxy was purportedly leaving her for another woman. A well-chosen proxy can help to ensure against abuse.

While the animosity between Kim and Dee sparked violence, Kim was also concerned that the other woman might be a con artist who wanted Dee's money.

Through her job, the woman could access Dee's pension files. "Con people have a knack for being able to turn you completely around, and you don't even realize it. And they definitely have those characteristics." In this instance, *they* was a coded pronoun referring to Dee's friend. Kim was also afraid that telemarketers would draw Kim into a scam. She tired of solicitors trying to manipulate her to get her money.

Substance abuse is also a form of self-abuse (Cook-Daniels, 1997) and can lead to serious physical and psychological illnesses and death. Reasons for substance abuse among old lesbians are probably as varied as those among old heterosexuals. Additional stressors can include an effort to cope with low self-esteem secondary to *internalized homophobia* (the fear of one's homosexuality), the stress of living in a heterosexist society, and a historic reliance upon gathering at bars (Aaron et al., 2001; Cook-Daniels, 1997; American Medical Association, 1996; Dean et al., 2000; Mays et al., 2002). Besides the self-abuse and the difficulty sustaining healthy relationships inherent in alcohol and drug abuse, old lesbians can become victims or perpetrators of alcohol and drug related crimes. Ilene I. spent seven years with a heroin addict. When she realized that her lover and her friends would "steal your eyeteeth for another fix," she left the relationship. Many of Ilene's friends died of drug and alcohol related illnesses, including her ex-lover of 38 years. Ilene quit drinking heavily so she could afford to start her own business. Although she said she was no longer an alcoholic, at age 82 this tiny woman still frequented bars. She said she would stop after three drinks.

The senior complex in which Josephine J. lived attempted to use technology to ensure resident safety. It was partially successful. The closed-circuit monitor in her apartment allowed Jo to identify visitors. She must press a button before they could enter the building. However, unauthorized visitors frequently slipped in when the doors was opened for legitimate visitors, thereby putting the residents at risk for assault or robbery. Jo complained that young people paid their doctors to declare them disabled so that they could live in the subsidized senior complex.

> There's dope and everything in here. . . . You have to have evidence to get these people out. And, a lot of people are afraid because if they find out who told on them, they'd bump 'em off or something. . . . There's a park right across [the street.] It used to be, a long time ago, we could go to the park and sit out and have your lunch and enjoy yourself. . . . The bums take over. So, we have to stay in with our doors locked. . . . We have a little place [to] sit there by the water fountain, when it's on. We're surrounded by these guys asking for a cigarette [or a] quarter.

Nevertheless, Jo felt "pretty safe" because she was well known in her neighborhood. People watched out for her when she took her walks around the block.

> They sort of respect me. . . . I think it's the way I carry myself. . . . I don't curse. [Unlike some of the women] I don't beg. . . . [Young people are] willing to go to the store for me, but most of them want money. . . . I've been quite fortunate.

Respect, a key theme among participants, is the antithesis of abuse. Providers' disrespect for patients can lead to overt or subtle abuses. As noted in the *Patient-Medical Provider Relationships* section of this discussion, Bernie B.'s history of abuse at the hands of physicians began as a four-year old when her doctor shone a light on her naked body so that his colleagues could observe her misshapen form. Ilene I.'s early memories included the physician who burned the external and internal organs of her hermaphroditic sister. Clinic officials attempted to cover up their culpability when Hillary H.'s daughter nearly died after staff neglected the dialysis machine.

Just as self-neglect can be considered a form of self-abuse, providers' neglect or purposeful impeding of usual and appropriate services can be considered abuse (Cook-

Daniels, 1997). Such subtle abuses are more difficult to quantify or prove, but they put patients' physical and mental health at risk. Perpetrators can include health care administrators and insurance companies. For instance, Josephine J. lived in poverty. She paid off a twenty-year endowment years ago, but the company refused to pay her. Despite numerous phone calls, they continued to tell her that they would "look it up." Josephine believed that the company was waiting for her to die.

As with other elders, physical and mental health care providers might excuse withheld treatment by attributing disease symptoms to old age. Only subtle cues and intuition can tell an old lesbian if a prejudiced provider chooses not to pursue treatment options, make specialist referrals, or conduct necessary testing that would prevent or cure health problems. Even if neglect or abuse can be proven, providers can hope that the patients lack the energy, persistence, health care awareness, and knowledge of the system to pursue recourse. Therefore, it is incumbent upon patients' rights advocates, ombudsmen, and adult protective services personnel to educate themselves about old lesbian issues.

LGBT elders might be reticent to allow service providers into their homes fearing blackmail or abuse (Cook-Daniels, 1997). Many expressed fear of abuse and discrimination in nursing homes. One federal study reported deficiencies that endanger people's health or lives were present in one-quarter of nursing homes (Tanner, 1999).

Kim K. would "rather lay down and die" than live in a nursing home. She had seen how people in nursing homes are treated, but she saw her present situation with Dee as similarly degrading.

> Everything [in a nursing home] is controlled. . . . Some of them have been really abused, misused, ignored completely, humiliated to the end. And I just can't see myself being subjected to a condition like that. Although, in a sense, I'm being humiliated anyway, right here.

Kim was vague about whether or not she would commit suicide to avoid admission to a nursing home. She re-emphasized that she would rather die, especially if she were useless.

> Even if you have the potential of doing something, being useful, they would limit you. . . . They have rules, like any institution. And you have to abide by them. If you didn't abide by them, then they would use any measure that they see fit to keep you in place. They wouldn't want you to be an example for anybody else. . . . And, I feel so sorry for those people in nursing homes. . . . And families are so quick about dumping you in a nursing home, when you get a certain way. Furthermore, . . . they usually take your social security and your pension when you go in. And they don't even deserve what they get. You don't get nothing for it in return.

Hillary H. explained her perception of heterosexually-based nursing homes: "I would hate to get to the point where I didn't know if I was clean or dirty, . . . and damn those nurses. Why don't they change their clothes for them?" She thought a gay nursing home "would be a blast! We could sing and dance and change our diapers together! Who would care?" Four participants expressed interest in residential facilities for older lesbians. Their discourses inferred expectations of quality care in such places.

Abused lesbian elders who strictly guard their privacy might hesitate to call upon adult protective services and law enforcement agencies. They might fear that even nonsexual abuse can lead to outsiders' knowledge of their lesbianism. Cook-Daniels (1997) summarized the need for sensitive handling of lesbian elder abuse issues:

> Adult protective service workers, no matter how skilled and caring, cannot begin to negate or compensate for the violence and prejudice lesbian . . . elders face. What they can do is try to be more aware of the perhaps-hidden realities of clients' lives and be more skilled at addressing clients' fears and needs. (p. 43)

CONCLUSIONS

The goal of these case studies was not to create statistical data but to strengthen the understanding of individual old lesbians' health care experiences. These interviews took place in a unique setting at a specific time. They were guided by the flow of conversation between investigator and subject. Rather than this hindering the validity of the study, the natural settings and interactions increase the likelihood that the derived information is valid. In contrast, quantitative researchers often meet subjects in unnatural settings, asking them to respond to unnatural questions that the subjects cannot qualify with explanation (Bailey, 1997).

While the information gleaned from this study cannot be generalized to the greater population of the lesbians over 60, it adds to the slight but growing body of knowledge about old lesbians. In theory, the underlying themes associated with the experiences are themes that other persons may attribute to other circumstances. In other words, one may seek to understand the human experience through the study of individuals' experiences (van Manen, 1990). Thus, those who professionally or personally interact with old lesbians might gain a greater insight into the individual by considering whether or not this study's findings might apply to her personality and life situations. Because of the dearth of information about old lesbians, readers might feel tempted to generalize lesbian elders' needs and preferences. The heterogeneity of lesbian elders is emphasized in this study through maximum variety sampling. Lesbianism intersects with other life factors. One should remember that ethnicity, age cohort, coming out cohort, religion, family behavior patterns, economic status, health status, social norms, and personal experiences play varying roles in defining an individual's health care perspectives.

Several of this study's lesbian elders claimed their orientation had nothing to do with their health care. Yet, the discussion above underscores the interplay among old lesbians' informal and formal support networks, their utilization of services, and their methods of coping with social stigma. Subjects' coping techniques included isolation, self-sufficiency, intergenerational support, and compartmentalizing career, home, families of birth, and families of choice.

The subjects' discourses suggested an acceptance of life's ambiguities. For instance, some of the subjects expressed conviction that being out to their health care providers was irrelevant to the quality of their health care. The same subjects voice their beliefs their health care interactions would be easier and more accurate if their providers knew their sexual orientation.

After years of practice, these women learned to adapt to negative attitudes and policies that consigned them to the borders of the social structure. Specific adaptations as they apply to health care acquisition were similar to those described in Hitchcock and Wilson's (1992) personal risking theory. All but 1 participant had documented their wills and health care directives. Some participants asked friends, family, or lesbian organizations for referrals to open-minded providers. They dropped hints or withheld wanted information depending on whether or not they want the providers to know of their lesbianism. They also looked for subtle cues that the providers understood or shared their orientation. They were concerned about breaches of confidentiality, loss of health care, or inferior treatment. Indirect adaptations included delayed health care, avoidance of heterosexually-based elder services, dependence on health care advice and treatment from family or friends, adherence to coping patterns learned in childhood, social selectivity, and isolation.

For 9 participants, a desire to maintain internal and environmental control and independence contributed to their consideration of active or passive suicide as an alternative to extreme pain, physical dependence, or mental deterioration. Participants expressed concerns about carrying out end-of-life decisions: A failed suicide attempt could lead to a persistent vegetative state. Others must not be implicated in the death. God might not forgive suicide. Also, one might become too debilitated to carry out her end-of-life plans. Two participants believed they could will themselves to die.

Participants' tentative plans were based on the hope their health would remain the same or improve. Regarding her future, Esther E., 76, summed up the nonchalance of the older old, "I'm sorry. I'm allergic to the word *future*. Can you use another word?" She settled on the phrase *the rest of my life*. She joked that she was an optimist because she kept a calendar.

The younger participants spoke of aging in place or moving to locations conducive to retirement. The older old were more concerned with their abilities to age in safe, supportive, affordable environments where they would be treated with respect.

Respect was a keyword among the interviewees. Some remained closeted so as not to lose respect from health care providers, family, friends, and co-workers. Two ethnic minority women believed it was incumbent upon them to demonstrate their intelligence in order to gain common respect. Others believed their ages and life experiences commanded respect. They were intolerant of disrespect that originated from racism, sexism, or ageism. However, participants appeared more resigned to the inevitability of homophobia and heterosexism. Deborah D. explained, "I do not want society looking at me and judging me. No matter what you say, [heterosexual people] are not going to accept you as they are. You could wish it for a thousand years, it's not going to happen."

Among participants, nursing homes had a reputation for humiliation and degradation. However, lesbian nursing homes/retirement communities were assumed to be settings of respect and affirmation.

Only 1 participant reported ever having received professional mental health services. Another spoke of her lover serving as her counselor. Likewise, a participant's daughter treated her for stress-related pain using the Feldenkrais method. Such preferences for health care services via informal support systems were common among the subjects.

Judging from the interviews, illicit drugs and alcohol abuse played prominently in the lives of only 2 participants. One son of Hillary H. was in prison and the other was living in poverty because of drug addiction. Hillary felt no one else would love them if she were to die. Ilene's former lover was addicted heroin. Ilene and her longtime partner were heavy drinkers.

Kim K. and Hillary H. reported physical abuse. As a young woman, Hillary was raped and her two sons were sexually molested by people they knew. An impending breakup ignited a physical altercation and threats of violence between Kim K. and her partner. Josephine J. balanced her needs for self-determination with her awareness of illegal drug trafficking in her senior housing complex and neighborhood. Participants were concerned about potential abuses, including scams, social security fraud, nursing home neglect and abuse, and property damage or personal assault in response to their lesbianism.

While many of the old lesbians' experiences and concerns were similar to those that might be found among old heterosexual women, one difference predominates: the old lesbians must circumvent or function within the dominant heterosexually-based social structures and institutions that tolerate them at best and, at worst, put them at risk for abuse, neglect, or early death. Deevey (1990) expressed the difference this way: "The relevant health issue in sexual orientation is not the patient's sexual behavior, but is instead the wear-and-tear of living in environments (including health care settings) that are homophobic or hostile to lesbians" (p. 38).

RECOMMENDATIONS

Recommendations for Research and Education

Further research is indicated in all areas of old lesbians' physical, mental, and spiritual health, including health care and social systems that support health and wellbeing. Replication of this study using a larger sample, different regions of the country, or rural lesbian elders would be beneficial. Researchers could narrow the scope of this study to focus on one race/ethnicity within the old lesbian population. Especially important would be learning from old lesbians of Asian and Middle Eastern descent.

An investigation of the prevalence of suicidal ideation among old lesbians might attempt to assess causative factors and whether such ideation is related to depression, rational independent thinking, or other influences. The participants, who were accustomed to independence, were concerned about health-induced dependency.

Therefore, future research should sample more old old and frail lesbians to learn how these women adapt to dependence. A comparative study between old lesbians in mainstream retirement and nursing homes and those in LGBT retirement and nursing homes might reveal interesting data about the ways in which identity groups influence lesbian elders' health and their abilities to function independently. In this study, old lesbians who nurtured intergenerational lesbian friendships appeared to be more willing to take coming out risks. Therefore, research on the effect of intergenerational relationships on old lesbian health would be indicated. Also, research should delve into the low incidence of LGBT elder services utilization by racial minorities.

Dean and colleagues (2000) of the Gay and Lesbian Medical Association recommended that lesbian and gay health issues be taught in medical schools. In addition, aging LGBT health issues should be taught in schools of gerontology, allied health professions, sociology, psychology, and religion.

Recommendations for Practice

Health care administrators should work with lesbian and gay senior advisors to address issues of institutional discrimination. Health care providers would do well to examine their personal biases and attitudes and to question whether or not they have created a health care environment that is user-friendly for elders, women, and lesbians. All staff members should receive continuing education to improve cultural competence including sensitivity to old lesbians' needs and the expectation that staff honor diversity in their patients and coworkers. Although not targeted specifically to the old, two useful resources are available. One is *A Provider's Handbook on Culturally Competent Care: Lesbian, Gay, Bisexual and Transgendered Population,* published by Kaiser

Permanente's National Diversity Council (Arnold, 2001). Another is *A Provider's Introduction to Substance Abuse Treatment for Lesbian, Gay, Bisexual, and Transgender,* published by the federal agency Substance Abuse and Mental Health Services Administration and its Center for Substance Abuse Treatment (Craft & Mulvey, 2001).

Lesbian sensitivity should extend to health care colleagues as well. While these individuals may not choose to come out, it is important to remember that their personal lives intersect with their professional lives. Their lesbian worldviews can help to shape their understandings of other disadvantaged groups. Their partners and communities offer them the emotional and sometimes financial foundations from which they may build their careers (Hansen, 2002).

To create a "lesbian sensitive" environment (Rankow & Tessaro, 1998; Saulnier, 2002), a facility and its staff makeup should reflect the diversity of its clients. Just as educational posters and brochures should depict a range of races and ages, they should also include old lesbians. For example, a health awareness poster showing two old women might read, "Because we care, we remind each other to schedule our annual mammograms." Brochures or posters promoting powers of attorney and living wills could depict two old women and might read, "Who would speak for you if you couldn't? Name a trusted loved one to carry out your wishes." Since old lesbians might not come out to their providers, pamphlets on women's health issues should include indications from lesbian health studies such as the possible increased risk of breast cancer among lesbians or that lesbians and celibate women are not immune to cervical cancer.

A partnered lesbian who reads on a form choices for married, single, widowed, or divorced must divine if the inquiry is regarding social support or legal status. Providers should ask themselves why each question appears on their forms. Is the knowledge of legal marital status vital? More important issues may be the need to know who is responsible for bills and decision-making in emergencies and with whom the provider may discuss the patients' needs. If the marital status questions are necessary, the forms should include a category for registered domestic partner followed by a choice of male or female.

An understanding of the process of personal risking (Hitchcock & Wilson, 1992) may help providers to deliver quality health care to elder lesbians, not only in the clinic but in the more invasive hospital or home care settings. The provider should respect the role of the significant other in information sharing and health care decisions (White & Dull, 1997). Providers should use the client's language to refer to their significant others (e.g. *friend* or *partner*). If sensing that a *roommate* is possibly a *significant other*, Cook-Daniels (1997) recommended that the health care provider "begin asking the type of questions you would ask a married couple rather than the type of questions you would ask about a neighbor" (p. 1664). Also, the provider should invite patients to bring their partners or friends and written lists of questions and comments to their appointments. Not only would this method help to put the patients at ease and affirm the patients' significant relationships, but it would also improve communication and follow-through.

Health care providers would be remiss to assume old lesbians are not at risk for STDs, breast cancer, cervical cancer, or other health factors typical of old women. Lesbians often remain sexually active as they age and may experience off-time life events (Slusher, .Mayer, & Dunkle, 1996) including coming out in later life after their husbands die (Poor, 1982). Health care providers should rule out STDs, even among old lesbians, through sensitive interviewing or laboratory testing. When applicable, they should also educate their old lesbian clients about health risks associated with nulliparity.

Effective health care is difficult to implement without a trusting relationship between patient and provider. Rethinking heterosexist paradigms is a vital first step in better serving the needs of old lesbians.

Recommendations for Health Care Policy

In this study, most partnered participants called for lesbian marriage rights or some method of insuring the recognition of their families. In 2003, several years after the last interviews, the U.S. Supreme Court decriminalized private sexual contact between same-gender consenting adults, thus removing a major rationale for discrimination (O'Connor, 2004). Federal and state lesbian and gay marriage rights would be a major step in protecting old lesbians' socioeconomic wellbeing and thereby their access to healthy lifestyles and health care (Dean et al., 2000; Hall, 2003). Currently, federal law does not recognize lesbian and gay marriages (pending in Massachusetts), civil unions (available in Vermont only), or domestic partnerships (Markowitz, 2000). Consequently, old lesbian couples do not have the marriage rights accorded heterosexual couples in the areas of social security benefits, right to sue for medical malpractice/wrongful death, workers' compensation benefits, immigration, taxes, inheritance, 401k rollovers for surviving spouses, alimony, homestead protections, automatic powers of attorney when the spouse becomes incapacitated, and authority over arrangements after a spouse's death, to name a few of over 1000 inaccessible rights and benefits (National Center for Lesbian Rights, 2003). Therefore, providers should guide their clients toward legally codifying their wishes for hospital visitation, direction of medical care if incapacitated, and financial management through the use of legal documents such as medical powers of attorney, living wills, and durable powers of attorney (Cook-Daniels, 1997).

To effectively meet lesbian elders' health care needs, government and private agencies must collaborate in planning, implementation, and financial backing. If responses from study participants are indicative of the need for elder lesbian housing, support programs, and long-term care facilities, policy is far behind demand. However, a few model programs have emerged which others should replicate or adapt. Hollywood, California's Community Redevelopment Agency and a nonprofit group have received approval for a low-and middle-income LGBT senior housing complex (First housing for gay, 2003; Smith, 2003). Also, the Florida Department of Elder Affairs, the Sunshine Cathedral Metropolitan Community Church, and the Area Agency on Aging have planned Florida's first day center for lesbian and gay elders (Fort Lauderdale plans, 2002) to be opened in April, 2004 (Sunshine Cathedral representative, personal conversation, Feb. 16, 2004). In addition, the Massachusetts Office of Elder Affairs has mandated that Area Agencies on Aging (AAA) improve the outreach efforts to LGBT elders (Scheible, 2003).

Changes in health care policy, heterosexist institutions, and provider attitudes must not wait for the deaths of these hard-to-reach cohorts of lesbians who lived with stigma before the social changes brought on by the LGBT rights movement. It is incumbent upon all who serve elder communities to prepare themselves to meet the needs of this population.

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APPENIDIX A

Interview #1: Allison A., March 1998

Italian American Allison A, age 66 ½, resides with her partner, Kate, a 41-year-old African American, in a middle class neighborhood of a coastal metropolis. A church musician, Kate is studying for the Episcopal priesthood. Allison has earned two master's degrees and owns a business that serves the Roman Catholic Church. During her "other life," Allison married a man, moved from the Midwest to the West Coast, and bore three daughters. She divorced her husband after 37 years. When she moved in with her partner, her grown children knew the situation and approved.

