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SOCIAL NETWORKS, SOCIAL SUPPORT, AND GENERAL WELL-BEING OF LESBIANS WITH CHRONIC ILLNESS OR HIDDEN DISABILITIES

by

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DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF NURSING SCIENCE

in the

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San Francisco

[redacted]

DEDICATION

To the women who shared
their precious time and energy with me
to participate in this study

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ABSTRACT

SOCIAL NETWORKS, SOCIAL SUPPORT AND GENERAL WELL-BEING OF LESBIANS WITH CHRONIC ILLNESS OR HIDDEN DISABILITIES

A survey of 66 lesbians with chronic physical illness or hidden disabilities described their social networks, social support, and general psychological well-being. Relationships of lesbian and chronic illness identities, social networks, and social support to general well-being were examined. Characteristics of support and non-support for both potentially stigmatizing identities were explored in interviews with 22 participants.

The mean general well-being score was 71.7 as compared to 78.1 and 77.7 for healthy women in 2 other studies. General well-being was positively correlated with duration of (.35, p=.005) and satisfaction with relationships with network members (.33, p=.008). Greater age and higher social class were correlated with higher well being (.29, p=.019, .21, p=.036 respectively).

Network support for the lesbian identity was positively correlated with knowledge of the identity (.59, p=.00), percent of lesbians (.72, p=.000), women (.46, p=.000), and non-kin (.37, p=.003) in the network, and support for the chronic illness (.36, p=.004). Support for the chronic illness identity was positively correlated with knowledge of this identity (.61, p=.000), availability (.27, p=.033), general supportiveness of network members (.32, p=.010), and the participant's satisfaction with the relationship (.25, p=.048). Support for both identities was positively correlated with knowledge of the lesbian (r=.29, p=.004) and chronic illness identities (.27, p=.011) and negatively correlated with density (-.21, p=.039). Density was the number of other relationships among network members.

Non-supportive and supportive behaviors for each identity were similar. Non-support included physical and verbal abuse, avoiding interaction, disbelief in existence of the identity, being blamed for the identity, minimizing or maximizing the consequences of the identity and lack of collaboration in meeting illness-related needs. Support included belief in existence of identity, willingness to interact, acceptance of the identity, and normalizing the identity through collaboration in meeting identity-related needs. Conditions affecting interpretation of behavior as supportive or non-supportive included visibility, chronicity, and variability of identity, timing of support, and intimacy of the relationship. Other lesbians and chronically ill were particularly supportive.

Nursing implications included acknowledgment of the potential stigma of being lesbian and chronically ill, self-exploration to identify one's own supportive and non-supportive behaviors so that nurses can provide a safe environment for disclosure of these identities, and assisting chronically ill lesbians to connect with like others for support.

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CHAPTER I

INTRODUCTION

This study addresses the social network, social support, and general psychological well-being of chronically ill lesbians. Both lesbian and chronically ill identities are conceptualized as potentially stigmatizing identities. A basic question addressed is what are the characteristics of the social networks of chronically ill lesbians? Other research questions addressed are: What is the well-being of chronically ill lesbians and what do chronically ill lesbians view as supportive and non-supportive to their identities as lesbians and as chronically ill people? What is the relationship between social networks and general psychological well-being for chronically ill lesbians?

Significance of the Study

Limited Research

One of the critical reasons for this research is that very little is known about this group, especially in relation to health. Much existing research about homosexuality assumes without evidence that homosexuality is pathological. Most homosexuality research has been done on males and assumed to apply to lesbians. Thus, there is very little scholarly work that provides information about the physical or emotional health of lesbians. At least five percent of the female population is estimated to be lesbian (Kinsey, 1965; Wolf, 1979), and we do not know how many of these women have chronic illnesses.

