



Healthcare practices and issues of rural lesbians
by Julia Ann Dybbro

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Nursing
Montana State University

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Abstract:

Rural lesbians constitute a unique population of women in which scant has been published. Little is known of their healthcare experiences, practices, and issues. This qualitative study attempts to fill in the gaps between rural and urban lesbian studies. Purpose: The purpose of this study is to describe and document rural lesbians' healthcare issues, practices, and experiences.

Method: A total of 14 rural self-identified lesbians were interviewed using open-ended questions and an ethnographic approach to data analysis. The interview questions centered on health status, healthcare experiences and practices, healthcare provider (HCP) preferences, philosophies around health and healthcare, disclosure of sexual preference to the HCP, and related tangents. Marginalization served well as the conceptual framework for this study as rural lesbians occupy the margins of rural mainstream society in several ways based on their gender, sexual orientation, and access to services.

Findings: All 14 informants were in good health and only three had serious health concerns in the past that involved extensive interaction with the healthcare system. There was an overwhelming preference for alternative healthcare and alternative HCPs although allopathic medicine was utilized with serious illness and in emergencies. A glaring lack of regular healthcare existed among the sample. Only 29% of the informants received annual PAP smears with the remaining PAP smear interval ranging from 2-18 years. Other healthcare issues emerging from the data included disclosure issues, isolation, drug and alcohol abuse, and depression and self-esteem issues. The barriers to optimal healthcare identified by the informants in the study included the lack of comfortable means for disclosing sexuality to the HCP, lack of anonymity and confidentiality in rural healthcare settings, homophobia in rural settings, and lack of financial resources. However, emerging from the data was a pattern of resiliency and creativity described by many of the informants as a way of adapting to living in the rural environment.

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of

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This thesis has been read by each member of the thesis committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

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VITA

J. A. Dybbro was born in Fairbanks, Alaska before Alaska became a state. She always wondered as a child if this made her a Russian in reality. Her Father started one of the first grocery stores in Alaska and her mother was a W.W.II pilot in the Women's Air Service Corps. Adolescence was whiled away on the Willamette River in Newburg, Oregon and horses became a passion in high school on Vashon Island, Washington. Horses continued to drain the bank account all through college at Washington State University but didn't stop the slow progress towards an anthropology degree. Discovering one needed a PhD to work with Jane Goodall in the jungle, Julie went back to school to be a nurse so she could at least travel to the jungle. Travel she did, but the closest she ever got to Jane was at a lecture in Seattle where she at least got an autograph. After 10 years of nursing in ICU's and home health, Julie careened back to school when it became evident there might be a different kind of fun to be had in the ever-powerful profession of nursing. Though not jungle-like, Montana was a great adventure nonetheless.

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ABSTRACT

Rural lesbians constitute a unique population of women in which scant has been published. Little is known of their healthcare experiences, practices, and issues. This qualitative study attempts to fill in the gaps between rural and urban lesbian studies.

Purpose: The purpose of this study is to describe and document rural lesbians' healthcare issues, practices, and experiences.

Method: A total of 14 rural self-identified lesbians were interviewed using open-ended questions and an ethnographic approach to data analysis. The interview questions centered on health status, healthcare experiences and practices, healthcare provider (HCP) preferences, philosophies around health and healthcare, disclosure of sexual preference to the HCP, and related tangents. Marginalization served well as the conceptual framework for this study as rural lesbians occupy the margins of rural mainstream society in several ways based on their gender, sexual orientation, and access to services.

Findings: All 14 informants were in good health and only three had serious health concerns in the past that involved extensive interaction with the healthcare system. There was an overwhelming preference for alternative healthcare and alternative HCPs although allopathic medicine was utilized with serious illness and in emergencies. A glaring lack of regular healthcare existed among the sample. Only 29% of the informants received annual PAP smears with the remaining PAP smear interval ranging from 2-18 years. Other healthcare issues emerging from the data included disclosure issues, isolation, drug and alcohol abuse, and depression and self-esteem issues. The barriers to optimal healthcare identified by the informants in the study included the lack of comfortable means for disclosing sexuality to the HCP, lack of anonymity and confidentiality in rural healthcare settings, homophobia in rural settings, and lack of financial resources. However, emerging from the data was a pattern of resiliency and creativity described by many of the informants as a way of adapting to living in the rural environment.

CHAPTER 1

INTRODUCTION

Lesbians as a population of women are a distinct subculture with characteristic behaviors and shared experiences. They are bound culturally by an affiliation with other women that may or may not include sexual, political, spiritual, social, psychological, and familial aspects. This is not to say that all lesbians are alike; they are as diverse a population as one could find.

Our society has struggled with the existence and acceptance of the lesbian individual as well as the lesbian culture. This societal non-acceptance has resulted in a healthcare system that does not adequately serve the needs of lesbians (Stevens, 1992). This study investigating the healthcare issues and experiences of rural lesbians would be unnecessary if lesbianism was accepted as a healthy variation of human sexuality. There would not be the perception as held by many lesbians that there was something to hide from the health care provider or that the healthcare system was anything but a safe place to get appropriate, quality, humane healthcare.

Purpose

To deliver quality health care it is imperative that the needs, perceptions, and common life experiences of the client be known. Using research, facts can be separated from myths concerning lesbian healthcare needs and client-perceived health issues. No studies have been published that address the health issues and practices of rural lesbians.

The purpose of this study is to begin documenting the personal and life experience of rural lesbians in relation to their health issues and practices. The findings will assist healthcare providers (HCP's) to have a better understanding of rural lesbian health issues and therefore provide more holistic care to these clients.