In her self-introduction, Allison states,

> This was the very biggest change in my conscious life. . . . Up to that time, I think I was . . . living the script that everybody lived who became an adult in the fifties. You know, you get married, you have kids, you stay home, you don't have a career, the husband goes to work, and it's unhappiness ever after. . . . Very late in my life and, certainly, late in the marriage, I decided . . . I'm not going to live this way anymore.

Allison's coming out was very easy, "the most natural thing in the world," and something she had needed to do since she was 13 or 14 years old. She repeatedly emphasizes the advantages to coming out within the support system of a large lesbian community. When she retires or completely converts her church supply business to the anonymity of the Internet, she plans to come "fully out," making "no apologies for my lifestyle."

While churches often supply elders with formal and informal support systems, Allison is ambivalent about her relationship with the Catholic Church. A member of a Catholic parish, she is also dependent upon the church for her livelihood. "Basically, I'm selling to the enemy." She would never donate money because "it's very repressive for women," and "some of those people would be the first to stone me if they knew my life." She explains that she is "very attached" to Christianity, which "is a religion of love." On the other hand, "the church as an institution is pretty fucked. . . . Do you think Jesus Christ would've spit on somebody who is gay? I don't think so."

Her parish priest has recently reached out to gay members, but she will not respond. "That's for the other ones. You know, you guys go do it, not me." She is concerned about loss of livelihood and "rocks thrown through my windows." Even after she retires, she will not come out to her parish. "I feel no need to smack 'em in the eye." When she feels "a need to partake of the Catholic experience," she attends Catholic mass far out of town where her partner is a paid musician. Yet, ambivalence reigns here, also.

"I am entirely welcome. And I suspect everybody knows exactly who my partner and I are. We have never discussed it." Allison's partner, Kate, must protect her lesbian identity because she is studying for the Episcopal priesthood. A paid music minister, she is only out to her bishop, priest, and vestry. Allison explains, "Now, the Episcopalians are grand people. I mean, it's okay if you're a woman. It's okay if you're a lesbian." Yet, the fact of their lesbianism is "on a need-to-know basis."

Allison repeatedly differentiates between church as business and church as spiritual sustenance and support. She frequently disengages from discussions about the latter by reiterating that church is a business, and she and her partner are under no obligation to be supportive of or to share themselves with this business. Should her lesbianism be found out, she believes she would be ruined financially, and professional friends would also be suspect. She summarizes her "odd and peculiar twist" on her relationship with the church, "I'm kind of happy in my loose state."

Elders often look to family for informal support. Lesbian families may include kin and/or fictive kin. Allison considers herself fortunate to list many people as her family. She mentions her three daughters, her partner, an emotionally close sister in the Midwest, and a nephew, all of whom know she is a lesbian. She also includes her other Midwest brothers and sisters, who don't know about her orientation, and "an extended family in the [lesbian] community. I mean, all those women who welcomed me warmly, and some of whom have become very close friends . . . I'd say there are about ten." Although Kate has "limited contact" with her extended family, Allison considers them her family, also. Kate's grandmother, who reared her, has stayed with the couple, and "we get along fine, but . . . not much of it is too real" because the two are closeted. Likewise, Allison remains closeted from all but one Midwest sibling because "I don't really like them," they cannot come to invade her West Coast life because "they are poor," and the Midwest sister who knows about her lesbianism would have to bear the brunt of her siblings' negative attitudes.

Allison donates money to the lesbian community's "marvelous" support system in the coastal town that she has chosen for retirement.

> It's like petals on a blossom. . . . You're going to find an intimate support group, and then . . . a bit larger support group, and then . . . a big support group, so that, eventually, . . . everybody knows everybody else.

When she and Kate move, she plans to ask these people to refer her to lesbian-friendly doctors to whom she may comfortably come out. Allison will also make future social connections through her daughter, and she may attend Slightly Older Lesbians (SOL) activities. After the move, she may initially be lonely, but Allison is not inclined to seek social support via a church.

Regarding her physical health, Allison complains of pain that has persisted since her gallbladder removal two years prior. She is angry that her specialist put her through an expensive, invasive, and unnecessary endoscopy one year prior to her age qualification for Medicare. She remains with him because "he is a very excellent diagnostician." Nevertheless, "my discomfort and my concerns around it will have to get a lot worse before I will go . . . do that again." Instead, she has sought treatment from her daughter, who is studying Feldenkrais movement techniques and Chinese medicine.

Her daughter's treatments not only helped Allison physically, but helped them both to heal their sometimes difficult relationship. After this therapy, the physical pain subsided for four to six weeks. She and her daughter attribute the pain to "a lot of stomach acid" due to stress in the home. Specifically, Kate has started her dissertation and the couple is planning to move from the area within 18 months.

Allison believes she would feel differently about seeking professional medical help if her physician were "more personable" and "if I could talk to him." She complains that her doctor "doesn't ask any questions, and he doesn't invite patient input. And if I do say something, I mean, there is absolutely no response." Still, Allison retains him because her female gynecologist, who is "probably not the best," told her that she would choose him for herself.

Allison has been seeing her gynecologist for 20 years, since before her divorce. Although the gynecologist helped two of Allison's lesbian friends to conceive through insemination, Allison is reticent to come out.

> I'm moving on. And what is the point of getting into all this when my health concerns are not related to my sexual orientation? . . . I mean, a gallbladder is a gallbladder, whether you're a lesbian or a straight person. . . . She's not a good enough physician for me, so . . . why even get into this?

Although not conveniently located, Allison remains with her gynecologist.

> She's easy to talk to. . . . I know some MDs who treat patients like children. . . . She's entirely fair in her billing practices. She will speak to me on the phone and not charge me phone time, and she's a nice woman. I mean, there's a certain loyalty. I've been with her all these years, and she's now beginning to lose clients, because Medicare will no longer pay for annual physicals.

Recently, Allison learned she would have to pay $110 out of pocket for her annual pelvic exam and Pap test. The gynecologist's office cued her to claim a "weak bladder" so that Medicare would cover the cost.

> Medicare . . . is so crazy, it's irrational. They've only just now, this year, begun to pay for annual mammograms. . . . You could be dead in two years! . . . For God's sake, all we have to do is not build one bomber, and everybody in this country could have all the stuff they need in terms of wheelchairs and artificial limbs and God knows what.

As a new divorcée and small business owner, Allison had difficulty acquiring affordable health insurance. When she qualified for Medicare, she followed friends' advice and purchased a medigap insurance policy that covers prescriptions. She doesn't presently need prescriptions. Her $115 per month Blue Cross medigap premium is too expensive, but it gives her peace of mind for the future. She cannot purchase mental health coverage because she has received many years of therapy.

An unmarried sister was burdened with Allison's mother's care after she had a stroke. Friends in her daughter's liberal coastal town have told Allison of individuals who will board and care for one frail elderly person at a time in their homes. If Allison were to become dependent, she would prefer such an arrangement. Ultimately, she would prefer to enter a nursing home or residential care facility rather than burden her partner or daughter with her care.

While Allison does not have long term care insurance, she believes she can afford living expenses up to $1,500 a month. If not, she feels her daughters and her partner can equally share the additional expenses. "If we are lucky, we die quickly." Allison remarks.

> [I'd] like to be in control until the end, and if we don't get a rational health care system that allows physician-assisted suicide, I would . . . probably do it myself. It's all in quality of life and how much of the burden people who love me are going to be suffering....[My family doesn't] want to hear this. . . . I wouldn't involve anyone else in it.

Still, Allison sees a bigger picture. Both her father and a grandparent committed suicide. Before her father "blew his brains out," he offered to kill his disabled wife first. She declined. Allison expressed compassion for her mother, who was not capable of killing herself if she changed her mind. She was angry at her "brutal" father for not allowing his children to make their peace with him, but, ultimately, "I was glad he did it. I mean, what kind of monster am I?" Now she understands, "I'm perfectly capable of doing the same damn thing."

In suicide, Allison would not tell her family because of their feelings and the legal implications, but would leave an explanatory note. She feels she is like her father in that she prides herself on decisiveness. Several times, she mentions that her plans are moot if she is unable to "carry the plan through. . . . I will hate it! . . . I don't think any of us wants to die, but there's also such a thing is not wanting to live either."

Loss of independence is "very scary" for her. Her penchant for taking care of her personal responsibilities extends beyond her death. She has a will, a power of attorney for finances, and a medical power of attorney. She wants to change her will to insure that Kate receives her share of the estate even though she has explained her wishes to her daughters and partner. She realizes that people's attitudes can change when money is involved.

Allison believes that she knows a priest who will give her a Catholic burial. She struggles to explain her attachment to a church that rejects her. She compares her feelings to those of her Jewish ex-father-in-law, who converted to Catholicism to escape the Holocaust. In his heart, he was still a Jew and wanted to be buried in a Jewish cemetery. In Allison's heart, she is still an "old" Catholic, but when she dies, "I want all my people around me. I mean, the lesbians and the Jews and the Protestants." As is her style, she has documented these wishes for her family.

For financial purposes, Allison would like Kate or a daughter to be able to claim her as a dependent. However, at the time of the interview, neither her city nor her state offered domestic partner registration and benefits, and gay marriage is not yet legal in any U.S. state. This investigator referred her to the National Center for Lesbian Rights for further information.

In summary, Allison prides herself on taking personal responsibility for her life. She gathers health care information from experts, friends, and family, makes her decisions, and carries them out with "extreme independence." Consequently, she fears dependence and hopes to take her life before she becomes too dependent to do so. In anticipation of her decline and death, Allison has accepted the responsibility of documenting her wishes.

Allison also fears that knowledge of her lesbianism might result in loss of personal and financial independence. She frequently comments on how lucky she is to have a loving partner and attentive children and to live in a lesbian-friendly community. She compares the advantages of her life to the lives of isolated old women who lack intact support systems, financial stability, and access to health care.

Allison is loyal, even to the doctors she dislikes and to her Catholic Church, for which she expresses disdain, sadness, and hope. She has faith that sometime after her death, "change will come; it's coming rapidly. . . . When a bishop finally has the balls to ordain a woman, . . . Catholics will wake up in a totally brand new church."

APPENDIX B

Interview #2: Bernie B., April 1998

Sixty-one-year-old Bernie B. refers to herself as an "older lesbian feminist woman." Jewish by race and by "religion to a certain extent," she married a man at age 18, bore two children, divorced, and came out at age 48. Both children are grown, and she has two grandchildren.

Although Bernie has been committed to her partner, Beth, for two years, they will not live together until Bernie retires in 18 months. At that time, Beth and she will move from their working-class West Coast metropolitan neighborhood to a small town in northern California. Bernie participates in a lesbian reading group and hopes to identify such a group when she moves. Friends have supplied her with contact information for the small town's lesbian community.

Presently, Bernie enjoys writing and poetry. She has earned a bachelor's degree and has worked in human resources at a prominent university since 1978. The interview took place in her small utilitarian apartment.

When asked to identify her family, Bernie listed Beth, with whom she has had a commitment ceremony, and her "blood relatives," who include her children and grandchildren and her Southern Californian brother and parents. They all know she is a lesbian. From the beginning, her grown daughter has thought having a lesbian mother is "quirky" in the positive sense. Although Bernie introduced her "partner" at her father's family reunion, "it's not like they got it."

Both her parents are in their mid-eighties and are suffering health problems, which Bernie attributes primarily to their smoking for many years. Bernie has never smoked, so she feels that she will live to be about 100 years old.

Bernie lists three criteria necessary for living to be 100: having "enough money to live that long," not deciding prior to 100 that one's "debilitations make it unworthwhile to keep living," and having "someone that you're living with" as a "synergistic kind of thing" to "keep each other going." She points to her parents. They often fought when they were younger, but they grew "much more loving with each other" as they aged and had to depend on each other.

As with Allison A., Bernie would like the option to take her own life. "When you get to be in your late eighties, your nineties, it's just like a cascade of health things that come along." Given the possibilities of terminal, painful cancer, Alzheimer's disease, or a disease that would destroy her ability to communicate, Bernie would choose suicide. "I'm the kind of person that wants to be in control of my own life span." Beth and she have discussed the subject only superficially.

Bernie has a will, but, unlike Allison A., she has not taken other legal steps to ensure that her wishes are carried out were she to become incapacitated. "I'm not old enough yet or settled enough." After she and Beth retire, she will consider drawing up a living will and a medical power of attorney. She will name her daughter as decision maker because she trusts her to respect her wishes. Beth "wants to be in control of things herself. . . . Beth would just much rather do what she thought was best when the time came."

In the face of chronic illness, Bernie would prefer a lesbian support group, but she would consider going to a "mixed" group "if there weren't too many men in it."

Although generally closeted, Bernie believes she would come out to this group to test their supportiveness.

> I think it's fun to stir people up. You know, if you're sick, and everybody's sort of feeling sorry for you as well as for themselves, and then . . . people would have to think how they felt about gay people. And if your support group could not support you because they didn't approve of your lifestyle or whatever, then you wouldn't want to be in that support group.

Bernie is "madly saving money" in hopes that her savings, pension, and Social Security will see her through at least 30 years of retirement. She hopes that the government will eventually provide quality health and disability insurances and, with unions, will enforce strict standards of care in nursing homes. Her priorities are "good nursing care and caring people and cleanliness and decent food." She believes that the quality of nursing care is greatly influenced by whether or not the caregivers earn a living wage. People who earn poor wages can easily become apathetic or take out their resentments on their charges.

Like Allison A., Bernie becomes angry when discussing the possibility of facing a health care system without the legal protections and benefits of marriage.

> [I feel] cut out of society. . . . I guess the only other people that are not allowed a legally recognized spouse might be retarded people, but, I think even retarded people are allowed to get married to another retarded person legally. . . . It's weird to be singled out, to have this sort of population of people who are citizens of the United States, tax paying citizens, and they're selected out and discriminated against in this way. . . .
>
> I've committed myself to Beth, but in a way, I would never want to be . . . married again, because I kind of don't believe in the institution. But, on the other hand, I would like spousal benefits or recognition or something. There are so many things tied up into this. You know, tax laws and . . . assumptions. I was just looking at this gym up in [my retirement town], and you can join as a single person or you can join us a family unit, but a family unit is defined as husband and wife. A lot of things are defined in that way.

Bernie's memory of doctors begins at age four. One side of her body has always been smaller than the other side. Her doctor would show her off to his peers. "They just took your clothes off, they wrapped you in the sheet, and they put you out there and took the sheet away and projected this light on you." In this way, the doctors could see the shadow cast by her misshapen body.

Many bad doctors are hiding among the good, she believes. "I think that as a woman, you are treated as material for pornography with some doctors." She cites the dermatologist she consulted at age 19 when she had a rash. Her sister-in-law had assured her that he would only charge her what she could afford. When Bernie told him that she was not sure how she would pay for the visit, he said, "Alright, I want you to take all your clothes off." When she did so, he instructed her to turn around as he stared at her. He never sent her a bill.

Another time, she consulted a Kaiser HMO dermatologist about a rash on her breasts. He said, "Oh, gosh, this is really weird." She waited a long time until he returned with another doctor. Without acknowledging her, her doctor told the other man, "Here, I want to show you something." She describes her feelings: "It's like you're some kind of nonhuman or freak."

According to Bernie, a good doctor respects her time, listens, wants to talk to her, has a broad range of experience, treats her/his patients as equals rather than "father knows best," approaches the problem with an open mind, and is willing to search for the source of the problem. "It's personal dignity and the feeling of trust that you're getting adequate care."

Bernie still harbors some guilt for her husband's ulcer and intestinal problems. His doctor told him, "Behind every ulcer there's a woman." This is the only subject on which she declines to elaborate.

In general, Bernie prefers female to male doctors and old to young. She is forgiving of the old doctor whose hands trembled as he cut out a malignant mole from her face. Old doctors "have a lot of experience, and they can kind of pull out something, you know, that will work and might be old fashioned." In contrast, one female surgeon told Bernie that she would graft a large area of skin only if she found cancerous cells around the perimeter of where the mole had been removed. However, Bernie's general anesthetic had not taken effect when she heard the doctor tell her assistant that she would graft without checking for cancer cells. "It's not like she gave me the true story."

When one female Kaiser physician brushed off Bernie's back pain as arthritis, she switched to a university health plan. That plan's doctor ordered an MRI, discovered a protruding disk, and performed back surgery. However, the dermatologists in this new plan were surprised to learn what her previous Kaiser doctors knew: Melanoma can occur in skin moles. "One part of the health care system was not believing what the other part of the health care system was telling you, and you're getting two different stories."

Changing health plans has been one of Bernie's primary methods for advocating for her health care. Including her post-retirement medical plans, Bernie mentions six different health plans or groups. Finding satisfactory physicians is limited by her plan options. For instance, in one group plan, she found a good female primary care physician, but she did not like the plan's one optometrist and one dermatologist. She changed plans again. She is satisfied with her specialists in her current Pacificare plan, but does not like her female primary care physician, whom she had to pick from a list. Bernie complains that this doctor is scattered and, therefore, "isn't taking her patients seriously." The doctor left her in the treatment room for 20 minutes while tending to a phone call and other projects.

Upon her retirement at age 62, Bernie's company will offer her a Blue Shield plan, which will cost her in premiums and co-payments. This arrangement must suffice until she is eligible for Medicare at age 65. She is concerned about the quality of doctors, MRIs, mammogram machines, etc. that may be available at the small hospital in her retirement town. Bernie believes one person can have great influence in a small town. She might work with the small hospital to make changes or acquire equipment.

Bernie has ongoing back problems and a history of melanoma, and she is beginning to experience hearing and vision losses. Because hearing aids can cost $4,000 but are often ineffective, she will delay the purchase for as long as possible. She would rather spend her retirement savings on travel and enjoyment, "while I still can," and use the "leftovers" for hearing aids.

Bernie is not out as a lesbian to any of her doctors. In the smaller town, she will only come out if she wants Beth's involvement during a life-threatening situation. She believes that she and Beth will be able to "melt into the landscape" because "unless you wear a leather jacket or something, pierce your eyebrow, I think you get away with a lot as you get older. We're just these sweet old ladies, . . . not threatening."

Bernie has a history of advocating for her parents' health care as well as her own. She has noticed a dramatic decrease in the quantity and quality of nursing care since her first hospitalization in 1962. Her father was recently admitted to a private hospital. She and her brother found it necessary to advocate for him to ensure that he received proper meals and scheduled testing. Often receiving no response from pressing the nurse's call button, she had to leave the room to find help or to find the equipment that her father needed. "It's not a matter of how much money the patient has to spend on it. It's a matter of these HMOs investing the money they have in good quality care, and I think . . . the government has to be much more involved in regulating HMOs."

Asked what she would like people to know about old lesbians and the health care system, Bernie responds, "Be conscious and aware that all those sweet old ladies are not all straight women." Also, be patient with old people who have slowed down. Lastly, respect all people at each stage of their lives, especially teenagers and old people. "I think there are a lot of stereotypes floating out there about people."

In summary, Bernie feels that many doctors and health care workers disrespect and objectify their patients. They may misuse the power of their positions. Bernie's narrative emphasizes self-respect, self control, and personal responsibility. Successful aging includes her ability to blend into the dominant culture. As a lesbian, who does not have the legal protections of marriage, she has planned for her future and advocates for herself. On the other hand, she has delayed plans to arrange for alternate advocates prior to their necessity. As one who wants to be "in control of my own life span," her strategies may include suicide in the event of terminal or debilitating illness.

APPENDIX C

Interview #3: Cindy C., April 1998

Interview #3 was intriguing, given a 76-year-old Jewish lesbian with a Ph.D. in Education and a diagnosis of early stage Alzheimer's disease. However, the subject was deleted from the study because the tape recorder malfunctioned. Besides, the subject had lost her memory for much of the information requested in the interview. Therefore, the interview was not rescheduled, and the investigator chose an alternate subject. The 10 valid interviews are numbered 1-2 and 4-11.

APPENDIX D

Interview #4: Deborah D., April 1998

In 1994, 69 ½-year-old Deborah D. purchased her patio home in a middle- to upper-class suburban retirement community. Her 75-year-old partner, Peggy, had recently died of cancer after 39 years with Deborah. Deborah considers her race/ethnicity to be American, her orientation lesbian, and her politics Republican. Before her retirement, she operated computers for over 30 years at a major manufacturing and distribution company. Because Peggy worked in the same office, they were companions 24 hours a day. Neither was out as a lesbian at work or at home. The couple never joined LGBT organizations. While closeted, they were active in their local Republican party and were founding members of a now widespread, multifaceted hospice organization.