In San Francisco, California, Operation Concern is the only agency providing gay-identified psychotherapy services for disabled and chronically ill lesbians and gay men. It is estimated that from 15-20% of the city's population is disabled or chronically ill and that 15-20% of this number is gay or lesbian. Conservative estimates are that 35% of the homosexual population is lesbian. According to these rough estimates, there could be as many as 11,550 chronically ill/disabled lesbians in San Francisco alone (Kassoff, 1984). Little is known about the characteristics and special needs of this population.

High Risk Population

Because these women have chronic illnesses and/or disabilities they may be at higher risk than the general population for physical and emotional problems. In addition, they must often face negative attitudes and treatment because of their sexual orientation and their health status.

Health Providers' Attitudes Toward Lesbians

Health care providers, not surprisingly, have been demonstrated to hold similar attitudes as the general society in relation to lesbianism and homosexuality in general. Mental health professionals, including psychiatric nurses, hold a range of attitudes, including very negative ones (Garfinkle, 1979; White, 1979). More negative attitudes have been associated with male therapists (Garfinkle, 1979), and with less education, specific religions, and high levels of religiosity (White, 1979).

Although the American Psychological Association voted in 1973 to remove homosexuality from classification as a mental illness, a 1978 survey of 2500 members of the APA revealed that 69% saw homosexuality as pathological, 73% thought homosexuals were less happy than heterosexuals, 60% saw homosexuals as less capable of mature, loving relationships, 70% thought problems homosexuals have are due more to inner conflict than stigmatization, and 43% saw greater risk in having gays hold positions of responsibility (Gross, 1978). DiBella (1979) addresses the failure of homosexual families to seek therapy, and proposes that this may be because of the professionals' lack of sensitivity and acceptance of their lifestyle.

In general, people are more vulnerable when ill and seeking advice from health care providers. The lesbian who may have much to lose by exposure of her lesbianism (from self-esteem to custody of her children) is doubly vulnerable as she tries to hide her lesbian identity (Brossart, 1982). Aware of societal attitudes, lesbians approach the health care system fearful that this system too will be hostile to them (Brossart, 1982).

From the small amount of research that has been done on health issues of lesbians, it is clear that acceptance of one's sexual orientation by health care providers is important to lesbians seeking health care (Browne, 1983; Dardick & Grady, 1980; Johnson, 1981). It is hypothesized that many lesbians avoid seeking health care entirely because they expect rejection based on their sexual orientation (Whyte and Capaldini, 1979; Peteros & Miller, 1982). Homosexuals remain largely invisible within the health care system both as providers and clients. The heterosexual assumption is pervasive and creates an atmosphere that fosters homophobia and ignorance (Brossart, 1982).

Lesbians report experiencing stress about whether to come out to health care providers, having birth control forced on them, having difficulties getting inseminated, not being able to ask for needed information, and having their lesbianism treated as the problem (Browne, 1983; O'Donnell, 1978; Peteros & Miller, 1982). In addition to stresses related to their lesbianism, these women are subjected to the same sexist influences in health care as other women. For example, Browne (1983) found 43% of lesbians responding to a health survey at a music festival reported that they had been treated like a hysterical female by a health care provider.

Health Providers' Attitudes Toward the Chronically Ill

Although there is not much self-reflective literature from health care providers that deals openly with their attitudes toward the chronically ill, there has been much study of societal attitudes toward the disabled. This work documents generally, stereotyped, negative attitudes that result in lack of understanding of and stigmatization of the disabled.

Literature written from the perspective of the chronically ill/disabled shows that these people often perceive the negative attitudes of their health care providers.

Swartz has written a strong critique of health care providers who deny the humanity of the ill, do not value patients' knowledge or include them in decision making, and treat them by belittling and patronizing them (Swartz, 1970). Those who are ill or disabled are then labelled as uncooperative, poorly adjusted, and unable to be helped.

Hodgins, who had a stroke, points out the increased lack of understanding of health care providers when the bodily trauma is not visible. He also points out how different the perspectives are of health care providers and patients (Hodgins, 1966). McGabe (1960), in describing the hospitalized, severely ill from a nursing perspective, points out how reluctant patients are to ask for help, seeming to be ashamed and believing that they are not worthy of care.