Background and Significance of the Study

Lesbians are labeled the invisible minority in healthcare (Robertson, 1992). Stevens (1994) identified that 77% of the healthcare interactions experienced by the lesbians in her study were negative. The negative label stemmed from a) the providers' assumption that the client was heterosexual, b) the providers' disdain for the lesbian lifestyle, or c) the providers' lack of knowledge around the healthcare issues and needs of the lesbian client. These reactions have promoted the invisibility of lesbians in healthcare because many lesbian clients choose not to disclose their sexual orientation in order to avoid a negative experience. In a survey of 110 gynecologists in Florida, 50% stated they did not think any of their clients were lesbian (Robertson, 1992). This finding seems unlikely and, again, points to either lesbians' unwillingness to disclose who they are, or a significant percentage of providers are unaware of the sexual orientation of their clients.

It is not surprising that the end result of invisibility and negativity is sub-optimal healthcare for lesbians. Lesbians have a much lower rate of cancer screening and preventive healthcare visits than the general population (O'Hanlon, 1995). It appears that lesbians are actively avoiding interfacing with the healthcare system. This could put them at risk for increased morbidity and mortality with some very preventable diseases. Until recently there has been very scanty research on the actual health risks of lesbians. Many

lesbians and HCP's alike are under the false impression that all lesbians are at very low risk for sexually transmitted diseases (STD's). Research is in the beginning stages of documenting what constitutes risk behaviors for lesbians. Now we know, for instance, that the Human Papillomavirus (HPV) can be transmitted between women (Marrazzo, 1996). Since HPV causes the vast majority of cervical cancers, this indicates that lesbians could be at risk and should be receiving periodic PAP smears. This is just one example that substantiates the need for more knowledge about the healthcare practices and health issues of lesbians in order to design appropriate healthcare interventions and client education.

Rural lesbians may or may not have unique health concerns or barriers to optimal healthcare as has been reported in numerous studies about their urban counterparts. As previously mentioned, there were no published studies on rural lesbians found. In Bushy's (1993) article on rural women, she states "It is impossible . . . to discuss a woman's health status without considering her lifestyle in the context of family networks as well as the community in which she lives" (p.187). This statement may very well apply to rural lesbian women but the context of family and community may be profoundly different. Either way, however, the impact on health status remains significant.

The impact of homophobia on the rural lesbian dweller and the potential stress it creates also bears consideration. The duress of societal unacceptance has been found to have a very negative effect on urban lesbian's sense of internal well-being (Trippet, 1994). It warrants investigating whether the same is true for rural lesbians.

Research Question

In order to obtain information on the healthcare practices and perceived healthcare issues of rural lesbians, the following research question was used to guide this study: What are the healthcare experiences of lesbians living in a rural environment? Sub-questions were used to expand the above research question: a) What are the physical and mental health concerns of the rural lesbian? b) What are the healthcare practices of the rural lesbian? and c) Does the rural lesbian disclose her sexual orientation to the health care provider and what are the reasons for disclosure versus non-disclosure?

Conceptual Framework

The conceptual basis for this study is marginalization. Marginalization has been a long recognized concept in the fields of anthropology and sociology used to describe and characterize people on the periphery or fringes of the center (Mayer, 1970; Spradley, 1979). People on the margins occupy this fringe position by virtue of their “differentness” from those perceived to be at the center. The term implies that the “center” is the seat of power and the margins have considerably less power (Ferguson, 1990). Audre Lorde (1990), called this center the “mythical norm” because it had a narrow definition, i.e., “white, thin, male, young, heterosexual, Christian, and financially secure” (p. 282). All other members of society are measured decrementally against this definition.

Marginalization is the term used by Hall, Stevens, and Meleis (1994) to describe the process whereby individuals or groups of people on the periphery of society, by virtue of their decreased power, economic security, and social acceptance, find themselves at

the fringes of the established healthcare system as well. Being on the fringe means that the healthcare needs of the marginalized are often overlooked, ignored, or inadequately investigated.

Access is a key element that is compromised with marginalization. Full access implies that healthcare is affordable, geographically available, and socially and culturally appropriate (Stevens, 1993). Lesbians are marginalized in the healthcare system because of decreased social acceptance and full access is denied because of a lack of socially and culturally appropriate healthcare.

Vulnerability is a product of marginalization in that being on the edge of the center or mainstream means more exposure to potential (psychological or physical) harm (Hall et al., 1994). The physical harm could be manifested by sub-optimal or inappropriate healthcare and internalized homophobia creates a psychological strain via a marginalized person being bombarded by negative images of their identity.

The other side of vulnerability can be adaptive (Hall et al., 1994). There can be a reaction of resilience and durability that enhances the individuals ability to survive on the margins. There can be a creative ability manifested out of marginality and vulnerability that enhances maneuverability within an otherwise constricting environment. Lee (1991b) found in her study of rural adults that there was a significant relationship between the characteristic of hardiness and perceived mental and social health. In the case of rural lesbians, it would be helpful to ferret out their vulnerabilities and then capitalize on their adaptive behaviors in order to better accommodate their healthcare issues and needs.

Acknowledging that the healthcare experience of the marginalized can be very different from that of the mainstream helps to put their beliefs and behaviors into perspective. Knowledge and recognition of human diversity is an opportunity to empathically approach the healthcare needs of those on the margins.

This qualitative study provides a beginning to understand the experiences of rural lesbians in relation to their healthcare. The study describes through the informants' narratives the central domains of their experiences and perceptions as rural-dwelling lesbians interfacing with the healthcare system.

CHAPTER 2

REVIEW OF THE LITERATURE

Keeping the research questions and purpose of this study in mind, the review of the literature was divided into five major categories: a) lesbians' healthcare experiences and provider preferences, b) lesbians' mental and physical health issues, c) disclosure of sexual orientation to healthcare providers, d) barriers to optimal healthcare, and e) rural lesbian healthcare issues.