Peggy's daughter, Kelly, lived with the couple between ages 11 and 20. She currently lives in Deborah's other house in a nearby upscale suburb. She helps Deborah when necessary. Kelly, who is now 54 years old and a great-grandmother, only knew the couple as "roommates." When Peggy had stomach cancer, Deborah posed as her sister to visit her in the hospital. While they never discussed with Kelly their true relationship, "you'd have to be dumb, blind, and stupid, not to know. Especially with all the publicity [on TV] and all the talk." Regarding Peggy's biological family, Deborah states, "Like I said, I know they know. They know I know they know, but no one says anything."

Deborah does not think that gays, lesbians, or interracial couples should have children. She concedes that biracial children are decreasingly less stigmatized because they are increasingly more common. However, she believes children raised by homosexuals will never have the numbers necessary to remove the stigma. "I know it would be a loving relationship, but is it fair to that child? . . . Kids are cruel."

In her view, Peggy raised Kelly single-handedly because her partner made childrearing decisions and administered discipline, but "we did things together, went on vacations together, you know."

When asked whom she considers family, Deborah replies, "I don't have any family. Well, I do, but I'm a stranger, because of the situation. Peggy's daughter, she is beneficiary to everything."

She will not let Kelly's descendants call her *Grandma* "because I'm not! . . . They call me *Deb*. If I was related to 'em, it'd be different, but I'm not."

On the other hand, Deborah's face brightens when she speaks of her ability to help "the grandchildren" and "the great-grandchildren." She took only select possessions with her when she moved to Wentworth, the retirement community. Everything else, she allowed Kelly and her family to divide among themselves. She has set up trust funds "for the great great-grandchildren. . . . Things I do for 'em, I do for Peggy."

Deborah would never live with Kelly's family because she does not like Kelly's husband. Although she does not have long term care insurance, she could comfortably afford $40,000 a year for a private nursing home. Wentworth residents must be independent or able to privately hire assistance in their homes. Deborah would insist on a woman for personal care, but would feel comfortable hiring either sex for household assistance.

She would prefer living in a gay and lesbian retirement community, such as one she has heard about in Florida, but she would not move to Florida. "That's too far away from Kelly and the kids. Although I don't see 'em that much."

While priding herself on her independence in an emergency, Deborah would call upon Kelly, someone in Wentworth, or possibly someone from Women Over Fifty and Friends (WOFF), the lesbian social group with which she has been involved marginally for about a year.

However, the people in Wentworth and WOFF are only acquaintances. Her only friends are a few gay men who live an hour's drive away. "We have a lot of memories together," she says of a male couple who became involved at the same time as Peggy and she. Kelly grew up around their gay men friends, "but most of 'em were not obvious at all." She and Peggy eschewed both heterosexual and lesbian friendships because lesbians

> would cause trouble between partners and fooling around thing. . . . Because being as such [Peggy and Deborah being lesbians] and her with a daughter and everything, we never went with the lesbian crowd. And we didn't really have anything in common in the workplace with people. So, [we] really didn't have a group of friends to fall back on [when Peggy got sick].

Throughout the interview, Deborah hesitates to speak the word *lesbian* in reference to herself. Instead, she uses vague terms such as *the situation* or *being as such.* Also, she sometimes omits personal pronouns from her sentences. This is not uncommon among closeted lesbians, who may habitually edit gender and plurality from their speech.

Deborah's decision to remain closeted and her steadfast independence narrow her options for formal and informal support systems as she ages. For instance, Deborah knows of gay men and lesbians at Wentworth, but they are "obvious." Regarding her lesbian neighbors, she comments, "The masculine one, to me, it's obvious. Now, I don't know whether I'm obvious to people or not, I don't know." She would not mind socializing with "obvious" gays and lesbians within the context of a strictly gay function, but not in the world at large. Nevertheless, she would be willing to chat on the street with an apparent lesbian if the woman were walking her dog. "You know everyone around here by their dogs. You don't know them. You know their dogs."

At Wentworth, Deborah does not socialize with the heterosexuals because they talk about family and ask about hers, and she doesn't share any interests with them. She believes lesbians would be more inclined to take an interest in astronomy, her hobby.

Deborah would participate in a reminiscence group only if she were in a gay and/or lesbian retirement center or nursing home. Other than the friends mentioned above, Kelly is Deborah's only outlet for reminiscing, albeit edited, about her 39 years with Peggy. "We had a good life together. . . . I don't feel the need to talk about it."

Deborah has lived without a broad support system for most of her life. She grew up in Southern California, kissed her first girl at age 16 at a slumber party, and briefly attended nursing school in the 1940s. She and another woman "got caught" and were expelled. When her family found out, her father, an atheist like herself, knelt down and prayed. "And when he did that it just turned me off completely, and I said, 'Okay, goodbye.'" She cut off all contact with her family. "I've probably forgotten a lot of the hurt." She considered her father a "tyrant, selfish man," but her step-mother "was a nice person. That's one regret, that I think I probably hurt her." She only knows that her parents are dead and her brother is retired in Hawaii. Deborah is "matter-of-fact" about this and most other topics: "I don't think I'm unique at my age, of being pretty much alone. I think it's just life."

Asked what she would do if she could no longer live independently, Deborah answered, "I don't know how much I'd want to be in a home or anything. . . . I think I'd find a way to speed it up. . . . I've sent off for hemlock," a poisonous plant sometimes used for committing suicide.

Deborah appears slender and energetic. Healthy all her life, Deborah has experienced illnesses only in the past three or four years, including back pain from golfing and internal bleeding. She has never come out to a doctor. The university-based physician dealing with her internal bleeding is the only one who has asked her, when she said she lived alone, "Who did you live with before, a man or a woman?" When she said, "A woman," he replied, "I've always kind of wondered about you." While she is "past the age of getting caught," she wonders aloud what there was about her that led him to ask her the question.

Recently, Deborah found a lump in her neck. Because her primary care physician had retired, she consulted the ear, nose, and throat specialist at the Wentworth clinic. The biopsy showed malignancy. She received radiation treatments. Doctors removed her lymph nodes two months prior to the interview. One or two nodes contained metastases, but her surgeon thinks she is clear of cancer. "I think if it was going to be a long cancer thing or something else horrible like that, I'd definitely consider [suicide]." Deborah brings up the suicide option seven times during the interview.

She would rather have private insurance than Medicare.

> [At age 65] you have no choice. The government says so. Well, that's not the American way. . . . That is one step away from socialist care, which they're driving every day towards. . . . I think, when you provide for yourself as much as you can, the better off you are. The more you take from others, that much it diminishes you, as your own worth. I would think you would kill yourself.

Deborah's opinions on the formal U.S. health care systems differ dramatically from those of the first two interviewees. She believes "Medicare was a big mistake" because it spurs spiraling medical costs, and much of the money is absorbed into the government's "huge bureaucracy and waste." Her retirement package includes Blue Cross/Blue Shield Supplemental, and she is comfortable paying out-of-pocket for the portion that is not covered. If an elder cannot afford health care, she thinks that their children or spouses should pay rather than the government. Excepting government care for "indigents," she believes the marketplace should drive health care. "I think HMOs are getting there. I think they're on the right track," but she is concerned that "maybe too many of 'em are cutting corners too much."

"I don't approve," Deborah opines about society's current open discussions of homosexuality and the push to legalize gay and lesbian marriages. "There's so much that comes out now that never would have even been thought of or discussed: . . . the gay parade . . . these marriage ceremonies, that type of thing."

Deborah would not have married Peggy if she had had the opportunity. They were both "independent" yet "committed. . . . We didn't need . . . to have one income protect the other person. . . . Now, maybe, if that hadn't been the situation, I might think differently." She summarizes her perspective on lesbians' and gays' efforts to integrate as equals into American society at large:

> To me, and it's a personal thing, I do not want society looking at me and judging me. No matter what you say, they are not going to accept you as they are. . . . You could wish it for a thousand years, it's not going to happen! . . . I don't have this urge to flaunt it, to declare it.

As the interview concludes, Deborah takes a black and white photograph from where she keeps it discretely tucked away. The picture shows Peggy and her as young adults partying with friends. Deborah's demeanor brightens as she tells about her good life with Peggy. Earlier in the interview, she has said about nearing 70, "You still think like you're twenty, though. I mean, you feel like you're twenty inside. It's funny. I never thought I'd ever look back and, Good God, you're what?!"

In summary, this ardently independent lesbian has led a self-imposed socially restrictive life resulting in a limited social support network in her old age. Healthy and active until three or four years ago, she has been diagnosed with back pain, internal bleeding, and metastatic cancer in her lymph nodes.

Deborah expresses her opinions much more freely than her feelings. She is practiced at speaking in vague phrases and altered pronouns when discussing her lesbianism. Her thoughts appear to contradict her feelings in regard to her relationship with her lover's daughter. She states that she does not think of Kelly as family, but her affect suggests a family-like attachment to Kelly and her descendants. Likewise, she states she does not feel the need to discuss her former life with her partner, Peggy. Yet, her affect brightens dramatically when she decides to take a picture out of hiding to share with the researcher. Like most subjects in the study, Deborah would choose (and possibly did choose) suicide over dependence.

Four months after this interview and weeks before her 70th birthday, Deborah D. died in her Wentworth home. She had not mentioned illness to mutual contacts. Her obituary identified Kelly as Deborah's niece and also listed Kelly's children and grandchildren as Deborah's survivors. Memorial gifts were to be donated to the hospice program that she had helped to establish. This investigator was not granted access to county records to learn her cause of death.

APPENDIX E

Interview #5: Esther E., April, 1998

Having fled Nazi Austria as a child with her parents, 76-year-old Esther E. considers herself an American lesbian. Her physical ancestry is Austrian, "but mentally and spiritually, no." She has spent most of her adult life working in Asia and traveling throughout the world. Prior to her mother's death, she would return once a year to the United States. She would spend three weeks on the East Coast to oversee her mother's affairs and one week on the West Coast where she was free to be herself. Four years prior to the interview, she settled in a West Coast upper-class suburb. Her apartment building's ground floor reception desk offers her the security and isolation that she requires. Her meticulous apartment reflects her diverse interests: the Far East, philosophy, feminism, lesbianism, gardening, hiking, art, and writing.

Her belief system is strongly "influenced by eastern religions, by [their] freedom, by Zen Buddhism." She has been "impressed" with the Unitarian Universalist Church "because it's completely free and liberal and not ritualistic, and I don't believe in one patron saint or god. . . . I don't want to have anything to do with structured religion."

Before beginning the taping, Esther interviews this researcher until she is certain that both parties can fulfill each other's expectations. A "loner" with few acquaintances and fewer friends, she finds that people sometimes choose her for a friend because "I've lived a totally different lifestyle from theirs. . . . I don't like my brains to be picked. Just because it's of interest to them. . . . It's my own business and nobody else's." Nevertheless, Esther does not mind this researcher's inquiries. "You're picking my brains for a purpose." She explains,

> I'm not an outgoing person. I haven't sought any social contact. I could've involved myself a great deal more in the gay community than I did. . . . What I have enjoyed is occasionally younger women wanted to share their life experiences or wanted to get my opinion. I mean, I enjoy what is now called mentoring. . . . I know a lot of isolated groups from my arts interests and my gardening interests and my hiking interests and so on, but they don't interlock, and I don't want them to.

Except for her writers' workshop, her interest groups consist only of women, most of whom are retired, none of whom are out lesbians. Although she loves travel, she has no interest in lesbian travel events because she does not like structure imposed upon her. She would not want to live in a LGBT retirement community if it were based on socialization, but would live in a lesbian apartment complex "that leaves you alone, and you're under no compulsion to participate. But, most gay people tend to be rather social, and they also come in pairs."

Esther avoids interaction with heterosexual couples because she has no patience for discussing what they eat for lunch (she's a vegetarian) or what grades their grandchildren make. As with the previous interviewees, she doesn't care for heterosexual men.

> I find most men fairly intolerable . . . because they're intolerant, because they're insecure, and because I'm not into beer drinking, and I'm not into ball games. . . . Some of the [single] men that I know are gay artists or whatever. We share interests.

Esther traces her self-sufficiency and her emotional distancing to her early childhood. Her father, "a very good provider" and "very intelligent," was also a "bully" who "took absolutely no interest in me as a person, because I was a girl." He came to respect her as a teenager for her intelligence, "but we never related." Extended family "power politics" was intertwined with Austria's pre-war politics, which "made my childhood miserable and spoiled my parents' marriage." As a young adult, she broke with her father's relatives without regret to "create my own life." Consequently, she is "very much anti-family, because, well, my thesis is, you can choose your friends, but you can't choose your family."

At age eleven, Esther approached her mother, Mary, about a problem with a classmate. After listening, Mary said,

> "Look kid. You got yourself into that. You get yourself out of it." That was the last time I asked my mother for advice. . . . This is when I learned to cope on my own. . . . My mother was stubborn, and that stubbornness I have inherited.

Esther's father died when she was 22. Post-war finances forced Esther to continue living with her mother, who was working as a commercial artist and drawing Social Security. Neither had medical insurance. Although Mary bought groceries, she saved the rest of her income at Esther's insistence. Esther worked, supported the two of them, and attended college at night. In 1952, to get away from her mother after college, she eagerly accepted an overseas assignment. She cherished her independence and the different cultures. However, she still supported Mary and helped her to navigate "papers and things and documents," on her yearly visits. Her mother "did not feel neglected" and "didn't really want to know" about Esther's life.

> [My mother was] eventually very proud of me, which I heard from a third person. Never touched me. She never praised me. So, from my point of view, we were not close. But she felt very close, and that was important to me. I was her support. That was my responsibility that I fulfilled.

This responsibility was challenged when her mother began to physically deteriorate in her 90s. Between Esther's yearly visits, Mary's honest maid took care of Mary's banking. Mary's concentration and ability to perform simple tasks became impaired, so she required a second housekeeper. She lived independently in a retirement community. The community's social worker gave Esther recommendations for long-term care facilities, which Esther was secretly investigating. Unexpectedly, Esther's mother collapsed and was hospitalized. "It was really as if Mother had guessed it. She waited until I came [home from Asia] before she collapsed."

Esther knew nothing about Medicare, AARP, or the American health care system. Although she knew of Mary's desire for no intervention, Esther had to make a quick decision, so she told the hospital staff to "give her a fighting chance. . . . Then it was up to her. . . . It was a murderous decision that I had to make. . . . It was agonizing. . . . I authorized the absolute minimum."

Mary's doctor was "young, brash," but Mary had chosen him because he would make house calls. Esther and the doctor immediately disliked each other. "He was the back-slapping kind, and he was fat and handsome and thought he was the world's blessing to old ladies. . . . I mean, she could have been his grandmother. And his entire manner: much too jovial."

> The doctor and Esther plunged into a power struggle. The doctor insisted, "You are killing your mother." . . . He didn't see the stress I was under. He didn't give a shit. . . . I would've expected him to be thoughtful of my motives and my considerations, because it wasn't unthinking or anything. I said, "My mother had said, 'No interference.'" She's had ninety-four years. I said, "If she was sixty, that's a different story." So, he hassled me morally, and I had to find out who actually would have jurisdiction.

Esther spoke with a "very concerned, very thoughtful intern," who explained that Esther had the authority to make decisions for her mother. The doctor was the secondary authority, and the hospital the tertiary.

> [My mother's doctor] never stopped hassling me. . . . It was one of the most

> difficult and painful periods of my life. I think he wanted to assert himself. . . . He wanted to show his prowess and probably, maybe statistical figures of how many geriatric patients he could save. I don't know. And he really didn't give a damn about her. . . . I was there on my own, on my leave, faced with the situation. I had no background information.

The social worker invited Esther to come into her office, where she locked the door.

> [She] more or less encouraged me to break down. For the first time in my life, I did. . . . I needed somebody to, well, literally or whatever, pat my back. Just to listen. Just to be a support. And she did; she was great. . . . She said, "Just let go, Esther." And I did. By that time I had made my decision.

Esther has never received psychotherapy. "Pulled myself up by my bootstraps," she explains. She describes the feeling of breaking down:

> [It felt] peculiar. . . . It was . . . something I had never done. I wouldn't have done it if she hadn't invited me. She saw the need. I appreciated that. It hasn't happened since. I hope it'll never happen.

Esther's mother "rallied," then "faded." Fortunately, "it was a public hospital, I think, county hospital, and they were willing to keep her on, on the Medicare" instead of discharging her to a nursing facility. She didn't recognize Esther. "Then I had to make another agonizing decision." Because she didn't know if death would come in days or months, Esther decided to return to her job in Asia. She paid Mary's maid to visit her and to keep Esther appraised of her mother's condition. Mary died three weeks later, and the maid arranged for cremation.

Esther eventually returned to the U. S. to dispose of her mother's possessions. She saved only one suitcase full of items. She experienced "emptiness" at the mortuary when making internment arrangements with the social worker and the maid. Still, Esther recalls her primary connection with Mary:

> [I felt] a strong feeling of responsibility. So, suddenly I wasn't responsible for anybody. . . . It was strange. . . . I'm very pragmatic. I am not a sentimental person. I tend to make the best and the most of any given situation. It's not always easy.

In many ways, Esther's discourse can be summed up a few words: responsibility, independence, self-determination, and intelligence. She has seldom requested help from anyone.

Recently, Esther received radiation treatments for spleenomegaly, an enlarged spleen, caused by myelodisplastic disorder, a blood disease she has had for 14 or 15 years. The spleenomegaly left her extremely weak. Because she needed to visit her CPA, she asked two women friends who had previously offered their assistance to drive her. When the friends arrived at Esther's apartment, she could not walk, was in "excruciating pain," and her voice and hearing were significantly diminished. They arranged to mail the papers to the CPA, and then they discreetly called the director of the local LGBT center. Esther praised the director for helping her without taking over.

> She intercepted my phone calls. . . . She called the doctor. . . . She alerted a few other women to come here, and she grabbed my laundry and did it one day. And one other woman came and cleaned the kitchen floor because [the radiation treatment had given me] uncontrollable diarrhea. . . . Everybody offered to bring me groceries, . . .and they helped me with transportation. . . . She was very tactful. I mean, everybody knows that independence is very important for me. But, she saw where her help was needed. She didn't interfere.

While she has acquaintances around the world, Esther considers these women "friends in the true sense." She contrasts their helpful approach to that of the hospital staff who "very obviously wanted to do a procedure simply because they were afraid of litigation." Esther refused and checked herself out of the hospital. "I didn't want anyone to get into trouble because I was not following orders. Taking responsibility for yourself, to me, means that you really take responsibility, come what may."

Hospital staff called her several times to ascertain that she had notified her friend who has medical power of attorney. "They were scared I wouldn't survive the weekend." However, that friend was himself hospitalized.

Esther plans to change her medical power of attorney to someone who is healthier and younger than she. In her wallet, she keeps a living will, instructing emergency personnel that they should not perform heroic measures or put her on life supports.

Having retired from many years as a multilingual trade specialist, Esther lives off investment income and Social Security, for which she is grateful. She plans to amend her will to include a bequest to the LGBT center. Other funds will go to the Ms. Foundation and to some old friends' grown daughters. In these ways, she wants her entire estate to advance women's educations.

> [So that] they don't have to go through the same shit that I and my generation had to go through [such as] the suppression and the professional limitations. I mean, my particular generation was aided by the war, if you wanted to take advantage of it, because there weren't any men around. And, this is how I got my chance and climbed up the executive ladder, but then . . . when the guys came back, . . . many of [the women] wanted to be homemakers. Well, bully for them. I'm all for choice. . . . And, I grabbed mine with all fours.

During World War II, when Esther was 20, she married a military man 12 years her senior. Although she recognized, "I wasn't somebody who was cut out for living with anyone," a marriage certificate offered certain advantages: He could receive leave to visit his wife and could assign part of his pay to her for savings. When he returned after the war, she realized she had outgrown him. After a year, she filed for an annulment.

Esther believes that her 20-year-old cohort was naïve, unlike today's 20-year-olds. After her divorce, when she realized her attraction to women, she told herself,

> "No, for God's sake, you've got enough handicaps against you, being a woman in this world, in [Asia]. You don't need that on top of it." So, I pushed myself. But, I had fun with a capital F, okay? And, very soon learned to separate sex from everything else. And, I enjoyed it, on a certain level.

Although she tried lesbian bars on the East Coast, she felt shut out because "women came in pairs." As a single woman, she was considered a "predator," which she denies, and "they shot daggers at me." Consequently, she suppressed her desires and had many enjoyable sexual relationships with men.