In her study of diabetes as a stigmatizing condition, Hopper (1981) finds that it is not uncommon for health care providers to stereotype diabetics as people who are incapable of complying and who lack self-control because of their lower intelligence, poverty, or lack of character. She states that the large body of literature on patient compliance is full of value judgments of the character of patients.

From the view of the consumer of health care services in this country, there are many failures of the system. These failures take on special significance for the chronically ill, because, as a rule, the system is still set up to deal with acute rather than chronic illness (Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, & Weiner, 1984; Strauss & Glaser, 1975). People with chronic illness and permanent disability do not fit into the concept of sick role appropriate for the acute ill, and yet look to this system to meet their health needs. Often it is the patient who is blamed for the frustration felt by health care providers as they struggle to cure and control chronic illness.

Significance to Nursing of Studying Lesbians

This research is particularly important for the nursing profession. There is almost no literature within nursing that even acknowledges the existence of lesbians. Heterosexuality is assumed in most theory, research, and practice, in spite of evidence that lesbians do indeed exist both as clients and providers within the health care system. With no knowledge base, it is irresponsible to assume that nurses are adequately meeting the needs of this group.

There are additional reasons why the study of lesbians may be of particular value to nurses and the profession of nursing. Many of the problems of the nursing profession have been associated with the fact that nurses are predominately female, and their practice is controlled by male doctors and hospital administrators. Nurse-doctor relationships mimic female-male relationships in our society, where females and their work are consistently undervalued. As nurses we have often blamed ourselves for our slow progress as a profession without understanding the societal pressures that work against our growth. Women who do not conform to traditional sex role stereotypes are often viewed as deviant in our society. Nurses, like other women, are often put in the bind of being accused of being unfeminine, hostile, man-hating, even lesbians, when they try to assert themselves as autonomous professionals. As long as nurses have and claim little or no knowledge of lesbians, we remain vulnerable to believing myths about lesbians and letting such labels limit our progress as a profession. We also create an atmosphere within the profession that may increase the stress and limit the productivity of lesbian nurses (Ashley, 1976).

By increasing our knowledge of the experience of being lesbian and chronically ill in our society we can not only learn how to better meet health needs of this group, but also learn survival strategies that may be helpful in our struggle as we deviate from traditional norms to become a more autonomous profession.

Significance to Nursing of Studying Chronic Illness

The number of people in our country with chronic illness is large. In 1974, approximately 26 million people, 13% of the population, and almost one-half of the people 65 and over, reported some limitation of activity due to one or more chronic conditions. Of the ten leading causes of death in the U.S. in 1970, several are clearly chronic diseases. They include ischemic heart disease (34.7%), malignant neoplasm (17.2%), cerebrovascular disease (10.8%), diabetes (2%), arteriosclerosis (1.6%), cirrhosis of the lever (1.6%), bronchitis, emphysema, and asthma (1.6%) (Lee, Brown, & Red, 1981). In the 17-64 age group, activity limitations were due to heart conditions, arthritis and rheumatism, impairments of back and spine, mental and nervous conditions. In the 65 and over age group, heart disease, arthritis, visual impairments, and hypertension were leading causes of limitation (Chronic conditions, 1971).

The U.S. population is getting older and has more years to develop health problems associated with old age. Older and younger people are also kept alive by high technology. Most people in the hospital are there not for treatment of acute diseases but for problems associated with chronic illnesses. Many patients have diseases for which a genuine

cure does not exist. Society is beginning to seriously consider our responsibility to preserve the quality as well as quantity of life. This must include a critique of the quality of life for the many who have chronic illnesses (Strauss et al., 1975).

The study of specific chronic illnesses has long been a part of nursing education. Nursing practice involves much work with people who have chronic illness. Often, however, the perspective is of what the health care provider knows about the disease and the patient. This study will address the perspective of the chronically ill person in her daily life, acknowledging the potential for stigmatization.