Lesbians' Healthcare Experiences and Provider Preference

There is overwhelming evidence in the literature that lesbians have had a plethora of negative experiences when interfacing the institution of traditional healthcare in the U.S. and abroad (Conway & Humphries, 1994; Denenberg, 1995; Hall, 1994; Hitchcock & Wilson, 1992; James, Harding, & Corbett, 1994; O'Hanlon, 1995; Quam & Whitford, 1992; Robertson, 1992; Stevens, 1992; Stevens, 1994; Stevens & Hall, 1988; Trippet, 1994; Zeidenstein, 1990). Some of the negative experiences documented are a) attitudes ranging from blatant disdain with refusal to give care to embarrassment and uncertainty from the healthcare provider (HCP) when sexual orientation of the lesbian patient was disclosed, b) ignorance of lesbian lifestyles and sexual practices on the part of the HCP, rendering her/him ill-prepared to handle specific lesbian healthcare issues, c) inappropriate questioning and care based on an assumption of heterosexuality by the

HCP, d) exclusion of the patients' partner in the healthcare interaction, e) breach of confidentiality, f) attempts to refer to mental healthcare for "curing" of the lesbian lifestyle, g) rough physical handling, h) no comfortable opportunity to disclose sexuality, and i) a generally unsupportive atmosphere (Lucas, 1992; Stevens, 1992; Stevens & Hall, 1988).

One of the most common scenarios cited in the literature that renders a healthcare experience uncomfortable is the assumption of heterosexuality (Hitchcock & Wilson, 1992; Robertson, 1992; Stevens, 1992; Stevens, 1994; Stevens & Hall, 1988). Often, the lesbian client chooses not to or is not given an opportunity to disclose her sexuality and one of the first questions asked by the HCP is "Are you sexually active?" This immediately puts the lesbian client on the spot. If she is sexually active with women only and she answers the question "Yes," the next question, of course, is "What birth control method do you use?" She answers "None" and then must face the sequelae of questions as to whether she wants to get pregnant and why she does not use birth control. If she answers "No," then the HCP may query her as to why she is not sexually active; "Are you afraid of getting AIDS, is there some sexual dysfunction?" These circumstances cause a distancing between client and HCP if the client does not feel safe or confident in disclosing her sexuality under these circumstances and covers the questioning with outright lies or is vague in her answers. The end result is that the client feels uncomfortable, the HCP does not have the full picture, and the opportunity for a meaningful accurate exchange of information and appropriate education has been missed.

Stevens' (1994) study examined healthcare interactions from a wide variety of settings. Forty-five lesbians recounted 332 separate interactions, 77% of which were deemed negative by the respondents. What is even more significant is that 44% of the respondents stopped seeking healthcare as a result of the negative experiences. In Stevens' (1992) review of lesbian research, of the 19 studies exploring lesbians' healthcare experiences, all reported varying levels of negative experiences or fear of negative reactions from the HCP. Half of the studies stated that the respondents either delayed or hesitated using the healthcare system altogether because of the negativity and disclosure issues.

The good news is that negativity is not the only reaction lesbians have experienced, even though the literature is more heavily weighted on that end of the scale. In a 1980 study done by McGhee and Owen (Stevens, 1992), 73% of the respondents disclosed their sexuality to the HCP and of those, 42% said they got a positive response from the HCP. Another study revealed that respondents often felt comfortable disclosing to female HCP's.

The HCP preferences of lesbians have predictably been shaped by their collective experiences in the healthcare arena. Overwhelmingly, females were the provider of choice (Hitchcock & Wilson, 1992; Lucas, 1992; Robertson, 1992; Stevens, 1992). Lesbian HCP's took precedence over female HCP's in Lucas' (1992) study while the reverse was true in the study done by Trippet and Bain (1992). Female family practice physicians and female nurse practitioners were very close to one another at the top of the priority list of HCP's (Lucas, 1992). Female obstetrician/gynecologist physicians and

then female physician assistants came in 3rd and 4th in provider preference. Alternative providers were not mentioned in the study, although there is a large body of evidence in the literature that lesbians have a predilection for alternative practitioners including naturopaths, chiropractors, massage therapists, herbalists and homeopaths, acupuncturists, and energy healers (Robertson, 1992; Stevens & Hall, 1988; Trippet & Bain, 1992; Williams & Riehle, 1995). It is intimated this predilection comes from the perception that alternative practitioners are less judgmental, more holistic in their practice philosophy, have a greater emphasis on prevention and education, show more respect, and communicate better (Trippet & Bain, 1992). These perceptions are often coupled with a stated distrust of the mainstream medical model (Denenberg, 1995; Stevens, 1992; Trippet & Bain, 1992).

Lesbians' Health Issues

The main impetus of this literature review is not to make comparisons between the health issues of lesbians and heterosexual women; their issues may be similar in some areas and different in others. The importance lies in identifying the health risks and barriers to optimal healthcare of the lesbian community in order that they may be addressed. It is difficult to determine the prevalence of health problems in lesbians because of the lack of studies but the health issues identified in the literature include a) cervical and breast cancer, b) STD's, c) alcohol and tobacco abuse, d) depression and other mental health issues.

The literature points to a glaring lack of regular healthcare screening and check-ups in the lesbian population. On the one hand, lesbians say their top health priority is

cancer screening and detection and well woman care (Lucas, 1992). Lesbians, however, had a three-fold greater time interval in-between PAP's than heterosexual women (O'Hanlon, 1995). In 2 large surveys, 5-10% of the respondents had never had a PAP screening. Zeidenstein (1990) found a 50% rate of yearly PAP smears in her study respondents, with the other half ranging from never to 3-5 years. Denenberg's (1995) report cites that gynecological exams are deferred by lesbians secondary to lack of funds, lack of knowledge of their risk factors, and fear of a negative experience as mentioned earlier. The respondents who did not get yearly PAP's felt they did not need gynecological care so often because of their lesbianism; many felt their risk for an abnormal PAP was far less than heterosexual women (Zeidenstein, 1990).