The lesbian community in Asia had no formal support networks such as bars or other meeting places. When she did meet lesbians, they were not up to her standards. During this time, she cautiously fell in love with her friend Pauline. Their eight years together is the only long-relationship of Esther's life. After Pauline left her, they remained friends. They still travel together once a year.

Since the couple's breakup, Esther has "dabbled" with a few "desperate" women, essentially "servicing them. . . . I'm not into commitments, and I'm not that sexually active anymore, and, for awhile, I still had very strong sexual urges. Well, there's always self-service, you know."

Despite a long history of numerous sex partners, she has never come out to a health care provider. "I don't volunteer any information, let alone sexual information. . . . I consider it irrelevant." She would answer truthfully if a doctor asked directly, especially in America's present more tolerant climate.

As with Deborah D., health care providers have stretched her diagnoses to fall within the categories required by her health insurances. For instance, in her sixties, she broke her hip while skiing in the Alps during a business trip. Her doctor documented that she had "slipped on ice" so that her company travel insurance would cover the treatment and physical therapy. She was impressed with the European hospital system that initiated her physical therapy on her second day of hospitalization. She began upper body strengthening in preparation for walking with crutches up a flight of stairs to her Asian penthouse office. Upon returning to Asia, "I went on crutches to the physiotherapist who pitched me higher and higher." Priding herself on personal motivation, Esther reported that she has experienced complete recovery from the hip fracture.

Esther also hopes for a full recovery from her spleenomegaly. To improve her stamina and strengthen, she has initiated reconditioning exercises and has requested a physical therapy referral from the HMO to which she has assigned her Medicare. She also requires weekly injections. In this situation, she has again enlisted sympathetic health professionals to stretch the truth. A home health nurse had planned to teach Esther to inject herself subcutaneously, a task she cannot imagine doing. The nurse then asked her leading questions in order to document that Esther's hands are "trembly" and her "vision isn't so good." However, preauthorization requirements have delayed her shots by a week, which Esther finds frustrating.

Esther's extreme independence facilitated her present weakened state. "I have always been self-reliant, maybe too much so. . . . I've brazened it out for myself." Before she left Asia about 1 ½ years ago, her physician had told her to "watch" her enlarged spleen. "Well, how do you watch a spleen?" she shrugs. The physician also referred her to an endocrinologist who diagnosed osteoporosis.

> That's normal for women my age. Didn't particularly scare me, but I said, "No, I don't want to fall down and become incapacitated." . . . So, there is a new medication for that now which I took. It's expensive, but, anything to avoid brittle bones. And, it gives you a whole long list of side effects that you have with that. And I managed to get them all. . . . They were discomforts. They were not pain. It affected my stomach, affected my digestion, affected my urination, but as I say, "Grin and bear it if this is the price I have to pay." Until last fall, when I suddenly found a huge lump in my side. With that, I went to the doctor. That turned out to be my enormously enlarged spleen. And all these side effects were not caused by the osteoporosis medicine, but by the spleen pushing against . . . my stomach, my intestines, my urination system. When I had to go, I had to go, and no two ways about it.

Subsequently, her doctors initiated radiation treatments in an effort to avoid removing her spleen. Her delay in alerting the doctors to the effects of the radiation treatment resulted in her nearly dying, as previously described.

In the long term, Esther would be willing to accept "a bit of help" with housecleaning and similar chores. As with all previous interviewees, when asked what she would do if she could not physically take care of herself, she states that she plans to commit suicide.

> [I'd] kick the bucket. But, I'll need help for that. . . . There is the Hemlock Society to which I belong. Now, if I don't feel like a nursing home or any of these things, if I can't take care of myself physically or mentally, if life is not worthwhile living, no. I want to finish it.

She states that her end-of-life decisions will be influenced by her early life experiences and her experiences with her mother's death, nine years prior to the interview. The friend who has medical power of attorney has agreed to help "implement" her suicide, if necessary, but he "doesn't agree with me." An artist friend, who knows of her plans, lives in a distant city, so "he can't help very much, either." She has discussed with her doctor her desires for pain relief and no resuscitation.

> If necessary, give me a shot . . . to speed it up . . . . I don't know whether he goes along with that completely. . . . I mean, whatever is legal. You know, they have their legal limitations. . . . Look, I've had a very ample and very busy and very full life and whenever I'm ready, I'll be ready. . . . if I'm not mentally or physically in control.

Asked to be more specific, Esther replies, "I don't know. I suppose it's typical that I have not thought about it in detail." The few times that Esther brings up suicide, she quickly drops the subject, apparently not because of its social taboos, but because her personality dictates that she gather all her facts before charting a course for herself.

Esther will not speak of her future, "I'm sorry. I'm allergic to the word *future*. Can you use another word?" She settles on the phrase *the rest of my life*. She jokes that she is an "optimist" because she keeps a calendar.

During the rest of her life, Esther hopes to continue her experiences in "ecological travel," to very remote locations around the globe. Unlike her younger years, she now prefers to travel with a companion. "A trip is an enterprise. I enjoy it more by sharing and sharing the, uh, well, the hazards."

Provided she recovers sufficiently from spleenomegaly, she will continue to volunteer at an art gallery and as a propagator at a non-profit garden. She hopes to grow strong enough to join her group for their two-hour hikes. However, she is unaccustomed to walking up hills because she has been a smoker most of her life.

About her life after her retirement and prior to her present illness, Esther comments, "It was the first time in my life that I could really indulge myself in a variety of things." Work had always taken priority over leisure, which was "to be shoved aside." After retirement, she purposely pursued interests in different fields "so that I was stimulated. . . . I need a structured life without the pressure."

In summary, Esther E. is a complex , self-reliant, highly intelligent woman who believes strongly in personal responsibility. She prizes independence, solitude, and self-imposed structure. She has seldom become emotionally involved with people. Illness has allowed her to experience the help of friends. Her approach to life's challenges is consistent: She gathers pertinent information about her subject, analyzes her options, applies her formal and informal resources pragmatically, and persists until she succeeds. She plans to use these skills to recover from her illness, to adapt to disability, or to end her life.

APPENDIX F

Interview #6: Frieda F., April 1998

Sixty-six-year-old Frieda F. considers herself a "lesbian" in California, but a "bull dagger" in her native urban city, fictitiously named Shiloh, which is located in the northeastern United States. She claims "Afro American" and Native American heritage and a middle-class upbringing.

Frieda's 96-year-old mother lives in a Shiloh nursing home. Her married sister, who lives nearby in Shiloh, watches over her mother's needs. Her California family consists of her former lover and current roommate named Casey, a former landlady, and three women from her Buddhist temple. Casey, an educator and writer, is her primary fictive kin. The two live in a comfortable two-bedroom third-floor apartment in an urban area of Northern California. Energetic and healthy, Frieda easily carries groceries up two flights of stairs.

Frieda has early memories of the workings of the U. S. health care system. Unlike Caucasian people, who lived in rich and poor sections of the city, "Blacks were lumped together" regardless of income. Ahead of his time, their Yale-educated physician treated patients with "herbs and vinegar" as well as prescription medication.

"We had our own business and we did have more than most." They lived on the edge of the Black section near a liberal area that was relatively safe for interracial couples and gays and lesbians. Consequently, she grew up playing with Black children and White children. With her African American friends, "we had an expression, 'You're my nigger if you don't get no bigger.'" She was age 10 when a Caucasian child was reprimanded for calling her a nigger. However, family and community support against racism did not carryover to heterosexism. Otherwise-polite people would murmur the word bull dagger, the African American slang for a butch or mannish lesbian

> I can't tell you the hurt that word [bull dagger] has caused me. . . . I remember as a child in the thirties. . . . You can't imagine how older Black people can say it to cut your heart out. Like it was the worst thing in the world to be. It was murderer, two steps above bull dagger; rapist, a step above bull dagger. That's how they made you feel. . . . They, the outsiders, the so-called straight world. . . .

As a child, Frieda heard men caution against allowing bull daggers to get their women.

> I felt a mixture of fear and respect. . . . If I'm that, I have powers. I was so proud of them 'cause I knew one day I was gonna be that. . . . I didn't exactly know what it meant, but I knew it was me.

Recently, Frieda and Casey have encouraged African American lesbians to reclaim the word bull dagger, so it "makes me strong, . . . [not] small . . . and hurt."

Nevertheless, Frieda still has difficulty referring to herself as a lesbian, because it had a "dirty" connotation when she was growing up. A believer in lifelong personal growth, she has challenged herself to learn to use the word lesbian freely.

Although health care was generally segregated in the 1930s, Frieda remembers Caucasian people in the hospital where her sister became one of the first premature newborns to be kept alive using an incubator. She thinks her family's light colored skin may have opened doors for them. The family did not have health insurance, but "things weren't that expensive then."

Because her mother never learned to drive, 11-year-old Frieda began driving the family car. She transported her sick father to the hospital and her sister and herself to receive inoculations.

In 1948, her father died at age 48 of an unidentified lung disease contracted during World War I. Seventeen-year-old Frieda was left to be "the man of the house." Because the family financially depended on her father's locksmith business, Frieda became the first African American female locksmith business owner in her region. "I had to take over everything, including taking care of my mother and my sister." Her mother has always been the type "that she needed someone to care for her, and she prefers that." Frieda also studied pre-med in college for three years. However, she dropped out so that her family could live off of her college savings. Not one to completely relinquish her dreams, Frieda plans to return to college soon for a bachelor's degree in business.

As a young adult, Frieda "hid" in the gay/lesbian/interracial section of Shiloh. Ten years ago, Frieda was preparing to retire after 25 years as an investment banker. Her mother's forgetfulness prompted Frieda to take her into her home. As when Esther E. and her mother lived together, Frieda "felt sort of trapped" and felt her lesbian life was over. She spent long days away from the house only to come home to find that her mother had forgotten to eat the food she had left for her to microwave. However, "the Black population . . . has a thing about putting your mother in a home. I don't know, maybe it's other nationalities also, but I know the Black people. I mean, it's a bad thing." Mother and daughter lived together for about 18 months.

When Frieda was preparing to move to California, Casey offered that her mother live with them. Frieda knew her mother would be jealous of any attention Frieda gave Casey. Although Frieda's sister had a large home and no children, the couple both worked, so they declined to take in the mother. Frieda spoke to religious leaders and prayed. "I was her daughter. I could do everything for her, I thought. And it was killing me. It was the hardest time of my life, I think."

When informal support systems had failed, Frieda sought formal support. A social worker interviewed the two daughters and the mother and helped her mother decide to go into a retirement home that Shiloh's paper rated with five stars. The mother likes being with people her age and enjoys being taken care of. Frieda laments the turnover in nurse's aides, and like Bernie B., she believes this is because "they don't pay 'em hardly anything but minimum wage."

Angry that Frieda moved to California and left her to watch after their mother in the nursing home, Frieda's sister did not speak to Frieda for two or three years. "She forgot the fact that I took care of [Mother] all of these years. And her too! She's forgotten that." After prayer, Frieda made the overture to repair the relationship.

During the interview, it occurs to Frieda that her sister may want Frieda to acknowledge that she has worked well and responsibly on her mother's behalf. She determines to extend the praise during her next phone call.

Frieda can tell from her weekly phone calls that her mother is deteriorating. She still feels guilty, especially when two "old fashioned" Shiloh ex-lovers berated her for putting her mother in a nursing home. Still, Frieda believes their criticism is a cover for their unspoken complaints about her moving away from Shiloh.

While Frieda's mother is quite demanding and unappreciative of her children, she refuses to tell doctors more than, "I'm fine." They recently discovered that she is blind in one eye. She refuses to wear glasses because, "I can see fine," and denies that arthritis bothers her, saying instead, "I just want to sit in the wheelchair." Frieda adds, "She's always proud of the pain she can endure." She believes that her mother is afraid of doctors. Even as a child, Frieda had to make all dentist and doctor appointments for the family, as well as driving the family to the appointments.

Just as Esther is much like her mother, Frieda believes she has her mother's high pain tolerance. Also, her locksmith father taught her to apply pressure to a cut and continue working. "You were always . . . poking a screwdriver in your hand. . . . You couldn't stop to cry about that." Casey screamed and insisted that Frieda go to the hospital when she punctured her foot with a dropped drill bit. Frieda had dabbed the wound with tissue and continued working.

Other than the aforementioned wounds, Frieda believes in seeking health care at the first sign of a problem, then following the doctor's advice, including exercising. From her early adulthood, she has undergone annual physicals. She never came out to her doctors. "Nobody" in Shiloh was out. When doctors ask, "Do you have any problems with intercourse or anything?" she simply answers, "No."

Frieda credits her good health and her mother's longevity to The Doctor's Book by which her mother reared her children. Published in the 1930s, the book advised readers to avoid frying foods, to eat lamb instead of other meats, and to eat a lot of vegetables. Her diet was quite different from that of her African American neighbors.

In California, Frieda belongs to a Kaiser HMO plan through her customer service agent job. She requested a Black female primary care physician in order to vicariously live her thwarted dream of becoming a doctor. She is satisfied with the Chinese woman doctor Kaiser assigned her instead.

Kaiser automatically contacts her for her annual checkup appointments. Tests include a complete blood count and whatever the doctor deems necessary for a woman her age. She receives an annual Pap test and a mammogram every other year. About the mammogram, she adds, "Cold steel. Mashing you. A man thought this up!"

Frieda has had three benign tumors removed from her breasts. Also in her late 30s or early 40s, her uterus was removed along with about 7 benign tumors, ranging in size from "a cantaloupe on down to a lemon." Of the hysterectomy, Frieda says,

> Being a lesbian, . . . I consider myself butch, and periods were not the thing that I wanted. Whenever they'd come around, it would sort of like take me down a peg. You know, I didn't feel so butchy. [The hysterectomy] was the greatest thing that ever happened to me.

Five years ago, Kaiser discovered "polyps in my intestines." Frieda was able to watch their removal. "They have a TV monitor and they put this camera in your rectum. . . . It's the most fascinating thing!"

Her only other illness has been thyroid surgery. She takes a thyroid replacement pill.

Frieda qualifies for Medicare, but prefers to stay with her regular plan until she retires. She does not have enough money set aside for retirement, so she will be somewhat dependent on Social Security. She has 401Ks, stocks, and insurance policies, but she lost a lot of money on a bad investment. Also, the cost of living in California is high.

> You always think you're gonna get [financially sound], but something always happens, you know, to wipe you out. . . . There's nothing I can do about it, and worrying just gets me into the nursing home sooner. . . . This is part of being a Buddhist also, day by day, and it's gonna work out.

Frieda will probably work another 10 years. After her move to California, she tried retirement for two years, but she grew restless and also needed the money. Seeking an easy, enjoyable job, she accepted a position in which she processes parking tickets.

> As long as I feel good about getting up and going to work, I will continue, because I enjoy working. It keeps me going. It gives me energy. It's a nice feeling to have a place to go every morning.

Frieda enjoys imparting Buddhist philosophy to upset customers, reasoning that a parking ticket "is not life or death." She keeps a thick file of thank you letters from customers. "I feel that this is what life is about: having comfort and comforting others."

Frieda contrasts this approach with other workers who shout back at clients. "I think it's because I'm older. I've had more experience. I'm more grounded, and I can talk to people."

Regarding her health care future, Frieda foresees herself with her ex-lover and best friend, Casey.

> We have no family, because we have no children, you know. . . . So, Casey is the only family I've got. And I'm the only family she's got. She's got two brothers [who are] straight, and they're all wrapped up in their families. . . . So, we're gonna take care of each other. . . . And, I think this is what lesbians do mostly.

Casey, who is 21 years her junior, has medical power of attorney for Frieda. She will inherit all of her assets. Frieda's living will specifies no life supports, and it authorizes organs to be donated to science.

Frieda concedes that "Casey might get a lover." In this case, if Casey "doesn't want to be bothered with me, a nursing home is fine, although I wish there was a lesbian nursing home around somewhere."

Although she doesn't "have a problem with gay men, an all-lesbian retirement home would be paradise." If plans with her informal support system do not work out, and "if I was a big burden on whoever was taking care of me, . . . then I would go in [a lesbian retirement home] and get professional help." Her second choice would be a Buddhist home, but a lesbian home would "be more fun." Ultimately, she is prepared to go into a "straight" nursing home, but she would do so as an out lesbian. "At that age or whenever that time is, it won't matter. . . . It might get me a room to myself! . . . Where I wouldn't have to share a room. It might work to my benefit!"

Were she to become seriously incapacitated, she would consider suicide.

> [I'd] figure it's time to just pack it in. . . . 'Cause I don't have any problem with dying, . . . but I don't want to be a burden on anyone. Because I've seen how hard it is on people. My mother, you know, I've lived that life, where it was a burden, and it didn't have to be.

Frieda would passively allow herself to die. "I just have this sort of thing where I could just die if I wanted to. I could say, 'This is enough of this.'"

As a young adult, Frieda tried to kill herself when a lover jilted her. She swallowed a bottle of over-the-counter sleeping pills but "didn't even go to sleep." She grew nauseous and vomited pills. She decided,

> If I don't do it this time, I might never get anymore [chances. As a Buddhist,] we're taught that life is the most precious thing that you have, in fact, it's the only thing that you have, that you are in control of. . . . If I was a useless, . . . I'd just will myself to die. I'd just let go and just go on.

In her immediate future, Frieda plans to enjoy a satisfying social life. She and Casey occasionally attend events sponsored by a group of African American lesbians over 40. However, the events are in a city approximately two hours' drive from their home. She does not care to avail herself of resources at her local LGBT center, because "when you live with Blacks only for most of your life, you like to get together with just Blacks."

Frieda will also preside over a lesbian commitment ceremony. She was ordained a Pentecostal minister in 1953. She is proud to have spiritually married several other lesbian couples.

In conclusion, Frieda F. is a self-directed woman with a rich spiritual life, informed by her Buddhist religion, African American culture, and lesbian worldview. She places value on interdependence among her fictive kin, personal and family responsibilities, working, staying healthy, being happy, and helping others to find happiness. She believes in doing what she can to help ensure her financial security, but chooses not to worry about the uncontrollable. If she were to become a burden, she would will herself to die.

APPENDIX G

Interview #7: Gloria G., June 1999

Sixty-two-year-old Mexican American Gloria G. taught middle school students for 40 years. She retired two years ago. She co-owns a meticulously kept middle-class home with her partner of 15 years, Maggie. Gloria left her family in the Midwest at 22 because "I've always wanted to see what was on the other side of the mountain." Her Northern California urban setting is "the place to be" in terms of weather and diversity.

The couple has no children, but Gloria includes a five and one-half-year-old goddaughter in her "family." Maggie, along with the goddaughter, the godchild's mother, and a few friends, are Gloria's "here family." Her birth family still lives in the Midwest, where she grew up. It includes her 84-year-old father and her married brother, eight years her junior, but she does not include her step nieces and nephews. Gloria's mother is deceased.

Gloria has nothing but praise for her birth family. Both her parents had "terrible upbringings" by alcoholics with "diseases. But these two people rose beyond these problems. . . . Dad is not your typical Mexican male. He's not 'tortillas on the table at 5:00.' . . . He was always busy, as he says, 'chasing the dollar.' . . . I've always said that had God allowed me, I could not have chosen a better mother, father, or brother."

Although currently 1, 500 miles away, Gloria draws on her family history of reciprocal financial and emotional support for her present strength. Despite their poverty, Gloria's parents presumed their children would graduate from college. Her mother had only a fifth-grade education. Her father, who had been abandoned at age 10 at the home of a German couple, had no formal education because he did not want to begin first grade with much younger classmates. "I've oft times thought, 'If [my parents] had been given the advantages that they gave my brother and I, how far might they have gone?" Gloria attended college through the patronage of a wealthy woman in her hometown. Gloria also worked several jobs. Upon her entry into the workforce, she honored her agreement to pay the woman back, without interest, so that others may receive her patronage. "This is part of destiny and part of 'qué será será.' Had she not [taken] care of financing my education, I don't know how it could've happened." In turn, Gloria and her family helped put her brother through college.

Despite, or perhaps because of, her excellent relationship with her birth family, Gloria has never come out as a lesbian to them. As a young adult, she could not afford to go home often. When she brought girlfriends home with her, their closeness blended into a family of

> huggers. . . . I never had to share. . . . [It's a] scary thing. It's an admission that would have caused *them* consternation, not me. . . . And also, I've always adhered to the situation that if they don't ask, they don't want to know. So, why burden them?