Significance to Nursing of Studying Chronically Ill Lesbians

The importance to the nursing profession of studying lesbian health issues as well as the issues of people with chronic illnesses has been addressed. There is added significance in studying women who possess both of these devalued identities. We may learn how having multiple potentially stigmatizing identities affects one's experience of support, non-support, and well-being.

Chronically ill lesbians exemplify a group vulnerable to high levels of stigmatization and discrimination in our society. By learning how this group is able to maintain health in a society that does not value lesbianism or chronic illness, we may discover strategies that are applicable to other groups who also experience stigma. For example, the elderly or those from minority racial, or cultural groups who are also ill or disabled may benefit from the findings of such a study.

Format of Dissertation Presentation

Chapter I introduces the area of study, the need for such a study, and the significance of the study for the nursing profession. Chapter II provides a review of the relevant literature, the conceptual framework of the study, and the specific research questions. Chapter III discusses the methodology, tools, data analysis procedures used for the study as well as a description of the sample including data related to the lesbian and chronic illness identities. Chapter IV presents both the quantitative and qualitative findings related to the research questions. Chapter V discusses the meaning of the findings. Chapter VI summarizes the research, limitations, implications, and suggestions for future research.

CHAPTER II

REVIEW OF THE LITERATURE, CONCEPTUAL FRAMEWORK AND RESEARCH QUESTIONS

The review of literature has three major sections. The first section, The Lesbian Experience, includes literature on the lesbian identity and deviance, lesbians and social networks/social environment, and lesbians and well-being. The second section, The Chronic Illness Experience, relates literature on chronic illness and the sick role, chronic illness as deviance, and literature relating chronic illness, social networks and psychological well-being. The third section includes studies of potential relevance to the chronically ill lesbians as well as literature specifically about chronically ill lesbians.

Following the review of the literature are these sections: Assumptions Underlying the Study, Conceptual Framework, and Research Questions.

The Lesbian Experience

The Lesbian Identity and Deviance

Much theory and research in the health sciences as well as elsewhere has been concerned with men. Men are more often the subjects as well as the initiators of research studies that are generally available to the scientific community. Often when research has been done with male subjects, the assumption is made that this represents the human experience, and that findings can justifiably be generalized to females.

This general trend is also reflected in the research on homosexuality. Much of the earlier research is on male homosexuals, with lesbians largely ignored, or the assumption made that the lesbian experience was basically parallel to that of male homosexuals.

Research often reflects the values of the culture from which it emerges. The stigma attached to homosexuality is evident when one examines research to see if the possibility of homosexuality as well as heterosexuality is explored. For instance, much of the social network research examines the impact of the marital relationship (Bott, 1977); however, nowhere is acknowledged the existence of homosexual partnerships. The common classification system used in research takes into consideration heterosexual marriages and single status and seldom other options.

Recently, several books as well as numerous articles have been written that reflect the importance of the lesbian identity (Ponse, 1978; Moses, 1978; Tanner, 1978; Brooks, 1981; Lewis, 1979). There is a wide range of definitions of what lesbian means. Both Martin and Lyon (1972) and Klaich (1975) offer useful definitions. From Martin and Lyon, "a lesbian is a woman whose primary erotic, psychological, emotional, and social interest is in a member of her own sex, though that interest may not be overtly expressed (1972, p. 7). Klaich adds a societal perspective: "Lesbianism is generally defined as pertaining to women whose <u>primary</u> sexual and emotional attractions are fulfilled by, not men, which is considered the societal norm, but by women, which is not considered the societal norm" (1974, p. 10).

Lewis (1979) addresses one reason why being lesbian can be a crucial part of one's identity. The lesbian identity represents alienation from the traditional female sex role and all of its manifestations (Lewis, 1979). Since our society and all of its institutions, rituals, etc., assume heterosexuality, the claiming of a homosexual identity has many diverse and pervasive implications for one's life.