In general, lesbians may be in the lowest risk categories for sexually transmitted diseases (STD's) and their incidence of the more common forms of vaginitis seem to be less than heterosexual women (Edwards & Thin, 1990; O'Hanlon, 1995). However, it is difficult to determine the exact risk that lesbians face in terms of STD's and cervical and breast cancer for several reasons: a) very few studies on STD's and cancer have been done that select specifically for lesbians (Edwards & Thin, 1990; Marrazzo, 1996), and b) it has been approximated that 70-80% of lesbians have had at one time or still have sexual relations with men (Cochran & Mays, 1988; O'Hanlon, 1995; Marrazzo, 1996; Zeidenstein, 1990).

Human papillomavirus (HPV) is associated with cervical cancer; transmission of HPV between women was thought to be rare. For those infected, the etiology was probably due to previous sexual contact with men (Conway & Humphries, 1994;

Edwards & Thin, 1990). Recent clinical findings as well as research on women who only have had sex with women is revealing that there may be a mode of HPV transmission between women (Edwards & Thin, 1990; Marrazzo, 1996). The recommendation coming from these recent research findings is for lesbians to get yearly PAP's based on the prevalence of previous sex with men in the lesbian population plus the possibility of HPV transmission between women (Marrazzo, 1996).

The other STD's are fairly well documented in their prevalence with lesbians. Bacterial vaginosis, the most common reported STD among lesbians, is found to be easily transmitted between women (Edwards & Thin, 1990; Marrazzo, 1996; O'Hanlon, 1995). Vaginal monilia (yeast) infections and herpes simplex virus are also reported clinically and found to be transmittable along with trichomonas, although the latter seems to have a much lower incidence of being spread between women. Lesbians are in one of the lowest risk categories for chlamydia and gonorrhea, and unless IV drug use is a factor, are also thought to be at low risk for HIV transmission if sexual contact is with women exclusively (Edwards & Thin, 1990; Chu, Buehler, Fleming, & Berkelman, 1990).

Breast cancer may pose a serious threat to lesbians' health and longevity. No research has documented that lesbians have a higher incidence of breast cancer but studies report that lesbians tend to have a higher body fat ratio and a lower parity than the average female. It was surmised that their risk for breast cancer was higher than heterosexual women (Lucas, 1992; O'Hanlon, 1995). Brownworth (1993) cites Suzanne Haynes, Chief of Health Education at the National Cancer Institute, as saying the

incidence of breast cancer in lesbians is three times that of the general female population secondary to the risk factors mentioned above with the added belief that lesbians have a much higher alcohol and tobacco use. Self breast exam was performed by 21% of the lesbians surveyed as compared to 50-63% of the heterosexual women (Denenberg, 1995).

Studies report a higher rate of alcohol problems in lesbians; 20%-30% prevalence rate in lesbians compared to 10% in heterosexual women (Denenberg, 1995; Hall, 1994). There has been criticism of some of these studies in their convenience sampling techniques; i.e., surveys of bar patrons. Several subsequent studies have shown no higher alcohol consumption among lesbians (O'Hanlon, 1995; Rankow, 1995). However, it is not difficult to see how there may be a set-up or predisposition for alcohol abuse in the lesbian culture (Hall, 1994). Bars are often the only meeting place for lesbians. There may be an association between alcohol and the attempt to relieve stress. While this association has not been directly tested in the lesbian population, it is inferred in the literature (Bradford, Ryan, & Rothblum; 1994 Lipton, 1994).

According to three studies on lesbian's health habits, the rate of smoking varied from 27% to 31% (Denenberg, 1995). This percentage seems to be similar to the smoking rate of women in general (27%), but the difference is that lesbians' smoking rate increases with age whereas rates decline with older age in the general female population. Regardless of the increase or decline with age, smoking constitutes a significant health risk to lesbians as a whole if more than a quarter of the population is smoking.

Mental health issues documented in the lesbian population include depression, suicide, stress reactions, internalized homophobia, "coming out" or disclosure issues, religious conflicts, eating disorders, domestic abuse, relationship issues, and fear of homophobia including violence from hate crimes (Trippet, 1994). Some of the literature reports that lesbians have no higher depression and mental illness than heterosexual women (Bradford et al., 1994; Rankow, 1995). It has been postulated, however, that lesbians have a higher risk for depression secondary to the pressures of being homosexual in a non-accepting society with its concomitant lack of social support (Denenberg, 1995; Rankow, 1995). Several recent studies have shown that lesbians seek professional mental health services at a higher rate than heterosexual women (Bradford et al.). It has been speculated that lesbians have had to face and come to terms with the hard issues of being out, different, and oppressed. The more out the lesbian was, the greater the tendency to have used mental health counseling.

There exists an incredibly high risk for suicide in gay and lesbian adolescent youth. It has been suggested that homosexual youth constitute one third of all adolescent suicide (O'Hanlon, 1995). Suicide is the leading cause of death in lesbian adolescents (Denenberg, 1995). In Bradford's et al. (1994) National Health Care Survey, there was an 18% suicide attempt rate across the life span. The older segment of the study respondents had a lower likelihood of suicide attempts and African American and Latina women had a higher attempt rate. It is unclear from the literature what mental health challenges are pushing these women to the brink of suicide. Depression and suicide rates, when not

broken down by age, appear to be similar in heterosexual and lesbian samples; the exception is adolescents, where young lesbian women are at heightened risk.