Asked if she felt they may be waiting for her to tell them, Gloria comments, "Nope. I choose not to think that. . . . All my justifications are mine. . . . But, I never felt any less loved. . . . I don't think it would've changed anything."

Gloria supposes that her mother may have blamed herself for Gloria's orientation. Then muses, "Actually, I've never really thought it over. Maybe it is my own denial or hiding or not. I don't know. . . . I didn't tell them because I didn't want to bother them, hurt them." She did not tell her straight friends so that they would not need to lie for her if someone should ask.

She goes on to say that she had been especially careful to guard her secret while teaching. In her 40-year career, she only came out to one teacher, whom she had known for 20 years, because she needed some advice about her goddaughter.

While coming out could have hurt people, Gloria also realizes that her closeted life may have hurt others. For instance, when relating weekend activities to a coworker,

> I always had to change the words. . . and leave stories out. . . . I always had two lives. I had my work life and my personal life, not to say anything about my family life. . . . You learn. You adjust. . . . A woman's gotta do what a woman's gotta do. . . . You hope not to get too comfortable with the person so it should slip. And, I think I curtailed some of my times with straight people, too, because it was not worth the effort.

As with Frieda F., Gloria underwent a hysterectomy for fibroid tumors and has enjoyed her freedom from menstruation since 1977. Until two years ago, doctors had performed annual Pap tests. The doctor then told her she did not need the test because she has had a hysterectomy. She doesn't know if she has a cervix. She guesses that "the whole shooting match was taken out."

About a year ago, she had a skin rash of unknown etiology, which she has dubbed her "stigmata" because it occurs bilaterally. She says that doctors "never know anything. They lay a lot to the door of stress, and it was just after I got my computer so maybe (laughter)."

In general, Gloria feels fortunate that she is healthy, strong, and active. Besides breast cancer, her mother had diabetes and "stroke syndrome." Gloria recalls, "She was laying in her little sickbed once, and she said, "Honey, I'm sorry that all I'm able to leave you is my illnesses." What a character! But, she was serious about it, though. It was hurtful to her."

Through her retirement package, Gloria has Kaiser HMO medical coverage with free doctor visits and one dollar prescription co-payments. Her only prescription is hormone replacement therapy.

Gloria states that she isn't good at asking doctors questions because she did not go to doctors as a child and because she wants to finish her appointment and get on with her day. Afterward, her partner will often think of questions she should have asked.

When her primary care physician retired and when she needed a gynecologist and a dermatologist, she was content to take "the luck of the draw," that is, whichever doctors Kaiser assigns her. She's never come out to a doctor. Gloria has been concerned that if the fact of her lesbianism were shared, it might lead to denial of coverage.

> I've thought that I should. . . . It might change their diagnosis or their interpretation of information that I might give them if they realize that my sexual situation is not like they think it would be. . . . It just doesn't seem to be that important a thing. And, I think at one time I thought, "That's not a good idea for them to know, because then it would be information that could be shared by other groups." . . . I just thought, "Why bother? It's a can of worms that maybe is not worth opening

At age 23, on December 8, 1960, Gloria experienced her most serious medical crisis. In a car accident, she received a three-fingers-deep frontal skull fracture. A neurosurgeon at a highly reputable California hospital treated her. The doctor believed she would be unable to work throughout the following semester. In spite of this, with characteristic determination, she returned to teaching when school started the first week in January. For her, the worst aspect of the accident was that her parents knew her to be missing for 54 hours, but did not know if she was dead or alive. "It had to be hell." To alleviate their worry, she opted to have cranioplasty performed in the Midwest so her parents could be with her.

Gloria's early lessons have stayed with her. The family members were treated by an African American doctor, who allowed them to pay him in installments. Her parents taught her, "We aren't rich enough to buy anything in cash, so keep your credit impeccable." Poverty did not prevent the children from receiving immunizations. "Mom was a firm believer in all those kinds of things. She put her family first."

Regarding her future health and health care, Gloria will probably assign her Medicare to Kaiser. Since age 17, she has been addicted to cigarettes, but believes her two to four cigarettes each evening will not cause health problems. She limits her smoking because "I don't like to have anything that totally controls me."

Gloria also applies her family's "qué será será" philosophy of to her health care. Despite her mother's death from breast cancer at 71, she does not believe it is important to check her DNA for the breast cancer genetic marker. "My mom used to say, and Dad, too, that if it's your time to die, a mosquito bite will take you." She does not perform breast exams although she thinks she should. She depends on her doctor's yearly exam and on mammograms. Moreover, she would not be averse to undergoing a double mastectomy, if necessary. "I wouldn't dawdle around. It's just what you have to do. In fact, I know it would improve my golf and pool game if I didn't have those little things sticking out there!"

Gloria hopes for lifelong health. "I'd like to go to bed one night with great plans for the next day and then not wake up." She prays a similar dignified fate for her father and brother because they all had to endure her mother's slow death.

Gloria and Maggie have wills, powers of attorney for health care, and living wills. Should Gloria lose some of her independence, Maggie or her informal support system will help her. If this system should prove inadequate, she might be willing to approach formal support agencies.

Gloria hopes that California will follow Oregon's lead in legalizing euthanasia. She wants her estate to go to her family and friends, rather than her being kept alive to pay for a doctor's swimming pool. A suicide pill with a long shelf life would allow her to "live every minute that you can as fully as you can. But the moment a decline sets in, a major decline, I'd just as soon be gone."

In the event of illness, Gloria is willing to allow home health services. She kept the bathroom grab bars that she installed for her mother's visits. However, she may kill herself before allowing someone else to bathe or toilet her because the thought is repulsive. Realizing that her need to be active may change as she ages, she will assess the situations as they arise. She fears a failed suicide attempt might leave her in a vegetative state.

Although her partner would not help with Gloria's suicide, she has three friends who hope to help each other if they can do so without implicating themselves with the law. For legal reasons, Gloria once denied suicide assistance to a friend with AIDS. She believes an ideal assisted suicide law would include a clause that requires doctors to uphold "the dignity of a person, not just the life of the person." Also, she believes that a person with a mental illness that cannot be alleviated should be allowed to "opt out" of life.

Gloria's belief in God is solid, and she believes God does not have a problem with her lesbianism. Lutheran as a child, she was a member of the local Congregational

Church until recently. Her partner grew up there and was the associate minister for nearly 30 years. Gloria believes that the church board forced Maggie's retirement "because she spoke her mind and made them look inept in a couple of situations." Also, Gloria thinks Maggie's lesbianism became apparent when Gloria began attending the church. "When you look at me living with her, I don't think anybody looks at me and doesn't think 'lesbian.' I think I'm very obvious, always have been." Regarding her dismissal from her church, Maggie "was very hurt and still recovering from that, I'm sure. Don't think she ever will. We may never go to an organized church again."

Asked if she would ever turn to a church for any type of assistance or support, Gloria replies,

> I think I'd go to the LGBT Center before I'd go to a church. Not because I'm anti-church, but because I'm pro-me, and I can be me at the LGBT Center. I've never come out at church. People may think what they wish, but . . . my vocalizing was only in the choir.

Gloria has also sung in a women's chorale, in which she was out, but she has taken a sabbatical from the group. In its place, she has begun flying lessons.

Unlike Frieda F.'s African American experience, Gloria believes that she has experienced more discrimination as a Mexican American than as a lesbian. Numerous times, she has been assumed to be a laborer or delivery person rather than a customer. She thinks that "white bread" people may assume that her obvious lesbian appearance is characteristic of her Mexican heritage. At times of discrimination, she finds herself speaking with "fifty cent" words to prove that she is educated, and "I'm as good as you. . . . This is not your regular riffraff. This is your superior riffraff!" As a child, she saw signs in Texas reading, "Mexicans not served."

One word she has not yet grown accustomed to is *lesbian*, which she refers to as *the L word.* In the past, she has used the term *gay* and has only recently identified herself as a lesbian. Besides the "ugly connotation," she is disgruntled that lesbians are "stuck with the big ol' scientific" word while gay men "have such a neat little ha-ha-happy term."

In summary, Gloria is a witty, active, healthy retiree with a limited smoking habit. She speaks in terms of what she thinks rather than how she feels. She is cautious with her friendships, especially with heterosexuals who may inadvertently learn that she is a lesbian. She believes that coming out may be hurtful to some of her support systems, yet not coming out can also be hurtful. Although she has never come out to a health care provider, she thinks it might in some way benefit her care.

Gloria loves her birth family and is proud that she and they have risen above their previous poverty and limited educations. Gloria is also proud of her Mexican American heritage. She responds to prejudice by attempting to prove her intelligence. Gloria is independent and believes in self-determination, including the right to end her own life if her dignity were at stake. While she does not like to be controlled, she is nonchalant about her health and her health care providers. In this regard, she believes what will be will be, and her fate is in God's hands.

APPENDIX H

Interview #8: Hillary H., July 1999

Hillary H. did not expect to live to be 60, much less her 70 years. Her mother died at 47 of stomach cancer, and her father died at 60 of heart failure. Living this long has been "a big shock" both financially and emotionally. This moderately obese lesbian, whose ethnicity is "a wonderful mixture" of African American, Native American, Spanish, and Anglo, resides in a lower-class neighborhood in a semi-rural Southwest Coastal town. She and her "significant other" own the home as tenants in common, to insure right of survivorship. However, the land belongs to an association.

Hillary has a will, and she and her partner have reciprocal powers of attorney. They had planned to buy a home for their retirement from savings that never materialized. Hillary had also planned that her significant other would take care of her as she grows increasingly disabled. However, her partner was recently diagnosed with "dermamyocytis," a paralyzing disease of the skin and underlying muscles, that has left her dependent in all her activities of daily living. The significant other had to move in with her sister who lives a two-hour drive away. Because of this, Hillary is uncertain whether or not she should change her power of attorney to someone who lives closer. But, she supposed she will leave her designations as they are.

Hillary counts three careers in her adulthood: She taught elementary school for 25 years while singing professionally, "just as a pastime, and I got to see most of the world." Later, she counseled for at-risk reentry college students and taught African studies. "Really, I'm a teacher at heart, so, it doesn't matter what else I do." Unable to retire for lack of funds, she became a children's librarian, in which "you're just teaching all day." Increasing disability compelled her to half-time status. Recent funding cuts have left her without work. She depends on Social Security, and a small pension. She only has a few hundred dollars in savings.

Hillary considers her family to be her oldest son and his three sons and her "significant other, . . . But, she doesn't really understand me . . . and I know it, but I'm willing to let that go." Hillary also has several fictive "adopted children," whom she counseled while working at a college. Lastly, she includes her cousin and his wife. She never mentions this secondary family as a source of substantive support.

After a lifetime of caring for others, Hillary is alone with no dependable informal support system. Her 46-year-old son lives in poverty. He lost his home and family after returning to cocaine use. Her younger son has spent two-thirds of his 44 years in prison on drug, alcohol, and robbery charges. Hillary worries about dying and leaving her sons.

> If I go, they don't, either one of them have a prayer. . . . I'm the only person that cares whether they live or die. . . . The little bits[of money] that I can pass their way and a little loving note or a letter or a kind word, and that's all they've got. It's so sad.

Hillary alternates between anger and sorrow when explaining about her sons' childhoods. They were "beautiful" children. As a single mother singing in the church choir, she knew some "perfectly nice gentlemen," who were gay. "By allowing them to go places with these guys, I thought I was allowing them to have a male figure." She found out only eight years ago that the men were pedophiles, and they sexually molested her sons. She explains, "I thought men were like girls. They had lovers, and I didn't think they were interested in anybody else." Her sons believed that she knew about the molestation when it was happening. Consequently, the older son kept her grandchildren away from her for many years.

The only child of a poor couple, the young Hillary took private dance and music lessons from African American teachers during the Great Depression of the 1930s. Unfortunately, “women and children who were raised in the families that were aspiring away from poverty or whatever background they had didn’t discuss financial things.” Therefore, despite her bachelor’s and master’s degrees, Hillary did not know how to financially prepare for old age and disability.

Medical problems began early for Hillary and have continued throughout her life. A heart murmur, frequent childhood sprains and falls, and inflammation from dancing were probably side effects from undiagnosed rheumatic fever. Her father relieved her leg pain from “circulatory problems” with massage and Absorbine Junior, an over-the-counter ligament. As a teen, her bad nosebleeds were diagnosed as high blood pressure, for which she takes medication to this day. Her myopia and astigmatism were not discovered until she was 13 because she had memorized the eye chart when she assisted the nurse during elementary school.

Treating symptoms rather than searching for their etiology was common in those days. “You just didn’t use outside resources for medical things unless it was an absolute emergency.” Her mother, a dietitian who could only get work managing a public school cafeteria because of job segregation, believed in health maintenance through “fresh air and fresh vegetables.” Therefore, Hillary’s family raised chickens and produce after they left Central Los Angeles for a semirural area bordering what is now Watts.

Because Hillary was both anemic and poor, her five-cent school lunches included larger portions, especially of milk. However, because she was an only child, she “had a lot of luxuries that the kids I went to school with didn't have." The schools were not segregated, but her family chose to live in an African American neighborhood and to attend an all-Black church. She was born in a "Black hospital. . . . It was before the marvelous multiethnic revolution." She never had an African American school teacher until studying for her master's degree.

When Hillary was 17, her mother died despite treatment at the medically superior "White hospital," where the patients could be of any ethnicity, but the physicians must all be Caucasian. Hillary still tears up as she tells the story. Although both her parents worked for the city of Los Angeles, health insurance was not available to them. When her mother became ill, she hid her vomiting from her family. Her mother's work ethic, the ethic of the era, was "take two aspirin, suck it up, go to work." Eventually, the family's African American doctor diagnosed duodenal cancer. "She didn't want to go to the Black hospital, and [our doctor] couldn't go with her to any other hospital." After several months, she could no longer delay hospitalization. "So that's when he told my dad, 'You've got to put her in the hospital. I can get her into a nice hospital. I can't be her doctor there.'" After a short stay in the White hospital, her Caucasian doctor discharged her to save the family money. The burden of her mother's care was left to Hillary. "So I had to measure and change the dressings and stuff and cook for her and stuff, and she just kind of shrank away." Hillary's father never forgave their African American physician for not saving his wife's life.

In turn, Hillary quit speaking to her father because he arranged for his wife to be buried instead of honoring her wishes for cremation. At the funeral, the women who had been Hillary's mother's informal support system sparked Hillary's ire. "I got mad at them because they're all making goo-goo eyes at my dad, who was quite handsome." She did not forgive her father until after her daughter was born a few years later.

Lacking female relatives, Hillary made unfortunate decisions because of her naïveté. "I didn't know how not to get pregnant. . . . I thought that you could douche and that would keep the thing absolutely clean. . . . I was not a girl that was comfortable with talking about feelings, whatever kind they were. I expressed them through [my] music. " The year after she finished college, she married the man with whom she was having sex, so as not to shame her family were she to become pregnant. After her son was born, she asked her doctor about preventing pregnancy. While her physician suggested that her husband use condoms, the couple decided that the doctor should make Hillary a diaphragm.

> The diaphragm hurt. It got misplaced a lot and, consequently, I got pregnant two more times. And then I got unmarried. And then I was safe for a couple of years, and then I tried dating. . . . I really didn't like being married, and I was not physically abused, but I wasn't cherished either.

Hillary's husband abandoned her when he learned she was pregnant with their third child. Hillary sobs during her story telling, but continues when asked to explain her comment, "Then I was safe." She clarifies,

> It's important, because that's how I realized that I really was a lesbian and that I was much more comfortable with women. And I, quote unquote, felt that I would be safe with a woman. . . . I used to think maybe it was ethnic, but I don't think it is, but you hear how young women with children are such a prey for men, because men seem to think that the only thing you really need is some companionship and some more sex. And, they force themselves on you. And, I had some really bad experiences with my friends' husbands. . . . And then, I dated a few times. And I was still getting pregnant -- three abortions -- and the last one was a real mess, and I ended up in the hospital, and I thought, "I don't want to die and leave my babies, 'cause there's nobody to take care of them." And I didn't enjoy any of this, actually. Two of them were rapes, but they were like date rapes.

Hillary explains that the date rapes were not as bad as they could have been because

> I didn't get beat up. I was verbally threatened, . . "You wouldn't want your children to know. You wouldn't want your neighbors to know." . . . One was actually my ex-husband's brother who I foolishly allowed to stay with me for awhile. . . . There was always that brute strength. . . . That was the one that almost killed me, and I thought, "I'm sure not going to do this anymore." So it was a few more years before I met a woman, because I had decided I'd just be celibate for the rest of my life. . . . And then, I found out that all women are not safe either.

In her late thirties, while her children were still young, Hillary became involved with her first female lover, a younger woman. The lover was never violent but was the kind who had "absolutely no maternal instincts." The relationship lasted three years. "My heart is totally monogamous and my head, and I always wanted this lifelong partner, and I was determined to have it, but sometimes it's ludicrous." However, the relationship helped her find out "what love is all about. Experienced my first orgasm. . . . There's nothing like it. . . . The intimacy."

Meanwhile, Hillary taught school, but her district did not offer health insurance for several years. When it did, she paid a few more dollars for the best Blue Shield plan. "I was so thrilled that I could have a plan and that my kids would now be covered because I was so afraid that they would get sick, and I wouldn't have enough money to take care of them." Her ex-husband did not pay child support. In addition, she was not eligible for public assistance because she was employed. "If you aren't below the poverty line, you don't get any help. You just suffer it, tough it out."

Hillary was grateful for her health plan when her eight year-old daughter, Pam, required a partial thyroidectomy. Today, Hillary believes the thyroid problem was the initial symptom of lupus.

> That's before, again, before they knew that much about some of the blood diseases, and the only thing they knew about that they should check Black people for was sickle cell, which she didn't have. . . . And we never had anymore problems until she was 16. And she hid some of the first few months of problems from me. I didn't know she was sick at school and that she was getting herself excused to go lie down and was throwing up and stuff.

Hillary sent Pam to a children's hospital because she was gaining weight while eating little beyond lemonade and potato chips. The physician concluded that she was a typical teenage girl who ate too much junk food. After a three month delay, they consulted a doctor at a large teaching hospital. He conducted upper and lower gastrointestinal tests, but he found nothing. Because his own teenage daughter was sexually active, he diagnosed Pam with psychosomatic symptoms stemming from her presumed sexual relations.

Their anger at the doctors as well as Pam's preparations for high school graduation induced Hillary to wait until the week after Pam's graduation to begin searching for a new doctor. However, the night of her graduation, Pam's brother, whose wife was an LVN, told Hillary, "When I come home, if my sister is not in the hospital, I'll never speak to you again."

Pam's decision to forego the children's hospital for the university hospital was based on the latter's handsome physicians. She was near death. The doctors diagnosed kidney failure secondary to lupus. Dialysis rid her of 20 pounds of fluid.

The university hospital provided excellent care. "The staffs were all integrated. . . . Later on, she did find a Black doctor. And, they were united in soul and spirit." Hillary's health insurance and the Crippled Children's Society paid medical expenses.

Frequent dialysis required shunts implanted "everyplace on her body."

During her single years in the late 1960s and early 1970s, Hillary helped to found a gay and lesbian center. She acted as peer counselor for the young mothers who were coming out as lesbians. She also attended her first lesbian conference where she interacted with intelligent, educated lesbians who were confident with their orientation. There, she met Gail, "somebody really wonderful, but we only had seven years, and God wanted her back." Energetic and dynamic, Gail formed a special bond with Hillary's daughter, Pam, and helped them both through Pam's medical ordeals.

Six years after Pam's lupus diagnosis, the university hospital decided to "farm out" their overflow dialysis patients to a private hospital.

> They did seven patients at one time, and the nurse that was in charge wasn't really a trained dialysis technician, so she left the floor and went to get some coffee. And while she was gone, the main machine that was feeding into all of these blood units, that lets the special stuff in and it mixes, ran out of its mixture and, of course, the alarm went off in her office, but she wasn't there, and pure water got into the system, and they all got water in their veins

Three patients died. The others became seriously ill. "Evidently, it was the way your bed was placed. Fortunately, my daughter was the farthest away." When Pam saw the first patient dying and began to feel strange, she instructed an untrained technician how to remove her from the pump. He did so, although he feared he would lose his job for obeying her orders.