The lesbian identity can be viewed as deviant from at least four perspectives. Culturally, many people fear homosexuals, and find the idea of same-sex sexual relations disgusting (Tanner, 1978). Socially, homosexuals are ostracized because of this identity. Public opinion tends to be negative toward homosexuality, in some instances more so than toward other deviant groups (Simmons, 1969). The fact that many lesbians choose not to be totally open about this identity is a reflection of social attitudes. Psychologically, because of the stigma attached to the homosexual label, claiming one's lesbian identity involves management of this information. This can create psychic stresses. Statistically, in the United States, women claiming to be lesbian make up perhaps 10% of the population (Martin & Lyon, 1972; Tanner, 1978).

It is because lesbianism is seen as deviant, moving radically away from normative societal expectations and values, that the lesbian identity can become so central to how lesbians define themselves and live their lives. The lesbian identity is a counter-identity that directly challenges a society based on male-oriented heterosexuality. It goes contrary to what is expected of all women in our society.

One might wonder how it is that one comes to define herself a lesbian when there are so many forces working against this. The work done by Goffman (1963) on management of spoiled identities and stigma, and by Becker (1973), on deviance, are useful frameworks for understanding how some women come to know themselves, and present themselves to the rest of the world, as lesbians.

Goffman's classic work on stigma provides theory that is useful in understanding lesbianism and chronic illness (Goffman, 1963). According to Goffman, a stigma is an attribute that makes one different from others and less desirable. Such an attribute reduces one from a whole and usual person to a tainted, discounted one. Thus, stigma is closely related to the idea of identity, and can be defined as an undesirable discrepancy between virtual and actual social identities. Social identity is the classification or stereotyping of a person into categories. The actual social identity is the group of attributes a person actually possesses, whereas the virtual social identity is the group of attributes ascribed to one by others. Although stigma is often thought of in terms of an extreme "failing," Goffman points out that everyone experiences having a failing that may become apparent in social situations. Stigma management is a general feature of society that occurs whenever there are identity norms. The stigmatized person has generally internalized similar beliefs about identity and is apt to experience shame at possessing an undesirable attribute.

A major weakness of Goffman's work is the tendency to assume that certain attributes will inherently stigmatize an individual. Although he refers to the importance of processes, it is Becker's work (1973) on deviance that clarifies the stigmatization process. There are behaviors that some people approve of and others do not. Deviance is a process that involves the breaking of a rule established by a social group and the responses of others to that behavior. Deviance is a relative concept in that the point of view of those who engage in a behavior and those who condemn it are apt to be quite different. What gets viewed as deviant, therefore, is a matter of what group has the economic and political power to enforce their rules upon those who do not conform (Becker, 1973).

As is true of deviants in general, lesbians can be assumed to have nothing more in common with each other than the experience of living with that potentially stigmatizing label. Ponse (1978) has found that there is much diversity in the lesbian experience. Lesbians vary greatly in how they resolve questions about their sexual and personal identity. Because of this, it is particularly important to stay close to the actor as a source of meanings of how one defines oneself (Ponse, 1978).

Some others have applied these formal theoretical ideas specifically to the situation of the homosexual and more specifically to lesbians and the development of lesbian identity (Cass, 1979).

Lesbians and Social Networks/Social Environment

All identity develops in a social context. We discover who we are as we interact with others. There is much support in lesbian literature for the close relationship between development and maintenance of lesbian identity and the social environment. The exposure to other lesbians is critical in acknowledging one's own lesbianism. Often women who have sensed their difference from the heterosexual mainstream have difficulties disclosing or coming out to themselves and others as lesbians because of inaccessibility of supportive others. Becoming gay was found to fundamentally alter relation of self to others. The amount and type of information available about lesbians and lesbianism will affect if and how one affiliates with the social category, lesbian (Ponse, 1978).