Disclosure of Sexual Preference to Health Care Providers

Lesbians live with a constant decision dilemma surrounding disclosure of sexual orientation. Every new encounter carries with it measured increments of risk-taking surrounding the disclosure question. The decision to disclose is often based on safety, relevance, and intimacy of the contact. All these factors are true in the healthcare arena as well. Hitchcock and Wilson (1992) asked 33 lesbians how they dealt with the issue of disclosure with HCP's. It was discovered that the lesbians went through quite an elaborate internal process in order to weigh the safety of disclosing to their HCP.

The first step was to anticipate the risk of disclosure. This was akin to an assessment. Clues were obtained by a) the physical aspects of the office such as what magazines were on display in the waiting room, b) the characteristics of the staff such as eye contact and ease of interpersonal interaction, c) and the history intake form and whether there was a space to disclose sexual preference. If it was felt that their medical care may be compromised or their psychological comfort was threatened, disclosure was forgone. Disclosure could take on different forms, depending on the initial assessment. If neither choice of full disclosure or nondisclosure was made, the lesbian could drop different clues to the provider such as "I am absolutely certain there is no way I could be pregnant," or "I have no need whatsoever for birth control," thus leaving it up to the provider to figure out the rest .

When disclosure was made, the second step was assessing the reaction of the HCP. The positive or negative reaction of the HCP determined if the lesbian continued a relationship with that provider. It also affected encounters with future HCP's: negative experiences had a silencing effect on future sexuality disclosures to HCP's and sometimes even resulted in outright cessation of health care in order to avoid a negative encounter.

Another aspect surrounding lesbian's decision to disclose to the HCP included relevance to the health concern (Cochran & Mays, 1988; Hitchcock & Wilson, 1992). If the lesbian perceived that her sexuality had no contextual relevance to her health concern, the decision to not disclose was often taken. Confidentiality was also found to be a factor. In one study, 63% of the respondents felt that sexual preference should be disclosed but only 28% of those felt the information should be written on the medical record (Lucas, 1992). There exists the real fear that if their sexuality was recorded, it could be used against them, for example, in child custody battles (Trippett, 1994).

There have been numerous studies on the rates of disclosure to HCP's (Stevens, 1992). There was wide variability; from a low of 18% who disclosed to their gynecological HCP in the Midwest to highs of 73% disclosure in San Francisco and a 91% disclosure rate in a sample of 35 lesbian mothers seeking obstetrical care. Generally, there was a high rate of disclosure with mental health counselors as it was thought to be very relevant to their treatment (Hitchcock & Wilson, 1992). Hall (1994) reported in her ethnography of lesbians recovering from alcohol problems that there were often very negative reactions surrounding disclosure in alcohol recovery therapy groups.

The advice from one group leader to a lesbian participant was not to disclose her sexuality to the group, presumably because it would make them uncomfortable.

The reason for non-disclosure was overwhelmingly attached to fears of a) negative reactions from HCP's, b) compromised health care in the form of less care, fewer referrals, and unsafe treatment, and c) a general discomfort around the whole health care interaction (Stevens, 1992). In fact, many studies cited the fact that lesbians often delayed or completely quit seeking health care because of disclosure issues (Cochran & Mays, 1988; Hitchcock & Wilson, 1992; Stevens, 1992).

Barriers to Optimal Health Care

Barriers are factors that create obstacles that keep lesbians from receiving the best and most appropriate health care they are due; as any individual is due. We have seen from the literature how the negative reactions from HCP's, heterosexual assumptions, and disclosure and confidentiality scenarios have caused lesbians to shy away from the health care system. We have also seen that there is a lack of scientific research specifically looking at lesbian health issues and risks. Optimal health care access is barred to lesbians also because they often do not have insurance or do not have access to partners' insurance policies as married heterosexual couples have, since lesbian partnerships are not legally sanctioned (Denenberg, 1995). Lesbians make less money than their heterosexual counterparts even though they tend to be better educated (Bradford et al., 1994; Denenberg, 1995; O'Hanlon, 1995). Estrangement from families and their possible financial support as well as job discrimination against lesbians have been noted as possible explanations for the above demographics (Denenberg, 1995).

There is a two-fold ignorance that creates another barrier. The first is ignorance among health care providers of the lesbian lifestyle and what that means and does not mean in terms of health risk and needs (Stringer, 1995; Williams & Riehle, 1995). For instance, the assumption that lesbians never have sexual relations with men, do not have children, and do not have domestic violence in their partnerships keeps the HCP from considering these options when looking at the lesbian client. The HCP who does not know of the risk behaviors which lesbians may participate in loses the opportunity to educate clients. One lesbian client was refused an HIV test because the HCP said since she was a lesbian, she did not need it (Williams & Riehle, 1995).

The second ignorance lies with the lesbian herself. Many lesbians are unaware of what constitutes risky sexual behavior or what their health risks are around cervical and breast cancer and STD's because they do not see themselves in any of the statistics (Stringer, 1995). They too make assumptions based on an heterosexual interpretation of health information.

How the topic of homosexuality is taught in medical and nursing schools constitutes a barrier to optimal health care for lesbians by virtue of the lack of information conveyed to students (Wallick, Cambre, & Townsend, 1992). The average time devoted to gay and lesbian topics is three hours and most of that time is spent on the subject of human sexuality. According to studies done in the 80's and 90's, there is still a significant amount of homophobia among nurses, nursing students, and nurse educators (Eliason & Randall, 1991; Smith, 1993). In Randalls' 1989 study (Stevens, 1992), 34% of the nursing students surveyed found "what lesbians do is disgusting". This attitude

may reflect not only homophobia but also an ignorance of the lesbian lifestyle. It was found that those with the highest acceptance for lesbians had a personal familiarity with a lesbian, in other words, to know a lesbian predicted a higher level of tolerance and acceptance of the lifestyle. Homophobia flourishes in a culturally unaware health care system. It is the responsibility of higher education to turn out well qualified health practitioners and this must include cultural awareness diversity training (Stephany, 1992). Universities can be powerful progenitors of cultural tolerance and egalitarianism.