The private hospital called later to schedule Pam to complete her dialysis. They scheduled the other patients at different times and/or in different room to prevent them from talking to one another. However, Gail, who had witnessed the incident, visited all dialysis rooms and prepared all the victims for a lawsuit. The suit lasted two or three years. They proved that the hospital was at fault due to untrained staff and faulty machines. Hillary is proud that her family "did something about making the units safer." After expenses, Pam was awarded only a few thousand dollars. "But still, it was more money than we had ever seen."

Pam lived 10 ½ years more years. She died of kidney failure in 1983. Hillary is sad that dialysis was not as advanced as it is now.

> But, you're glad that these things help with learning. And you understand the need for more money for research. . . . But, yeah, it's hard. . . . When you bury your child, you bury part of yourself. And it's like the littlest things set it off again.

Hillary believes that she and her daughter would not have known how to pursue the lawsuit were it not for her partner, Gail. She believes women generally are not trained to look for information.

> People don't give it to you. . . . Number one, many of us are raised to think good of all people. And secondly, we don't like to fight. A lot of us don't. And if that's your personality, then people really do get away with a lot of stuff.

Like Gloria G., Hillary feels she must prove her intelligence.

> Doctors have a habit, still: They talk down to you because you're a woman, and they talk down to you because you're a minority. And sometimes, I get so mad I just want to spit. So, I have to hurry up and tell them what I do for a living. "Well, how come you know so much?" "I know so much because I can read, for one thing." . . . Fortunately, I've got an interesting group of doctors. . . They're pretty patient, so I ask questions for myself. But before, I didn't ask very many questions.

However, when queried if she will ask her doctor if her cervix was removed during her hysterectomy, Hillary insists, "I'm not asking him! And, the doctor who did the surgery is dead, so can't ask him." Even if she does have a cervix, she believes that her hysterectomy will prevent cervical cancer.

Gail was out as a lesbian to her doctor, to whom she took Hillary soon after they began dating.

> That was the first time that I was comfortable with a doctor, and we did all of our appointments together. . . . 'Cause I never told a doctor that I was a lesbian, and I think that our lifestyle is different, and some of the things that they're worried about and examining for are not even going to happen . . . [such as] infections and diseases. . . . I didn't have to hide anything, and I could say whatever I felt like saying.

At present, however, Hillary has not come out to her general practitioner, podiatrist, rheumatologist, orthopedic surgeon, or pain management specialist. "I don't know if they know, and we don't discuss it." Because her doctors are young and "enlightened," rather than "older and stiff and set in their ways," she believes they would be "cool" with her orientation.

Gail's doctor "was into modern things." When he found a small growth on Gail's pituitary, he "nuked it" with an experimental laser. She had refused chemotherapy to avoid losing her hair.

The couple lived together for six and one-half years before Gail felt a pain in her breast. Because she thought it was a mosquito bite, she applied Salonpas, a menthol-type pain relief patch. "This was in the 80s. We didn't do mammographies much." The doctor "was really concerned, and I guess they knew the signs, but we didn't." He told Gail that he would perform a biopsy immediately followed by a mastectomy, if necessary. After the surgery, the staff left it to Hillary to tell Gail that the doctor had removed her breast.

Two months later, Gail's lymph nodes were removed. She lost her hair from chemotherapy. Six months after that, the cancer had metastasized to her brain, causing excruciating pain. "Experimental stuff" relieved her pain. Hillary's "soul mate" died five months later in 1984 at the age of 56. Hillary's daughter had died only three months prior to Gail's passing. Hillary refers to Gail as

> the first counselor that I ever had. She went right to the center of my being and helped a lot, you know. And, we talked about a lot of stuff that I'd never talked about before. . . . I'm a marshmallow, but here was someone who was strong and authoritative, . . . and she was so sure of herself.

Although, with Gail's help, Hillary became a college counselor, she has not sought professional counseling for her many losses. Besides her reticence to speak to a stranger about personal matters, "money is a very important thing that we've always been short of! In those days, your insurance didn't cover [psychotherapy] either. . . . I did all my grieving in strange and terrible ways."

During their time together, Gail taught Hillary some of the things her mother did not live long enough to teach her. For instance, she learned that her monthly severe menstrual cramps, heavy blood flow, and fainting were abnormal. Together, they consulted a gynecologist for Hillary's first gynecological exam since her daughter was born 21 years prior. "I didn't want to go through that anymore, you know. I didn't want to be on a table with my legs in a stirrup."

While the gynecologist was snipping some polyps, Hillary sneezed, further collapsing her uterus. It "was coming out of my body, and that's why I was bleeding all the time." She underwent a hysterectomy followed by surgery for a collapsed bladder. She believes that the bladder repair is tipping her pelvis and causing back problems. Regarding the bladder surgeon, she complains,

> I don't know what he did to me, but I was very upset after the surgery. And, it took a long time to heal, and I didn't think it should of. And, I've really never

> been quite the same since they did that. . . . It didn't help anyway. The darn thing collapsed again. But, I'm not going to let them touch me.

Presently, back and leg pains and joint deterioration in her knees and ankles prevent Hillary from walking beyond short distances. She takes muscle relaxants and antidepressants that contain a pain-relief component. For a month, she received physical therapy, including hydrotherapy, hot packs, stretching, and massages. Then she learned that Medicare, and, by extension, her Blue Shield supplemental insurance do not cover hydrotherapy. She must wait another month before she is Medicare eligible to return to therapy. Regarding her future health care and Medicare's limitations, she comments,

"I would like is to see . . . something set into your health plan that says that you are entitled to some preventative care, like physical therapy or access to a gym or something." She pays out of pocket to use the YMCA pool. The Easter Seals pool, at eight dollars per visit, is too expensive. She believes access to health care should include transportation. Also, senior center pools should have a trained instructor on duty and pool water should be heated to therapeutic levels.

Hillary would accept home health care or round-the-clock in-home personal care. However, she does not believe her insurance would cover it, and she could not afford to pay out-of-pocket. She believes her insurances only allow for 100 days of hospitalization and 100 days in a nursing home. Rather than moving to a nursing home, she would "have to go say good-bye to y'all and take a trip to the beach by myself," her euphemism for drowning herself. She chose not elaborate on her mention of suicide.

Regarding confinement in a nursing home, she asks, "Have they got a gay one? . . . That would be a blast! We could sing and dance and change our diapers together!

Who would care?"

About nongay nursing homes, Hillary explains, "I would hate to get to the point where I didn't know if I was clean or dirty, . . . and damn those nurses. Why don't they change their clothes for them?"

In summary, at 70, Hillary H. finds herself alone, disabled, and poor. She has cared for and buried most of her loved ones. Remaining kin and fictive kin are not able to care for her in her old age. Naïveté led Hillary to make serious mistakes in her financial planning, physical and mental health, and child rearing. Her sons hid from her the fact of their sexual molestation. Likewise, she hid sexual abuse from her family. Also, she, her mother, her daughter, and the partner who was her soulmate tried to hide illness from the family and delayed their health care. The delays resulted in serious illness or death. Still, Hillary avoids gynecological checkups and does not feel comfortable discussing intimate health issues with her doctors.

Unlike some previous subjects, Hillary has not chosen to emotionally distance herself from others. She freely laughs and cries. She pauses the discussion numerous times, stating that she had not realized the interview would cause her to break into sobs. She mentions the option of suicide. Conversely, she does not want to abandon her sons and grandsons.

After the interview, Hillary showed this interviewer framed pictures of her family. Conspicuously missing are photographs of her troubled sons; however, she expresses hope for her grandsons. She notes that one grandchild has her sensitivity in his eyes.

APPENDIX I

Interview #9: Ilene I., July 1999

Ilene I., a petite 82-year-old gay woman, would stand about four feet eight inches tall were it not for her severe kyphosis, a forward curvature of the cervical and thoracic levels of the spine. As the interview progresses, her posture collapses more pronouncedly into a horseshoe shape. Also, her loud voice grows weaker causing difficulty for the transcriber. Because Ilene is extremely hard of hearing, her responses frequently do not correspond to the researcher's questions. Consequently, her meanings are sometimes difficult to ascertain. Despite these drawbacks, the investigator has gathered sufficient data for the purposes of this study.

The youngest of nine children born to a poor family of English, Scottish, and "American Indian" ancestry, Ilene was delivered at home in the north central U.S. by a neighbor, a Christian Science minister. No doctors lived in the vicinity, and in the winter, "a doctor couldn't have got through if he wanted to, because of snowstorms. . . . And, if somebody got sick, well, that's just tough." Consequently, Ilene's family depended on home remedies such as "mustard plasters, castor oil, [and] camphorated oil. And Mama made her own cough medicine. It was hard candy and honey. . . . We didn't have no alcohol.... Dad had some, I think, hid some place."

Nevertheless, Ilene started drinking alcohol "back in high school days. . . . I drank all the time. I was almost an alcoholic when I went into the service."

Ilene credits healthy eating she learned in the military for her longevity. She especially avoids fried foods.

Except for a niece, with whom she has only occasional contact, Ilene's family is deceased. Only one sister, a hermaphrodite, lived to age 82. Her mother died at 58 "of dropsy and heart trouble." At that time, the family was on welfare, but a doctor made a house call and gave her mother medicine that "didn't do her much good." Ilene feels that her mother may have survived had she received quality health care.

As a 10-year-old, Ilene enjoyed "toying with the anatomy" of a neighbor girl. Ilene "was raised as a boy," doing "boy's work." She wore dresses to school, but poverty compelled her to wear her brothers' hand-me-downs.

Her mother accepted Ilene's gay orientation because one of Ilene's older brothers was gay, and her sister was hermaphroditic.

> I didn't have to tell my mother I was gay, no! My mother told me! . . . She said when I put on my dad's suit, "I think if you're going to wear that very often, you'd better have it altered."

One of Ilene's earliest memories of the health care system relates to her older sister. "My sister was born with both male organs and female organs." When her sister was 15 years old,

> one of the doctors said, "Maybe I can straighten this out." And that damn doctor put a heat tube in her and . . . was called away on an emergency and got back and found out this tube was still inside of her vagina! . . . [It] burned everything out of her insides that she did have, whether it be inside genitals or outside. . . . She had several operations after that, and they tried to patch and fuse and do everything they could, but it was too far gone. Well, we couldn't sue the doctor, because we didn't have no money. . . . Oh, some of [the townspeople] was gonna take that doctor out and hang him to a tree. . . . The public only thought because she hadn't menstruated, that the doctor had burned her insides.

By her 15th year, Ilene had not begun menstruating. Her mother suggested she may have to take Ilene to a doctor.

> I didn't want to go to no doctor. . . . All I could see in my little mind was, "I don't want them to mess me up like they did [my sister]." I was pretty close to 16 when [Mama] seen the blood in the sheets, and then she said, "Well, I guess

I'm not going to worry anymore."

Her gay brother, her hermaphroditic sister, and Ilene all married to "keep people from talking, pure and simple." Before they married in 1942, Ilene's husband knew she was a lesbian who did not want to have children. The marriage lasted "about six weeks."

As did Esther E., Ilene credits World War II with instigating the social changes that gave women a choice. She also feels strongly that compulsory marriage "brought a lot of kids into the world that they really didn't want, and then you wonder why so many kids are in the street."

Immediately upon her divorce, 24-year-old Ilene joined the military, where "there were a lot of lesbians." She wanted to become a medic, but women doctors were criticized and blackballed until after World War II. Ilene also did not approve of "some of their dirty work." For instance, the military doctors used the recruits to test the efficacy of penicillin and sulfa drugs against influenza. She learned to pocket the pills in her cheeks and spit them out later. Of those who did swallow the pills, many "landed in the hospital with a kidney problem the rest of their lives" because the sulfa drugs "crystallized in the kidneys."

After three years in the military, Ilene had a seven year relationship with a heroin addict. When Ilene realized that her lover and her friends would "steal your eyeteeth for another fix," she left the relationship. Many of Ilene's friends died of drug and alcohol related illnesses, including her ex-lover.

Also in her younger years, Ilene was in the back seat of a car speeding 90 miles per hour when it hit another car. Her driver and front passenger were killed. Ilene only received a concussion. The doctor was amazed, and "he really got mad" that she had survived. "I said, 'To hell with you, too.'"

Ilene met Shirley, her partner for 38 years, in a bar. Although an alcoholic, Shirley "did taper off."

Ilene stopped drinking at age 60, when she retired from her state clerk's job. She attended only two Alcoholics Anonymous meetings, then "I made up my mind that I'm gonna take my drinking money, and I'm gonna invest it into a business that I can run myself!" She opened a furniture refinishing store. Ilene still drinks "socially" at gay bars, but stops at three drinks.

Around 1975, Ilene collapsed, "and there was blood all over." Shirley rushed her to the Veterans Administration (VA) hospital, which had "nice doctors." She underwent a hysterectomy. Ilene's understanding is that a benign tumor "was attached to the spine, and it was cutting off circulation, and something broke. And so, that tumor broke loose."

After several heart attacks, Shirley underwent an extended hospitalization. She died four months after being confined to a convalescent home and six years prior to the interview. Although their doctor knew them to be lesbians, Ilene posed as Shirley's sister while visiting her in the hospital, taking care of Shirley's end-of-life affairs, and dealing with the customers who knew them both. She chose this deception because "women nowadays are big blabbermouths," and "it's none of their damn concern. . . . I like that privacy, and I like that respect that goes with it."

After Shirley's death, Ilene initiated an affair with a woman who was married to a man with AIDS. She did not practice lesbian safe sex techniques. She asked her doctor if she could get AIDS from another woman. "You don't feel a strain to talk to him, to ask him questions that you think are kind of silly." However, she feels her doctor brushed her off because of her age. He told her that she could only get AIDS through blood exchange and added, "You just worry too much about things." Nevertheless, Ilene ended her affair for fear of AIDS.

Besides advice from her doctor, Ilene acquires her medical information from books. Ilene reads a lot, including books from a local LGBT bookstore. However, she keeps her books out of view of "nosey people."

Although two brothers died from smoking-related illnesses, Ilene continues to smoke a pack of cigarettes per day, a habit she started as a 10-year-old. She believes that her health is not particularly compromised by her smoking and that her brothers died because they each smoked two to three packs per day. Her doctor has stopped urging her to quit smoking, asking instead that she limit her smoking to less than one pack per day. Ilene can tolerate not smoking for 8 to 10 hours. After that, "it's just not worth it. I'm a bearcat to be around because of this withdrawal deal."

Ilene does not worry about her future health care. She is covered by Medicare, state supplemental insurance, and VA benefits. Her primary care physician is associated with a university hospital. Ilene is the only subject who has long term care insurance. Unlike some previous subjects, Ilene does not value advice from friends and neighbors. Others have recommended she buy more insurance, but she feels content with her present coverage. Her pension, Social Security, and personal income equal approximately $1, 500 per month. Although she has credit card debt, she is not concerned about it. She owns a small home in an old, well-kept neighborhood. She hopes to relocate to the Northwest Coast after she sells her business.

If Ilene should become unable to care for herself, she would accept home health care, or she would be satisfied with the convalescent home Shirley died in. "It's a small place. They take good care of their people." She appreciates the good menu and recreation programs. In general, though, nursing home life would be "dreary" because she would not be allowed to read in bed, garden, or eat what she pleases.

In the short term, Ilene hopes to get new glasses through her state insurance. In a drawer, she also has four ineffective hearing aids, for which she paid out-of-pocket. She has had difficulty finding a proper fit. One hearing aid was supposed to help her understand people on the telephone, but she only hears a "roar. . . . One of these days, I may call up the doctor" to complain that it doesn't work, or she may "let things ride."

Her dog chewed up the only hearing aid she has found beneficial. This one was purchased from Sears through her state insurance, and she has not told the company about its demise. Instead, "I'm going to be tempted to find some other stores and get one . . . [that is] 'keyed in' different." Ilene explains that her hearing is "clear as a bell" most mornings, but worsens as the day progresses. When this researcher met with the subject in the mid-afternoon, she had to shout in order for Ilene to somewhat comprehend the questions.

Ilene has adapted to her hearing problem by having her assistant answer the business phone. At home, she has acquired telephones with built-in amplifiers. She thinks the Department of Motor Vehicles (DMV) examiner will "get fussy about this hearing stuff" when she applies to have her license reinstated. When a DMV examiner "pulled" her license for "lack of skill," she "got mad." She had no points against her driving record. She hopes to earn her license back by attending driving school.

Not having a driver's license "has stymied the devil out of me!" She has been unable to attend the gay-oriented Metropolitan Community Church (MCC), browse the LGBT bookstore, or visit friends out of town. She has read in the church bulletin that a young lesbian couple holds weekly church gatherings at their house, which is within a five-minute walk from Ilene's home. She has not gone there because "I feel out of place . . . because of age." Even though the younger women do not talk down to her, she feels self-conscious. Ilene seems to be thinking out loud when she says, "Like, if I got to know those girls better, maybe I'd get over [myself consciousness]. But, I haven't yet. But gee, it's just a five-minute walk. It'd be a nice social meeting."

Ilene was reared Methodist and converted to Catholicism as a young adult in the military. Presently, she considers herself a "bad Catholic." On occasion, she attends MCC; however, she is not particularly religious.

Fear of harm is one reason Ilene hesitates to participate in a neighborhood activity that may identify her as gay.

> You read in the paper all the time, like those two [lesbian] girls that was killed in Medford and the two boys that was killed in Redding and the scrapes that they have in San Francisco. I'd just as soon just keep my mouth shut and not say one word to anybody.

Although she generally has a "pretty good attitude," Ilene complains, "my world has gotten pretty narrow." She has worked since she was eight years old and cannot tolerate the thought of watching television all day. Ilene enjoys painting, gardening, and traveling. She says several times that she "could" finish writing her second book on furniture refinishing, "if I wanted to." Ilene plans to live for another 10 years. "I've got a lot of living to do yet."

Asked what she would want others to know about old lesbians and their health care, Ilene responds, "I don't think health care has much to do with it. . . . If you're a lesbian and you live alone, you ain't got that privilege" of having someone to help you when you are sick.

Ilene tells what she believes old lesbians need:

> respect [and] understanding, because they have to cope with a family that probably has criticized them and blackballed them. . . . If a lesbian married a man and he beat up on her like crazy, she'd be more respected than if she was a lesbian. That don't make sense in my book

Ilene admires the organization Parents, Families, and Friends of Lesbians and Gays (PFLAG) because they promote understanding within families. Referring to Matthew Shepard, a gay youth who was murdered in Wyoming, Ilene advises,

> [Gays] don't want to be hung on a fence like the kid was in Arizona. . . . They don't want to be made fun of. . . . Don't push your kid into something he doesn't want. Now, that's my outlook.

In summary, Ilene I. chooses to remain closeted in most instances due to personal privacy as well as fear of reprisal. Ilene is the only subject who preferred to meet the researcher in a neutral, yet private, location (a church meeting room) instead of in a home. However, after the interview, she allowed the researcher to drive her home.

The losses of her driver's license, her hearing, and her lesbian peers have narrowed Ilene's world. She values independence and activity, but accepts that these, too, may wane. Unlike the majority of subjects, she did not mention suicide as an alternative to dependence. Her various insurances, including long-term care insurance, seem to bolster her feelings of self-sufficiency.

Ilene enjoys social interaction and expresses an energetic, positive attitude. On the other hand, she does not seem to trust easily, and she bristles when discussing people who think differently than she. Several of her stories tell of doctors and others who were “mad” at her. It is unclear whether or not Ilene may interpret as anger the necessity for one to shout to be heard. She did not say when she began to lose her hearing.

Ilene dismisses her severe kyphosis, forward curvature of the upper spine, as “a bad habit” resulting from refinishing furniture. Therefore, it is possible that she has also understated other health issues. She offhandedly mentions urinary urgency, melanomas, alcoholism, and smoking-related symptoms. Despite her postural problems, she does appear to have good walking and sitting balance and fair stamina.

APPENDIX J

Interview #10: Josephine J., May, 2000

Josephine (Jo) J., a 101-year-old Afro American lesbian, has recently enjoyed the limelight as the oldest out lesbian in America. She expresses disappointment when she learns that the interviews for this study are confidential. For this reason and because this notoriety is integral to her story, this researcher has not gone to extraordinary lengths to disguise her identity. However, identifying names and locations are changed.