In studying how lesbians manage their lesbian identity in specific situations, Moses (1978) concludes that it is probably not the situation per se that is important, but one's relationship with other people. This includes the woman's interpretation of self within the relationship as well as how she expects others will interpret her. Examining the negotiation of relationships provided a useful perspective for Ponse in interpreting her data. The major themes emerging from studies that examine the social worlds of lesbians include: The evolution of lesbian and gay subcultures, the importance of gay/lesbian culture for the discovery and maintenance of lesbian identity, the double lives many lesbians live in relation to their lesbianism, the problems encountered with parents and other biological family, and the lesbian world as the real world where one can be oneself.

Lesbian Culture--Lesbians with Each Other

There is a long history of gay society and culture that has remained mostly invisible to the predominant heterosexual culture. Prejudice, discrimination, lack of support and understanding from the larger culture has created the need for lesbians and gay men to band together in secret societies.

Lewis (1979) describes the social networks of friendship groups that developed as a survival strategy among lesbians before the gay and women's liberation movements. Through the interlocking of friendship networks, a national and international lesbian subculture existed that remained largely invisible. These networks served as "extended family" for lesbian women experiencing severe oppression.

Although there are many more visible individual lesbians and lesbian organizations now, it is clear from studies of today's lesbians that the impact of their lesbianism on their social networks is profound. The most outstanding issue for lesbians in their relationships with others is to know whether others are gay or straight. This becomes especially important in making friends and developing friendship networks since friendship increases the tension toward self disclosure (Ponse, 1978). Perhaps friendships take on added importance for lesbians because of the problems often encountered in gaining acceptance of their lesbianism from their families.

Lesbians with Parents and Families

Although it is generally acknowledged that people want understanding, acceptance, and approval most from their parents, Fleener's study (Lewis, 1979) found that only 42% of that sample had shared their lesbian identity with their parents and many of these women viewed it as the most difficult experience of their lives.

Problems dealing with parents and families who are not accepting of the lesbian identity are commonly reported (Lewis, 1979). These problems can be very threatening to the stability of each relationship. In Moses' study (1978), having relatives visit one's home was a frequently reported stressor for lesbians. Negotiating where to spend traditional family holidays is particularly troublesome for committed lesbian couples whose families continue to view them as single and expect their attendance at holiday celebrations (Tanner, 1978).

Lesbians at Work

In addition to strained relations with family, lesbians experience difficulties within work settings (Moses, 1978). Shacher (1979) found major role conflicts for lesbians in job situations where they were expected to conform to heterosexual behaviors and judged on such criteria rather than job competency. The lesbians experiencing this type of conflict had lower self-esteem and life satisfaction and higher anxiety than those who felt free to be openly lesbian in their work environments.

Albro and Tully (1979) found that their lesbian respondents felt isolated in the heterosexual macrocultures and turned to the homosexual microculture for social interactions, emotional support, and friends. Although living a divided existence, these women were able to function productively in these dual roles. Women whose only associations with heterosexuals was in work situations at an instrumental level tended to view the gay world as the real world where they could reveal their authentic selves (Ponse, 1978). Moses (1978) also found numerous lesbians who were living in two worlds, one public and one private. They found their private lives rich and fulfilling, but did not feel free to communicate this richness in their public lives. Social relationships were mostly with women or within the gay community.

Lesbians and Well-Being

Homosexuality as Pathology

The psychoanalytic school of thought and Freud have had a strong influence in the trend to view homosexuality as pathology. The research that is based on this assumption often focuses on trying to determine etiology, treatments, and cures for homosexuality (Tripp, 1975). If one accepts this assumption, it is not problematic that most of the homosexual groups studied have either been members of a patient or prisoner population. However, if homosexuality is not assumed pathological in itself, findings will obviously be skewed if limited to these populations. It is, of course, quite difficult to get a representative sample of homosexuals because of the great stigma attached to the label.

Thus, much of what we know about homosexuality is about male homosexuals in extenuating circumstances. It is questionable how much relevance this data has for lesbians who are not patients, prisoners, or males.