Rural Lesbian Healthcare Issues

No studies were located which addressed rural lesbian healthcare issues; in fact no studies were found that addressed rural lesbians from any aspect. Only one article was located during the literature review search. It was about the difficulty gay and lesbian dwellers face when trying to fit into rural communities (D'Augelli & Hart, 1987).

Summary

It is important to acknowledge the difficulties inherent in doing studies on lesbians. Sampling is a problematic issue. Lesbian research has relied on convenience and snowball sampling. Data are collected at lesbian cultural, political, or social gatherings. There must be the assumption made, therefore, that the lesbians being included in these studies identify with and participate in the lesbian culture. Because of the stigma against homosexuality in this country, it would be very difficult, for instance, to put an advertisement in the local newspaper requesting lesbian subjects for a research project. Lesbians have historically had an ability to blend into the mainstream of society because they do not always have obvious outward differences in their appearance

(Hitchcock & Wilson, 1992; Trippet & Bain, 1992). It is difficult for all these reasons to get a true random cross-section of lesbians.

Many studies and articles were written that combine lesbians and gay men or lesbians and heterosexual women studied together (Eliason, 1996; Quam & Whitford, 1992; Smith, 1993; Stevens, 1992; Trippet & Bain, 1992). Lesbians have very different issues and views of themselves in relation to society than do gay men or heterosexual women. This is very well documented in studies about their healthcare experiences, issues, and perceptions (Bradford et al., 1994; Buenting, 1992; Denenberg, 1995; Eliason, 1993; Robertson, 1992; Stevens & Hall, 1988; Trippet & Bain, 1992). Add to this the confusion of ferreting out the healthcare issues of lesbians when many self-identified lesbians also have sex with men (Cochran & Mays, 1988; Conway & Humphriès, 1994; Denenberg, 1995; Edwards & Thin, 1990; Marrazzo, 1996; Rankow, 1995; White & Levinson, 1995). These factors confuse the research picture we have of lesbians.

Lesbians as a distinct subculture are no more stereotypical than heterosexual women as a group. If one looked strictly at the demographics of most of the studies done on lesbians, one may be led to believe that the vast majority are white, upper-middle class, college-educated, and live in metropolitan areas (Bradford et al., 1994; Buenting, 1992; Hitchcock & Wilson, 1992; Stevens, 1992; Stevens & Hall, 1988; Trippet & Bain, 1993; Zeidenstein, 1988). It may be that the privilege of education and socioeconomic stability along with the anonymity afforded metropolitan dwellers makes for a more accessible, available, and willing study participant. It is a challenge to access the diverse segments of the lesbian subculture including the economically disadvantaged, lesbians of

color, rural lesbians, and those that choose not to openly participate in the lesbian subculture.

Five categories of information were developed from the review of literature on lesbians and healthcare. It was found from this review that lesbians have encountered an extraordinary amount of negative healthcare experiences. These encounters have taken on a variety of forms and intensities with the assumption of heterosexuality being the most common. Lesbians have been found to have a preference for women healthcare providers and may lean toward alternative healthcare practices and providers out of a developed mistrust of the Western medical system.

Because of a lack of studies on lesbians' health risks and disease susceptibility, there is scanty information to substantiate any strong statements of an increased or decreased prevalence or incidence of certain diseases. There is evidence that lesbians have a lower STD rate but new research shows that there is sexual transmissibility of many pathogens woman-to-woman that was previously unknown.

Many of the mental health issues of lesbians stems from dealing with external and internalized homophobia. The literature states that lesbians do not have significantly differing amounts of depression but that there is a higher incidence of suicide among lesbian teenagers.

Much has been written on disclosure of sexual orientation and there is a wide variety of experiences and adaptive behaviors that have come out of this phenomenon. Disclosure is generally based on perceived safety and acceptance from the HCP toward the lesbian client.

The barriers to healthcare identified in the literature were varied, including financial constraints, lack of insurance, ignorance of the HCP and the lesbian client of the healthcare issues and needs of lesbians, and the lack of information taught in medical and nursing schools around lesbian lifestyles and healthcare.

The last category of the review of literature was short because of the paucity of published information on rural lesbians. No studies were found that specifically addressed the healthcare needs or issues of rural lesbians.

CHAPTER 3

METHODOLOGY

Introduction

This chapter focuses on the research methods used to study the healthcare experiences, practices, and issues of rural lesbians. The design of the study, population, sample, data collection, protection of human subjects, and data analysis are discussed in this chapter.

Design of the Study

This study was an ethnography of the healthcare issues and practices of rural lesbians. Because of the lack of published research about rural lesbians, the population can be considered a relatively unstudied group. Spradley (1979) eloquently explains that the goal of an ethnography is “to describe and explain . . . variations in social behavior. If we are to understand this diversity, we must begin by carefully describing it.” For this reason, the ethnographic approach was used to document and describe the life experiences of the informants and their perspectives on healthcare practices and issues, healthcare access, and the healthcare system as these areas relate to lesbians.

Population and Sample

The population for this study was rural lesbians. It is extremely difficult to determine the population size of lesbians living rurally because the U.S. Census does not ask for individual sexual orientation. The results would be unreliable even if the question

were asked. Because of the history of homophobia, many lesbians may not reveal their sexual preference on the U.S. Census.