For most of her life, Jo has lived in a North Central U.S. industrial city, fictitiously named Newsom. Urban redevelopment has displaced her several times. For 30 years, she lived in a simple home with Sandy, her longtime partner-turned-roommate. Their house was torn down to widen the streets. As a result, Sandy and she "got separated." Sandy chose to live in a suburban senior facility near her job, and Jo chose an old residential hotel where "downtown was flourishing." About 13 years later, the city tore down the hotel to build a ballpark. Jo has since lived in a high-rise downtown "senior citizen building." This tiny, energetic woman says matter-of-factly, "I don't know how long I'll be [in this building]. It doesn't much matter, because I don't think I'll be living too long. . . . I'm getting tired now."

Jo is adamant that she will not go to a nursing home if she becomes frail. "Right here, where I live, will be my nursing home." She is confident that her "strong," 70-year-old neighbor and guardian, Ellen, can care for her because "there ain't nothin' to" Jo's 4 feet 8 inch, 80 pound frame. If Ellen could not care for her, she would turn to the younger lesbians who have been watching after her needs. She would do "whatever the girls decides to do with me," Jo believes that Kyleen, a young lesbian who has her power of attorney, would arrange for in-home care. She also believes that Medicare and her Blue Cross/Blue Shield supplemental plan would pay for in-home nursing and home care.

If she becomes frail, Jo will not overtly commit suicide, but she may stop eating. An elder friend in a convalescent home died when she "just got tired of living" and stopped eating. Jo's living will specifies no resuscitation and no life supports.

Jo has all the paperwork for a 20-year endowment, which she has paid in full. However, she and Ellen have not been able to compel the company to pay her for it. The service agents continually say that "they'll look it up." Jo believes they are waiting for her to die to avoid payment. Jo once owned and operated a print shop. Currently, Social Security and a small amount of money in the bank are Jo's only sources of income.

> [The government doesn't] want you to have too much in the bank, though. Not seniors. Because, they raise your rent. . . . I don't think it's fair. They ought to let seniors have as much as they can have. Just let them live, just a natural life--when they get over a hundred, anyway. . . . [The system is] not going to change the laws to . . . let the people live . . . without gouging them for every penny they can get out of 'em. . . . They want to know every penny you make! . . . That makes liars out of people, because they're not going to tell everything that they make.

Jo's base rent is more than her SSI check, so the government supplements all but $112 per month, which she pays out-of-pocket. The young "riffraff" who have been admitted to the senior housing have "spoiled it." Jo believes that these young people pay their doctors to lie about their disabilities in order to be admitted to the subsidized senior housing unit.

> They're able enough to run in and out of the building all day long. So, they [should] be able enough to work. . . . There's dope and everything in here. . . . You have to have evidence to get these people out. And, a lot of people are afraid because if they find out who told on them, they'd bump 'em off or something. . . .

> There's a park right across [the street.] It used to be, a long time ago, we could go to the park and sit out and have your lunch and enjoy yourself. . . . The bums take over. So, we have to stay in with our doors locked. . . . We have a little place [to] sit there by the water fountain, when it's on. We're surrounded by these guys asking for a cigarette [or a] quarter.

Nevertheless, Jo feels "pretty safe" because she is well known in her neighborhood. People watch out for her when she takes her walks around the block.

> They sort of respect me. . . . I think it's the way I carry myself. . . . I don't curse. [Unlike some of the women] I don't beg. . . . [Young people are] willing to go to the store for me, but most of them want money. . . . I've been quite fortunate. Never had a lot of money, but money doesn't count that much to me. Just enough to live off of.

Jo's birth family was poor. Although her family did not talk about it much, Josephine thinks both her parents were born into slavery in Tennessee. Her aunt was a wet nurse in "the big house," and her mother was born in 1864, the year the Civil War ended. She never saw her mother write, but her self-taught father had an extensive library and urged his children to "get an education." Of her three brothers, one grew up to be a doctor and musician. Jo, a slow learner, graduated from high school.

The family lived in a small Northern town, now a metropolis, a few hundred miles from Newsom. When Jo was 12, a stroke killed her mother. Since children were commonly kept ignorant of illness in those days, Jo does not know if her mother received medical attention.

Within a year after her mother's death, Jo experienced a bout of "rheumatism. It's arthritis. . . . I couldn't walk, [and] I couldn't straighten my arms out or anything." A doctor alleviated her arthritis.

Except for arthritis, Jo was generally healthy. The family "used a lot of home remedies. . . . If we had a sore throat, they'd give you some Sloan's [muscle] Liniment with some sugar." They used mustard plasters on chest colds and rubbed Vaseline petroleum jelly on cuts. When available, the family received vaccinations.

Financially, the family survived by planting a vegetable garden, peaches, and grapes. They also got the discarded parts from the slaughterhouse.

> I remember when we could get the insides of a hog for nothing: . . . chitterlings, . . . the heart and livers, . . . pig feet, pig tails. That was free. When they found out people were eating that stuff, shoot, they bleached those chitterlings and sold them. Now, they're as high as anything else.

Jo's "childhood wasn't that excitable." The family lived in an integrated neighborhood. The Irish Catholics next door did not allow their children to play with them, but another Caucasian family did allow it.

> But, it's a funny thing. They'll let you play with them before they go to school, but the minute they start going to school, something happens in school. They quit playing with you. Then, they separate. Colored [play with] Colored and the White with the White. : Lot of segregation. . . . Lot of racial hatred. I remember my [brothers] used to be chased home from high school [by] the Catholic boys.

However, the brothers banded together to protect themselves. The one who became a doctor also watched after Jo as she grew up without her mother.

Two of her brothers died in their 40s, one from a stroke; the other "got old suddenly." The youngest brother "went off the rock," her euphemism for insanity, and he died in the VA home at 86. Jo never mentions her father's death. She is the only family member still living. At her late age, she does not grieve her losses or attend funerals. Instead, she becomes more active with her hobbies.

As young adults in Newsom, Jo and her partner Sandy built a strong informal support system. Their house was a gathering place for gay and lesbian African Americans.

> It comes back to you. 'Cause, see, I helped these kids when they were trying to strive to go to college. . . . We'd take them in until they could find a job. . . . We didn't have much to give them, but then, it didn't take too much.

Jo still believes that whatever she does for another person will come back to benefit her in some way. However, her affect changes to sadness or hurt when she recalls the people she has helped who do not stay in contact with her. For instance, a woman whom Jo helped to earn a masters degree in music sends her a Christmas card each year, but never phones. "I'd like to stay in touch with people that I've known since childhood, since they were young! . . . They have other things that are more interesting. . . . They just forget about you."

Jo acknowledges, "I don't call them either." She believes younger people should call their elders out of respect. "They're just careless about keeping their friendships. . . . It's natural. It's the way society is. But, I like to keep my old friends as well as new ones."

Jo's former guardian lived only 40 miles away, but never visited despite buying a new Cadillac every year.

> We talk on the phone. She promised to come. She's never showed up." [So,] I got me a new guardian. . . . [Ellen] bugs me! Oh, she won't let me do nothin'. I said, 'Ellen, if you don't let me do something, pretty soon I won't be able to do anything.'"

Jo laughs when she speaks of Ellen waiting on her. She is concerned that other people take advantage of Ellen's generosity.

Even at 101, Jo has known very few illnesses. The "rheumatism" she suffered as a child has come back to some extent. "Just getting over it now. . . . For awhile, I could hardly open my fingers. My toes are numb. I don't get too much circulation in my feet."

She attributes the symptoms to "old age." Her doctor, who has treated her for 50 years, also attributes her choking and swallowing problems to old age. She eats a soft diet or baby food, but has been losing weight. When she chokes on her food in public, she wishes people would not try to perform the Heimlich maneuver. She would rather they allow her to hurry to the restroom so that she may cough privately.

Jo's vision is also troublesome for her. The young lesbians she calls her "girls" have given her a boom box with a radio, a cassette, and a CD player. However, she does not use it because she cannot read the labels on the controls without her magnifying glass. Even then, the glass sometimes blurs the words. Besides, "I'd rather look at television."

Jo gets her information about the world at large from television talk shows. She feels certain that a favorite court program is real, but she is not sure about the talk shows. Nevertheless, she is appalled at what she sees in these programs: lack of respect, cursing, teenage mothers, and unidentified fathers.

Her apartment is equipped with a TV monitor and a button that can unlock the door to the building when a visitor arrives. Jo's vision is sufficient to determine who has arrived, but "riffraff" can slip in behind admitted guests.

Jo has strong opinions about recent changes in her world. For instance, she despises automated answering systems because she cannot remember and respond to the multiple options. Her girls have told her to wait without responding until the system transfers her to a real person, but she hangs up instead. Jo could not comprehend how this researcher could call her California cell phone and have it ring in Newsom. She also cannot figure out automatic teller machines. "But, that's the way the world's going, see? We'll be left out, because most of us won't pursue it. They just give up." However, Jo has mastered retrieving messages from the answering machine her girls gave her.

Her girls have also provided her with a reading lamp, a raised toilet seat, and a bedside commode. "They give me anything they think I need. . . . Not many old people get that service, though. [So, they] just stay in their room or sit down [and] watch the people go by."

Most of Jo's needs can be met in the building or in the immediate vicinity. The pharmacy hand delivers Jo's high blood pressure medicine to her door. Ellen, Kyleen, and a "nosy" neighbor check on her daily. Jo complains that the elevators are frequently out of order and the bus service is not dependable. She is concerned for other seniors who will probably be displaced to the less accessible suburbs when the city redevelops the downtown "for the rich people."

Several years ago, Jo took a self-defense class at the senior center. Although she had never met a Caucasian lesbian, Jo decided the instructor was probably lesbian, based on "the way she dressed." Jo invited her to her apartment for lunch. From this contact, Jo met a large group of lesbians, her "girls." She explains, "That's when I started really getting friends, going places. . . . I started living all over again." The women took her dancing. "Everybody wondered, "Who's this old lady that dances so good?" Everybody wanted to dance with me."

> [Later, the self-defense teacher] said, "There's a [women's music] festival that we have every year where you can go up there, and you can get naked, and you can go any way you want to go and do anything you want to do." So, she said, "But, you wouldn't like that." Because she thought I was so modest. . . . I said, "How do you know what I'd like?" So, I started going to the festival. *That's*

> when I met people! Whoo! Eight-thousand women up there. All sorts.
>
> But, this festival you have to . . . build your own tent. . . . They had a bed for me, honey. I was a big shot. . . . They'd never seen a lesbian, ninety-some-odd years old. . . . Kyleen took care of me. [They] had somebody to bring my food to me, somebody to sleep with me, somebody to see that I was comfortable all the time. They just spoiled me. So, they've been doing that ever since.
>
> It's made me feel good. But, I couldn't see why they's doing it, 'cause I'd never done anything outstanding. They say, "You're an inspiration to us."

One of Jo's girls made a documentary of Jo's life. Jo has been traveling to screenings throughout the U.S. and Canada. Yet, she sets her own priorities to pace herself. She turned down an invitation to appear on the Oprah Winfrey talk show because she was too tired, and she refuses to attend screenings in Europe because the flight would be too long.

Jo has given away videos of her documentary to her senior center and her doctor. Although Jo hopes to make a little money from movie rights and sales of the video, she insists that the producer recoup her expenses first. Jo does not know what percentages she will get at that point. "I don't know. I don't care. I'm giving it away anyway. I'll give some to different places, the center and the church." The center she refers to is the newly created Josephine J. Center, a residential and social services center for LGBT homeless and at risk youths in Newsom.

Jo has already given away memorabilia to the new LGBT museum in Ann Arbor, Michigan. She feels society is not prepared for all its recent technological advances, but it can find strength and wisdom in its elders' legacies.

As she has done before, Jo plans to attend the annual summer gathering of Golden Threads, a national group of old lesbians. "I'm just trying to keep healthy enough to go" because "I'm at the age where you're going to start failing."

Jo has been active at her senior center both prior to and after finding her new lesbian support system. She bowls, shoots pool, and takes trips with the seniors. However, she will never again join them for long bus trips because it is "too tedious." Although she doesn't know any other lesbians in the senior group, Jo is out as a lesbian to them and has given them her video.

> They think the world of Joey. . . . So, I's with both. I'm with the seniors and with the lesbians all over the place. . . . I like my lesbians. . . . They're all my children. The gays and the lesbians. I've met a lot of nice people.

Asked the difference between interacting with heterosexuals vs. gay and lesbian people, Jo responds,

> I don't see any difference. That's what I try to ask them all the time. Because, every time I have a party, I invite both straight people and gay people. Everybody seems to get along, so where is the difference? Why do they hate us so? Some people. The straight people. Why do straight people hate us? The churches don't want to take us in. The church is even against us. But, I don't see why. We live just like anybody else.

Asked why she thinks it is that some heterosexuals and churches are against gay people, Jo laughs, "They think we're queer!"

She quit driving in the 1950s because most of her needs were within walking distance. Today, she can walk to the United Methodist Church (UMC) for services. As a young woman, she attended church, but most gays and lesbians "just stayed home, I guess. If they went, they didn't tell anybody they were gay." Since the 1970s, the UMC in Newsom has opened its doors to gays and lesbians.

However, she complains that this UMC mails financial appeals to her, but does not reach out to her.

> I used to go down there, because it's near me. The people down there got so they knew me. I'd go to church. Of course, there's the part of the ceremony where

> everybody hugs everybody and says their thing. And then, they go upstairs for a little . . . social gathering. I can sit at the table and get me a cookie and something. Nobody never comes near, as long as I've been doing that. So, I quit going.
>
> They don't reach out! . . . They have a senior citizen's center down here at the church on the fourth floor. . . . When I go down [there], I guess I'm just different from other people. If I see a stranger there, I go and introduce myself, and I sit down and talk to them. And I just look around, and I don't see anybody else go up there and talk to that person. They just sit there.
>
> I go to a Catholic organization across the street. . . . They have a senior group and everybody treats me lovely. . . . I came up in church and told 'em I was a lesbian.

At a banquet honoring elders the day before this interview, Jo offered a suggestion to Newsom's mayor: He should hold a reception before the banquet so that the generations can mingle instead of sitting at separate at tables. She believes people who work with old people need to take the time to listen to their stories and find out who they are. Also, if young people would spend one or two hours per week or month with old people or "find someone you can help," the youngsters would learn invaluable life lessons that would help to keep them out of trouble. In addition, the interaction and assistance would help old people to stay healthy.

In summary, Jo J. is a moderately healthy 101-year-old lesbian whose primary health-care discourse focuses on three subjects: (1) successful formation and maintenance of informal support systems throughout the life span, (2) successful execution of instrumental activities of daily living despite a fast-paced and ever-changing world, and (3) the need for intergenerational interaction to facilitate self respect and respect of others.

Jo J. died five months after the interview. Her swallowing difficulties caused progressive weight loss and, according to Kyleen, Jo simply decided to quit living.

APPENDIX K

Interview #11: Kim K., May 2000

Kim K., a 77-year-old Black, Native American, and Irish woman is *in the life*, her term for her homosexual orientation. She and her partner, Dee, are in the process of ending their relationship after 44 years. They are selling the home they helped to build in 1965 in the semirural outskirts of a North Central U.S. midsize industrial town.

This transcript is particularly challenging because Kim speaks softly and in sentence fragments. She frequently substitutes code words, altered pronouns, gestures, and/or facial expressions for nouns or phrases. It is probable that, like Deborah D., much of Kim's ambiguous discourse is habitual from her long-closeted life. However, the habit may be accentuated by the presence of Kim's 11-year-old grandson, Michael, who lives with the couple. Home sick from school, he sometimes wanders within earshot. The emotional stress of the breakup may also explain Kim's disjointed discourse.

> This is a bad situation that would create a lot of stress. How long is this going to last? How long will I have to fight with this? And then, if I'm by myself, I'll be living this, reviewing this day-in and day-out. And, especially, I don't have anybody on the side that could be by my side that I could talk to.

In response to her partner's exhortation to "get a life," Kim states that no matter where she goes, she and her problems will be with her. "You have these inner in-and-out emotions that you're fighting with that oscillate. I said, 'Lord, what is that? What is that? Help me!' So far, the answer hasn't come yet. I'm still fighting with it." Kim explains that she rescheduled the appointment for this interview after having canceled a previous appointment because it would give her an opportunity to talk through her feelings.

Despite 73-year-old Dee's denials, Kim is fairly certain that she is having an affair with a 48-year-old woman. Kim also feels strongly that Dee is leaving her for two reasons: to avoid having to care for Kim and to find someone who will care for her.

> I believe with all my heart and soul . . . she really doesn't want to be looking after me. Or, she feels like that I'll be leaning on her. . . . That she doesn't want to be responsible, . . . and, as time goes by, the longer I live, there'll probably be more [disabilities] that will follow. . . . Just like my eyes. I have glaucoma. Yes. And, it can lead to blindness. And, this is something that can come on you suddenly.
>
> I'm not useful anymore. . . . She's programming, finding someone who can look after her. This person is 25 years younger! . . . [Dee has] angina. . . . And, that's, in a way, sort of a fearsome thing.

On the other hand, Kim believes Dee's "friend" is a con artist who wants Dee's money. Through her job, the woman could access Dee's pension files. "Con people have a knack for being able to turn you completely around, and you don't even realize it. And they definitely have those characteristics." In this instance, *they* is a coded pronoun referring to Dee's friend.

Dee refuses to tell Kim where she is going, a courtesy they have always extended to each other. Kim has told her, "You don't have to tell me, but at least somebody knows if anything happens. [Dee says,] 'Oh, I'll be all right. I'll be all right.' That's the way old teenagers talk!"

Only recently has physical abuse entered into the relationship. When the two were struggling over Dee's cell phone, Dee pushed Kim. "I fell backwards, hit my head against the leg of the dresser. The next day, I had a black eye." She plans to treat the eye with cocoa butter when she can get to a drugstore.

At times, Kim feels she could "wring Dee's neck."

> I have tried to keep myself stable. . . . I am filled with rage to the point I feel like I could kill and not feel one way or the other about it. And then, there are moments I go through like a solitude. . . . My senses come to me and try to take over . . . this turmoil going on inside of me. . . . I still have a certain amount of sane thinking. It goes back to religion. It goes to God. That gives me that stabilization. . . . All my life, I've been doing the golden rule. . . .
>
> I've also thought about . . . taking my *own* life. That's the one thing you won't be forgiven for. That's a drawback. You won't be forgiven.

Kim has warned Dee:

> [Your] cup runneth over. . . . When . . . I didn't hit you, I didn't let that cup run over. I still have a certain amount of control. But, I had a strong urge to hit you as hard as I could. . . . Thank God, I didn't do it. Remember that!

Kim never mentions church as a resource for support. Kim occasionally attends the Unitarian church, which is "very cosmopolitan as far as relating to different people, different races. As far as I'm concerned, that's religion. That's the way religion should be. God made us all."

She believes that Black lesbians are "not as outgoing and flamboyant as Whites . . . 'cause they know that there's so much [African American community] negativeness that exists, attitude-wise toward the Black lesbians" She blames the Baptist church, which is "still in the woods."

Kim never came out to her parents. She knew of her lesbianism in elementary school and came out at 19. Unlike some other interviewees she did not move away from her parents to gain freedom to be a lesbian. On the contrary, Kim moved from the East Coast to be near her parents after enduring five consecutive failed lesbian relationships with "gads-about-town." As with previous closeted interviewees, Kim did not come out to her parents to avoid conflict and to maintain their respect.

> Never had any ugly experiences. . . . Everything was just normal. . . . I wouldn't have felt comfortable with my parents [knowing] anyway, because I wanted that respect that they gave me and vice versa. I gave them the utmost respect. . . . That's one of the main reasons why I didn't want to really put anything into words. . . . We get along. Why ruffle the feathers?

As a child, most of Kim's peers were Caucasian. In high school, a lifelong White friend began ignoring Kim at school, but she interacted with her at home. Responding to this apparent racism, Kim isolated herself throughout high school. The feelings she expresses about this early incident are similar to her current feelings of being ignored, disrespected, and unnoticed.

Kim's family did not have health insurance when she was growing up. They sometimes bartered physicians' services for her mother's canned vegetables. Kim had typhoid fever as an eight-year-old and always had bad hay fever.

Working in a factory for 28 years, Kim was exposed to many allergens, such as oils and chemicals. "Days at a time I'd just run down to First Aid. Didn't do a bit of good. They'd send me right back on the same job." The company usually won the struggle with her doctor who wanted to keep her off work when the chemicals made her ill. The circle of exposure, illness, and sick leave was constant. She was exposed to "a lot of things. . . . A lot of things I saw going on that wasn't right. But, who's right, the workers or the big company? They're always right. You're not. You don't stand a chance."