The informants for the study met the following criteria: a) self-identified as a lesbian, b) at least 21 years old, c) lived at least 40 miles from an urban area (urban is defined by the U.S. Bureau of the Census as any place with greater than 2,500 persons) (Lee, 1991a), d) spoke and understood English, and e) volunteered to participate in the study.

All 14 informants, obtained by convenience and snowball sampling, lived in Western Montana. The first few informants were known to the researcher. Others were contacted by the original informants and asked if they would be willing to participate. Contact was made with several informants at a large reunion of lesbians who had lived in one particular area of rural Montana over the last 15-plus years. No one who was asked refused to participate. Many stated that they thought the study was an important step in bridging the gap between lesbians and mainstream society; this further induced them to participate.

Purposefully, the informants were chosen from different geographic areas around Western Montana and from different circles of acquaintances. To the best knowledge of the researcher, without breaking confidentiality, the informants did not all know one another. The sample was not, necessarily, the most vocal and high-profile members of the lesbian community. This was also purposive in order to avoid creating an "elite bias" sample (Sandelowski, 1979, p. 32).

Data Collection

Data were collected from October, 1995 through September, 1996. Once an informant expressed a willingness to participate in the study, a convenient, private, and comfortable meeting place was arranged with the informant. All of the informants chose to meet in their own homes. Ten of the informants were in a partner relationship; 3 couples were interviewed together and 2 couples were interviewed separately. This happened not by design but secondary to time constraints. The remaining 4 informants were interviewed alone. The interviews lasted from 1-2 hours and were tape recorded.

The first part of the interview process was demographic data collection (Appendix A). To help get a perspective on life events and choices that may have an effect on health beliefs and practices, informants were queried about a) where they were born and raised, b) family-of-origin structure, c) how old they were when they self-identified as a lesbian, d) their current definition of family, e) past sexual identities and practices (heterosexual/bisexual/lesbian), f) why they lived in a rural area, g) education, h) occupation, i) health status, j) financial status, k) age, l) child-bearing and rearing history, and m) whether or not they had health insurance.

The interview consisted of in-depth open-ended questions (Appendix A). A certain flow of questions was used in an attempt to elicit the informant's beliefs and feelings around their own healthcare experiences in the past. Questions were asked, such as "What do you do when you have a serious illness?" and "Have you ever been hospitalized?" Then the questioning moved on to elicit preferences and beliefs around healthcare and health care providers (HCP's). Examples of these questions are "Do you

have a regular HCP?" "Who do you go see when you are sick?" and "Does the sex of the HCP matter to you?" There were questions asked about whether and under what conditions the respondent disclosed their sexual orientation to the HCP: "Does it make a difference (for disclosure) whether the HCP is in a rural clinic versus Missoula?" and "If you were going into the HCP for a vaginal infection, would you disclose?" The last section of questioning delved into the informant's beliefs around the general mental and physical health-related issues of the rural lesbian population: "Do you think rural lesbians have any higher rate of alcohol, drug, or tobacco use than lesbians who live in big cities?" Elaboration of issues and personal stories were encouraged. The emphasis of the interviews was on healthcare but the informants had many life experiences, though tangential, that related to their health beliefs and practices. Coming out and homophobia stories were examples of life experiences.

Protection of Human Subjects

Montana State University-Bozeman, College of Nursing's Human Subjects

Review was completed and the study met all the established criteria. A letter of introduction explaining the study was given to all the informants. The interview process along with the type of questions that would be asked was fully explained before permission to participate was requested. I inquired of the initial informants whether they knew of rural lesbians that may want to participate in the study, and if they would be willing to make the initial contact. In this manner, there was less pressure on the informants to consent than if the researcher asked them directly. All participants in the study read and signed a consent letter (Appendix B). The letter emphasized that the

participant could withdraw from the interview process at any time and there would be no pressure to resume the study at a later date. After consent to participate was obtained, permission to tape the interview was sought.

Confidentiality and anonymity of the participants was maintained throughout the study. Names were not attached to notes or tapes. Professional transcriptionists were utilized. The transcribed interviews used letters and numbers to differentiate them and only the researcher knew what names and numbers matched informants. The tapes were erased after the study was completed. The signed consent letters were also destroyed after completion of the study.

The potential benefit to the informants from this study was a sense of contributing insights of the lesbian subculture to nursing research, which may go on to help shape a more holistic and diversity-sensitive healthcare system. The risk involved included the potential for emotional feelings and psychological strain due to the personal nature of the questions.

Data Analysis

Data analysis started after the first interview was conducted. Prominent themes, categories, and important issues to the informant were noted and each subsequent interview built on the ones previous. As with any ethnography, it is important that the importance and relationship of the parts to the whole be defined by the informant (Spradley, 1979). As the interviews progressed, the themes and categories that stood out were emphasized and elaborated. Notes with themes, main ideas, categories, and tangents were made in the margins of the transcribed interviews as they were read. The margin

notes were very brief summaries; sometimes just a word. These notes were then compiled into lists and divided into categories. The main headings of the categories became the central domains or cover terms which represented the symbolic categories of the data. The data fell out into subcategories under their appropriate domain as the lists and notes from the margins were arranged and re-arranged into a meaningful organization. The transcribed interviews were read several times to ensure that all the relevant data was placed into an appropriate domain or subcategory.

Rigor of the study was tested using Guba and Lincoln's (Sandelowski, 1986) criteria for qualitative analysis. Credibility, the interpretation by the informants that the domains, subcategories, and findings of the study were correct and true, was verified by several of the informants. Several rural lesbians who were not in the study also verified the "fittingness" (p. 31) of the findings in relation to their own experiences. Auditability, the ability of other seasoned researchers to be able to track and concur with the analysis and conclusion of the study, was accomplished through the members of the thesis committee. Confirmability, or the striving for neutrality of the findings, was achieved when the above three criteria were established and was also scrutinized by the committee members.

The researcher made every attempt to form a representative view of the informants' life experiences. Undue emphasis in the analysis of the data was not focused on the bizarre nor the mundane (Sandelowski, 1986). Both the typical and atypical life experiences were represented in the findings to create a holistic picture of the population. "The artistic integrity, rather than the scientific objectivity, of research is achieved when

the researcher communicates the richness and diversity of human experience in an engaging and even poetic manner” (Eisner, 1981, as reworded by Sandelowski, 1986, p. 29).

CHAPTER 4

FINDINGS

Demographic Data

All the informants (N=14) for this qualitative study lived in rural Western Montana. Rural is defined here as a place with less than 2,500 persons (Lee, 1991a). All but one of the informants were Caucasian, with the exception being of South American descent. The informants were between the ages of 25-54 (with a mean of 40 years old), and had incomes ranging from \$12,000 to >\$60,000 a year. All but one of the informants had attended college, 11 had undergraduate degrees, two had masters degrees and two had completed at least one year towards a master's degree. Occupations were varied; tile contractor, crafts-person, counselor, musician and organic gardener, nursing supervisor, retail store-owners and managers, alternative healer, supervisor in a state agency, and wildlife habitat restoration expert. Fifty percent of the informants were self employed.

All informants were self-identified lesbians; two had been previously married and 10 of the 14 (71%) stated they had previously had sex with at least one man. When asked at what age they identified themselves as lesbian, the answers were from age five to 33. Eleven out of 14 of the informants were in committed partnership relationships ranging from one-and-a-half years to 13 years, with a mean of six years. One of the couples had an adopted child, and one other informant had raised two children from a previous

marriage with a man. Eight of the informants said they had health insurance, with five of these having their premiums paid by employers.

When asked why they lived in a rural area, they answered: "Because of the beauty of the country; the birds, trees, open spaces, and mountains." "It's a spiritual thing." "For privacy and solitude." "Quality of life." "I need absolute quiet." "I like to be alone a lot, for quiet." "So I can pee and go naked in my yard."

In order to create a context for documenting the healthcare experiences of rural lesbians, I inquired of the past and present health status of the informants. All described their health as good to excellent at the time of the interviews. Three had a history of serious illness in the past; a malignant tumor of the spine, Graves disease, and Lyme disease. Many of the informants reported various musculoskeletal injuries and strains, either related to previous auto accidents or occupational injuries.

Three of the informants currently smoke cigarettes, three consider themselves recovering alcoholics, and an additional three have made the choice to abstain from alcohol, although they do not necessarily feel they have an alcohol problem.

Most of the informants stated they had used or currently use a mental health counselor intermittently for periods of time, usually in response to life stressors such as relationship issues and episodic mild depression. Two revealed that they had been suicidal as adolescents. One informant had a diagnosis of manic depression as an adolescent, and another stated that she periodically seeks counseling for incest survival therapy. All felt that they were mentally healthy today.

The distance the informants traveled for healthcare ranged from 5-70 miles. Various healthcare clinics and facilities were available within 20 miles of the informants. The closest urban center, Missoula, with an approximate population of 50,000, was between 45-100 miles away from the informants. This community had a wide variety of healthcare options available to the informants.

Emergent Domains

As explained in the data analysis section of chapter three, the interviews were coded and central themes or domains were identified. Three central domains emerged out of this process: a) Lesbian Healthcare Practices, b) Lesbian Healthcare Issues, and c) Barriers to Healthcare. Under these domains, recurring experiences and perceptions of the informants were broken down further into subcategories. The subcategories often overlapped and had influence on more than one domain, but were placed under the domain for which they had the most meaningful relationship.

Lesbian Healthcare Practices

This domain was broken down into the following subcategories: a) alternative versus allopathic and b) healthcare-seeking patterns.

Alternative versus allopathic. An overwhelming preference for alternative over allopathic (Western medical model) healthcare was expressed. This was one of the most common recurring themes in the interviews. By "alternative", the informants referred to the following forms of healthcare: chiropractors, naturopathic doctors (ND's), herbal remedies, homeopathy, energy healing, body work (massage, therapeutic touch, etc.), acupuncture, vitamin therapy, and spiritual healing (including Native American healing

rituals). Eight out of the 14 informants said they would go to a ND first for an ailment or illness. All said they used some form of the above-mentioned alternative healthcare at some point. All but two said they would use Western medicine if they were seriously ill and the alternative route was not working.

The two that said they tend not to use allopathic healthcare primarily utilized a form of energy healing. One of them was a practitioner and explained that this method of energy healing involves muscle strength testing using the body's energy fields and numerical codes to diagnose and treat different ailments and illnesses. She and her partner use this on each other and their young daughter as well as their pets. One of them recounted the following story:

I was working for the Park service in California and I got bit by a tick and got Lyme disease. My insurance wouldn't cover alternative medicine so I went to a regular doctor and they put me on Doxycycline and I was on it and just kept getting sicker and sicker. I couldn't get out of bed, couldn't hardly eat or drink anything. Finally I went to an energy healer practitioner (this was before my partner got her training) and in four hours she had me sitting up at a desk and in two weeks I was back in the field again. That was really the major change for me from Western medicine to alternative.

This same couple has a child and they utilize a pediatrician because their insurance does not cover alternative medicine. However, they have chosen not to immunize or use fluoride for their child because of their belief that these things compromise the immune system. Along with energy healing, they have utilized homeopathy for poison oak outbreaks, herbal remedies such as peppermint oil for upset stomach, and chiropractors for musculoskeletal ailments.