Kim eventually requested a transfer to the sanitation department because janitors were exposed to fewer dangerous chemicals. She cannot prove any long-term effects of the chemical exposure. However, she suspects her hearing loss is attributable to the years of exposure to machine noise. She received her first hearing aids in her forties.

Currently, Kim can perform most of her personal care and some limited instrumental activities of daily living. Her fingers are somewhat gnarled from arthritis, and she has ulnar deviation of her wrists, but an anti-inflammatory relieves the pain. Primarily, she has difficulty walking due to arthritis in her knees and feet. She has a hammer toe, which impairs her balance. Her repeated goal is to be useful.

> Boy, if I can just turn this thing around and just be completely useful, but I can still do things. Sometimes, like if I'm lifting something down from overhead, my arms want to give out. . . . Do you think for one moment, like you see people who assist people who are having a problem? They never do. That upsets me. . . . [It's] degrading.

In this case, "they" is a coded pronoun referring to Dee. Dee did not want to help Kim bandage a sore toe, which would improve her walking. "It was just like pulling an eyetooth to get her to do that for me. She acts like I'm all right."

Her doctor has shown Kim exercises she can perform while sitting. Moderately obese, Kim has tried to lose weight, " but, it's harder for some people than others." She has inherited her grandmother's wide hips.

Kim can no longer work in the yard. Prior to the presumed affair, Dee and she had discussed moving to a condominium to ease the burden of home and yard maintenance. Recently, Kim became angry when Dee told their realtor to "tell *her* about the senior citizen's condominium." Dee had spoken as if Kim were "the only senior citizen sitting up here!"

Several years ago, Kim's friends, a Caucasian American lesbian couple in their 30s, took her to a diabetic clinic for a foot examination. "I didn't ever go to a doctor [about my feet]." During the educational component of the clinic, she was told that "family is very important" in monitoring the effects of diabetes. However, Dee refused to join her for future diabetic clinics. Dee "showed me then: no concern."

Kim describes a more recent incident that occurred in her local diabetic clinic. The waiting room was filled with "old White people" when she walked in. She received no response when she said, "Good morning." She was again ignored when she asked, "How are you today?" After one more attempt, she told her fellow patients that she was not going to hurt them. Finally, one person replied, "Good morning." Although one might assume that an old person is not threatening, Kim perceives a lot of fear among the races in her blue-collar town and overt racism within the local health care system.

Kim reports that she watches her health closely. She has never drunk alcohol or smoked cigarettes, and she consults doctors regularly. She subscribes to *Diabetes Self-Management Magazine* and *Diabetes Forecast*. Her factory workers' union provides excellent retirement benefits. Besides Medicare, she carries Blue Cross/Blue Shield supplemental health insurance and Metropolitan insurance for her vision and hearing.

Kim wears bilateral hearing aids, which Metropolitan will replace as necessary every two years. Her union pays all her insurance premiums. If she fills her prescriptions via the mail-order pharmacy contracted by her former employer, she pays $2 per prescription for a three-month supply. Otherwise, prescriptions from a drugstore cost her $5 each for a one month supply. Mail-order works well to keep her supplied with "medication I have to take on a long-term basis, like the insulin, like my high blood pressure." She uses another source for blood test strips and related paraphernalia. Although Kim has a blood testing kit which requires her to prick her finger, she paid $40 out-of-pocket for the testing kit called AtLast because the user can test on the forearm, leg, or other less sensitive places.

Kim is quite frugal with her money and complains that Dee has always been a "spendthrift." They keep separate bank accounts plus a household account, which Kim monitors. Lately, Dee has wanted to dip into the household account for entertainment; however, Kim believes the immediate future holds too many unknown variables to risk spending money on nonessentials. Kim's pension income is lower than Dee's.

Frequent telemarketing calls irritate Kim. She's afraid of being drawn into scam, and she tires of solicitors trying to manipulate her to get her money.

Kim is a "homebody. . . . This is my senior citizen's home. . . . Never have participated in anything outside of the home." Like Deborah D., she has purposely limited lesbian friendships over the years. She reflects,

> If I'd of known it would come to this, I would have been more outgoing. . . . And down through the years, . . . we used to go to parties a lot, we stopped going to parties too, because I've always had the concept that when you start a social life with a lot of people, there's a particular number of people you come in contact with that has the ability, especially when they see people getting along, and they've been together for a number of years, they make it a point to break it up. See how great I am? Puts a feather in their hat. I can do this. I'm gonna break it up.

Kim speaks of joining a computer class for seniors "when I get all of this out of my system and get settled down." However, her goal of learning to use the Internet and e-mail is to examine Dee's private correspondence for evidence of betrayal.

Kim, a professional photographer, shows off photographs of the people she considers family. She includes her older sister, her sister's husband, her three brothers, and a lot of nieces and nephews. As she lists each relative, she mentions their professions and emphasizes their high incomes. Her younger brother died from cancer, and her parents are both deceased.

Asked if she would consider going to live with a relative, she replies,

> Well, I haven't ever ever discussed my life with them. They accept me all right. They've never showed any hostility. None whatsoever. No. But, I have never actually laid it on line. And, I wouldn't want to go live with none of them, if they knew, and I knew that they wouldn't accept it after all these years.

Years ago, a brother asked her, "You messing around here with those funny people?" She replied,, "Well, what makes you say that?" Also, when her 21-year-old niece asked her directly if she were gay, she answered, "Well, I don't know whether you'll say I was or not. But, whatever you want to think is all right with me. Okay?"

Dee "has never promoted my family bond with my family." Kim says that Dee has resisted driving her to visit her family members. Kim still drives, but only off-highway driving for short distances. "They've always accepted her with open arms. She knows that. And they're sincere. They accept her in some instances, accept her more than they do me." Kim complains that in a recent visit to her brother's home, the family stayed up late visiting with Dee and ignoring Kim. "I felt shortchanged. . . . And I said, 'What about me? We're family. She wouldn't be here if it wasn't for me.'"

Although her mother lived to be 84, Kim has felt a premonition that she will die soon. "Probably be around next year or maybe the year after that." She wanted to see her brother once again. "And, I felt like I needed somebody. I felt like my family would be the only person that I could really feel real good. Rejuvenate me because they're blood. But, I was wrong." However, Kim did not tell her family members that she emotionally needed them. "I just felt like I would get that comfort."

Kim would "rather lay down and die" than live in a nursing home. She has seen how people in nursing homes are treated, but she sees her present situation with Dee as similarly degrading.

> Everything [in a nursing home] is controlled. . . . Some of them have been really abused, misused, ignored completely, humiliated to the end. And I just can't see myself being subjected to a condition like that. Although, in a sense, I'm being humiliated anyway, right here.

Kim is vague about whether or not she would commit suicide to avoid admission to a nursing home. She reemphasizes that she would rather die, especially if she were useless.

> Even if you have the potential of doing something, being useful, they would limit you. . . . They have rules, like any institution. And you have to abide by them. If you didn't abide by them, then they would use any measure that they see fit to keep you in place. They wouldn't want you to be an example for anybody else. . . . And, I feel so sorry for those people in nursing homes. . . . And families are so quick about dumping you in a nursing home, when you get a certain way. Furthermore, . . . they usually take your social security and your pension when you go in. And they don't even deserve what they get. You don't get nothing for it in return

Dee is currently Kim's power of attorney, and she is named in Kim's will. However, Kim plans to use her company's free attorney benefit to name a more trustworthy party to receive her power of attorney.

Kim has filled out the paperwork to donate her body to science, hopefully for diabetes research. Also, this would allow her life insurance money to go to her "family" instead of "in the ground."

The family Kim has named in her life insurance policy is different from the family mentioned above. She and Dee have a 38-year-old fictive daughter named Heather. The couple reared her from age 5 months to 18 months. The day before her adoption was to be finalized, her birth mother, Dee's relative, took Heather back. "We cried for days. Days. That was a trying situation." However, a year later, Heather's mother called the couple to tell them they could take her back. "We took *care* of her. We took *good* care of her. We *loved* that child. Love her to this day."

As with Deborah D.'s partner's child, Kim never refers to Heather as her daughter. Instead, Heather is "that child that I raised." She calls Heather's son, Michael, by name or refers to him as "that boy" or "this little boy." Yet, like Deborah D., Kim has bequeathed funds to Heather for her children's educations. Unlike Deborah D., Kim has not set up grants, but trusts Heather to carry out her wishes.

Not until last year did Kim and Dee tell Heather that they never adopted her.

> [Heather] acknowledged the fact that she had thought it, but didn't know for sure. But see, telling somebody something, coming out of your mouth, is what we felt was the right thing to do, and we did it. [We had not told her because] we were thinking maybe she would turn against us. But, we were wrong. She was very compassionate. She said, "Don't make no difference to me. You've always treated me nice." And, to this day, she is my friend.

Heather's birth mother, three brothers, and a sister died in a fire. Her birth father has no contact with her. When Heather joined the military, she left her infant son Michael for Kim and Dee to rear.

Kim and Dee do not know if Michael knows about their lesbian relationship.

> We never actually talked to him. We thought we'd wait until he got older, because I made a pledge that I would see to it that he graduated from high school, staying with it. . . . He's on [Dee's] side of the family, and I have given up myself to her family and her. I've neglected my family.

When Kim and Dee split up, Michael will live with Dee, because Heather and Michael are Dee's distant relatives and because Dee and Michael have a "rapport." Kim believes that she is the best parent because Dee is more of a buddy to Michael and his mother is emotionally detached from him.

Although she wears a Diabetes Alert necklace, if left alone, Kim worries that she would not be able to dial 911 were she to have a blood sugar reaction. She hopes to arrange for volunteer seniors to make welfare telephone calls every morning.

Other than the senior housing brochures their realtor gave her, Kim has not investigated retirement communities or assisted living facilities. "The prices were out of sight." She does not believe she is "helpless" enough yet to need assisted living.

Heather has offered for Kim to live with her, but her three-bedroom house is overcrowded.

> I'd hate to be piled up in somebody else's area. . . . I'll tell you another thing: Those two kids she's got are awful. They are soooo loud. I couldn't stand it. . . . And, her husband talks loud. That'd get on my nerves so bad. . . . I have quiet moments here. Now, [Michael's] quiet. . . . He talks soft and quiet most of the time. You should see the difference in him and those two that she's raised.

Kim also rejects the idea of living with the loving nephew who calls her every Mother's Day. She hates the humidity where he lives in the North East. While she is also fond of a niece, Kim does not speak of living with her.

Kim appears most inclined to live with the previously mentioned young White lesbian couple. The couple hopes to buy a 250 acre campground. They promise Kim she will have a large bedroom to herself. Kim recently helped these friends with electrical work in a house they are refurbishing. Such activity helps her to feel "as normal as possible. . . . You just do what you can do. That's all. If it's next to nothing, you still do that, instead of just giving up completely." She appreciates that her friends reciprocate. They are “very useful. . . . One of them took my feet, soaked it for me, massaged it, my feet, put the bandage on, trying to help me.”

The couple has also promised to help find Kim a new girlfriend.

> I want to be with somebody. I don’t want to be on my own. If I met someone . . . tomorrow, . . . I would have something to look forward to. . . . It would be just like picking me up from the beyond.

Social subtleties, especially nonverbal innuendoes, permeate Kim’s life as an old Black lesbian. They influence her choices for friendships, self-expression, and health care. Although for the interview she is dressed in a soft coral blouse and is wearing lipstick, she considers herself a *dyke*, not a *femme*, labels referring to the delineated male and female roles that were common in her generation. “I was always what you call a cosmetic representative of the [dykes]. She preferred dykes’ more comfortable tailored skirt suits and bowties.

As a young adult, Kim differentiated dykes from femmes by observing the subtleties of a couple’s interactions. Kim might later ask for a date with the one displaying more feminine nuances. Kim does not mind lesbians who are “suggestive.” However, as with some previous interviewees, she does not like to be around “flamboyant” or “boisterous” lesbians. Recently, Dee has been much too “flamboyant.”

Kim seldom verbalizes the term *Black* because “from just looking at them, you know who they are. You don’t have to specify that.” Likewise, she seldom uses her preferred term *in the life* because the people in a social gathering usually know intuitively who is one of them. They do not need to specify their “common interest.” Recently, a woman who seemed to be a lesbian denied it to Kim’s daughter, Heather.

Kim explained to Heather that denial upon direct questioning is "part of the game. . . . I don't care what she says. People don't always tell the truth."

The game grew complicated when Kim approached her "gorgeous" general practitioner about antidepressants to help her cope with her breakup. Regarding her doctor's orientation, Kim speculates,

> I don't really know. I look at her and I say, "Well, she *could* be.". . . I had nothing to go by talking with her or her attire, the way she presented herself. She's so smooth. . . . I've been listening to everything she says. See some kind of a key word she might give me.

Kim has never come out to any doctor, including the one mentioned above.

> Never mentioned it to my doctor. I started to one day. That's when this thing [with Dee] came up, and I became depressed. And I went into her office and I started, in so many words, I guess, I did. I told her I was depressed. And, she's a very compassionate person! And, she wanted to know why. And, I said, "Well, I have a friend, and I lost them." Just put it like that. General explanation. And I said, "My friend has been my friend for 43 years. We're not friends anymore. And, I feel really bad about it." She was . . . trying to give me encouragement.
>
> Then, the next time I went to her, I asked what kind of medication I could take. So, she prescribed capsules [for depression]. . . . And, I went home and took one. . . . I didn't like the reaction it gave me. . . . I felt like it was going to turn my stomach inside out. . . . I ain't taking no more of those. Not take anything that makes me feel bad or worse than I was. . . . I try to get over it the best way I can. Time will tell whether I can.

When Kim told her doctor about her reaction to the antidepressant, the doctor told her to discontinue it if it makes her feel "that uncomfortable," and Kim should let her know if she would like a referral to a psychiatrist. Whether or not the doctor understands the nature of the relationship between Kim and her lost friend, Kim "can't really say. . . . She may have misinterpreted. She may not have. . . . No follow-through to reassure me that she really understood. So, I can't really say."

Kim would reveal the nature of her relationship with Dee to a psychotherapist because "that's the only way I could get help. Somebody that's trained along that line that could tell me what I need to do."

Kim would only see a woman therapist because "they have a better understanding. . . . unless it's a gay man. But, if it's a woman, it'd be easier for me to talk to, let her know my true feelings."

To illustrate gay men's innate understanding, Kim points to their gay realtor, whom they hired precisely because they "sensed it right away" that he was gay. They did not tell him of their orientation, but they believe he indirectly confirmed his assumption about them.

> When he came back to put the sign up, he brought his friend with him. His friend is a teacher. . . . And these [homophobic] people got nerve enough to get all up in the air about no gay people teaching their kids. That's all that's been teaching them! For years. . . . It's a big joke!

Kim is one of several interviewees who speak of the social "joke" by which people in the life secretly and derisively laugh at unenlightened heterosexuals who openly ridicule gays and lesbians.

Kim summarizes her message to thesis readers about old lesbian health care issues:

> When I was gloriously happy, there would have been a lot of good positive things I could've elaborated on. But now . . . I'm going through this transition. . . . You have to have a composition of both [good and bad] to have really lived. . . . I certainly hope that . . . I will live through this with a good positiveness about life. . . . [I hope for a] rebirth, the desire to continue living.

In summary, the dissolution of this closeted woman's 44-year relationship has far-reaching financial, emotional, and medical consequences. Kim believes the breakup is rooted in her and Dee's medical problems and subsequent limited abilities. She has only a limited informal support network, but has excellent medical benefits. She cannot imagine living in a nursing home, yet she believes God does not forgive suicide.

Obsessed with her partner's betrayal, Kim's discourse encompasses expressions of rage, pain, confusion, wry humor, and hope. A barrier to accessing mental health services is the practiced subtlety with which she discusses this life crisis with her medical doctor.

Her current emotional stress has exacerbated some of Kim's medical conditions which include high blood pressure, arthritis, diabetes, poor hearing, and impaired mobility. She fears loss of financial resources, loss of control, and becoming useless and disrespected.

Kim is trying to rationally assess her life options. Although many relatives are still living, she will not live with anyone to whom she has not come out. This limits her options to her fictive daughter, Heather, whose husband is antigay, and to a young lesbian couple. She also hopes to find a new lover with whom to live.

APPENIDIX L

Interview Guide

Research Query: How do old lesbians view their past, present, and projected interactions with the health care system?

Initiating Interview: Sign Agreement to Participate In Research form, and read definition of health care. Reiterate format and purpose.

Interview Queries:

- Tell me about your experiences with the health care system.
- Tell me your experiences with the health care system.
- How do you feel about it?
- What does what you told me about your experiences with the health care system mean to you?
- Whom do you consider family?
- To whom or to what organization would you turn to if you were to need help?
- What kind of health care insurance do you have, and how do you feel about it?
- What were your experiences with the health care system like when you were younger?
- How do you feel about it?
- What does what you told me about your past mean to you?
- What do you think your health care is going to be like in the future?
- How do you feel about it?
- What does what you told me about your future mean to you?
- What do you want your experiences to be like?
- Why?
- What would you do if you (or your partner) could no longer take care of you?

Confirm Demographics: age; race/ethnicity terminology; term(s) for your orientation; define family; offspring; previous heterosexual marriage(s); years in significant relationship(s); profession(s); education; religion, if any; to what organizations, lesbian or nonlesbian, do you belong, if any?

Conclusion: May I speak with you again if I should have more questions?

Note: This is only an interview guide. The queries evolved during the individual interview and over the course of several interviews.

APPENIDIX M

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Sacramento, San Bernardino, San Diego,
San Francisco, San José, San Luis Obispo,
San Marcos, Sonoma, Stanislaus

AGREEMENT TO PARTICIPATE IN RESEARCH AT SAN JOSE STATE UNIVERSITY (SJSU)

RESPONSIBLE INVESTIGATOR: Nancy Hugman is a Registered Occupational Therapist and a graduate student in the Department of Gerontology at SJSU.

PURPOSE: I am conducting a research study in fulfillment of my Masters of Science Degree in Gerontology at San José State University. I have invited you to participate because you are at least 60 years old and you have identified yourself as a woman whose deep sexual and/or intimacy needs are best fulfilled in relationship with another woman. I am interested in learning about the experiences you have had with health care and how you feel about those experiences.

PROCEDURES: If you agree to participate in the study, I will ask you questions about how you feel about your health and health care in your past and currently, and what health care needs and concerns you may have for the future. The interview will take approximately one and a half hours, depending on how long you want to talk with me. You may schedule more interviews with me if you need more time or if you think you may have difficulty completing the interview in one sitting. We will meet in a location which is convenient for you and which will assure us enough privacy to help you to feel comfortable. I will tape record the interview(s).

RISKS/DISCOMFORTS: There is a risk of potential discomfort or embarrassment at being tape-recorded or in response to some of the interview questions. Your participation is entirely voluntary. You may decline to answer a particular question, and you may stop the discussion at any time.

Confidentiality will be handled with the utmost concern. Only my thesis advisor, the professional transcriber(s) and/or clerical person, and I will have access to the audio tapes and the transcriptions prior to changing the names and identities to protect confidentiality. These tapes and documents will be stored in a locked drawer. The transcriber(s) and clerical person will sign agreements that they will maintain confidentiality. No names or individual identities will be used in any reports or publications which may result from this study.

BENEFITS: Participation in this study will not benefit you directly, although you may find it personally beneficial to verbalize your feelings about your health care history and future plans. The information you provide may help to improve health care for older lesbians in general.

COSTS: There will be no costs to you for participating in this study.

PAYMENT: You will not receive payment for taking part in this study.

QUESTIONS AND CONCERNS: You have had the opportunity to ask me questions about this study. If you have further questions, you may call me, **Nancy Hugman**, at **(510)623-9133**. If I am not home, you may leave a confidential message. You may also e-mail me at **nhugman @aol.com**.

If you have comments or concerns about the study, you should first speak with me. If you would rather not speak with me, you may contact **Dr. Debra David**, Chairperson of San José State University's Department of Gerontology, at **(408)924-2972**. You may also contact **Dr. Serena Stanford**, SJSU Associate Academic Vice President for Graduate Studies and Research, at **(408)924-2480**.

CONSENT: You will be given a copy of this consent form for your records.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You may decline to be part of this study, or you may withdraw from the study at any time. Your decision whether or not to participate in this study will have no influence on your health care, your health care benefits, or your relationship with San José State University.

Your signature below will indicate your agreement to participate in this study.

Date	Signature of Study Participant
Date	Ms. Nancy Hugman, OTR, Researcher