Comparisons Between Lesbians and Heterosexual Women

There is a group of studies that compare homosexual and heterosexual women, usually measuring psychological functions. The findings of these works show that there is virtually no evidence to support the contention that lesbian women are less mentally healthy than heterosexual women.

In a review of research on female homosexuality from 1960 to 1974, Hoeffer (1977) found that, although a few studies report some negative psychological adjustment and functioning of homosexual women as compared with heterosexual women, many researchers have found no significant differences on these variables between the two groups. Hart (1978) suggests that these last findings may be due to subject selection, since lesbian populations tend to be independent and employed, whereas heterosexual populations tend to be unemployed, dependent, and married.

The only criterion on which lesbian and heterosexual women differ substantially is the choice of a love object (O'Leary, 1979). Both groups of women find sexual gratification without emotional involvement unsatisfactory, and lesbians are no more likely to engage in sexual liaisons with many partners than heterosexual women. Mannion (1966) found that the gender orientation of both partners in lesbian relationships was predominantly female. Wolff (1971) found a difference in lesbian relationships, for here the culturally prescribed sex roles were easily exchanged between partners, and there was a richness and variety not possible in the confines of traditional heterosexual relationships. O'Leary (1979) reports that there is some evidence for the homosexual woman being more inner-directed and self actualizing.

Women and Mental Health

Findings related to women and mental health provide a background for the study of the psychological well-being of lesbians. As women, they are subject to the institutions and attitudes that devalue them because of their sex as well as their sexual orientation. It has been well documented that depression is more common in women than men. At the same time women make less money than men, are concentrated in poorer paying jobs, and hold few positions of power in business, government, etc. (Guttentag, Salasin, & Bell, 1980). In addition to being in less powerful positions in the society, women are also subject to negative attitudes concerning their mental health. In Broverman's classic study (1971), it was documented that mental health professionals held a double standard for the mental health of women and men. A mentally healthy adult and mentally healthy male were both seen to be similar to the male sex-role stereotype, whereas mentally healthy women were those who conformed to the less highly valued female stereotype. Such standards make it impossible for a woman to be simultaneously judged as a healthy adult and a healthy woman. These findings were partially replicated in a study of psychiatric-mental health nurses (Kjervik & Palta, 1978).

While people who conform to more traditional sex roles may be judged by some to be more mentally healthy, Bem (1975) found higher levels of mental health associated with the ability to act in situation-specific ways rather than according to rigid sex-role prescriptions.

Managing Lesbian Identity and Well-Being

As discussed earlier, comparative research has demonstrated that lesbians are not any less mentally healthy than heterosexual women and, in some dimensions of mental health, may be healthier. But as a negatively sanctioned minority, lesbians are in a different position in our society than heterosexual women and have specific issues and needs related to maintenance of psychological well-being and mental health.

In most social situations the heterosexual assumption is in operation. Everyone is assumed to be heterosexual unless specifically known not to be. The relative invisibility of lesbians has implications

on two levels. First, because of lack of accurate information or role models, the woman who senses her difference from the heterosexual world would possibly have to go through a long and difficult process of discovering and accepting her own lesbian identity. Mental health may suffer when a person is struggling to define herself.

The second level is of more interest here. It involves the maintenance of the sense of psychological well-being and mental health that incorporate the lesbian identity over time. This is a life-long process of decisions about whether or not to share one's lesbian identity with others. Klotkowski (1980) speaks generally of the importance of self-disclosure for mental health, and Burack (1979) identifies decisions around coming out as a major mental health issue for lesbians.

Several major strategies have been identified for managing a potentially stigmatizing identity such as being lesbian. Each has implication for one's mental health. Withdrawal may protect one from exposure to negative attitudes toward oneself but can also lead to feelings of isolation and alienation (Brooks, 1981). Passing involves being in relationships where one does not reveal the lesbian identity. This strategy may provide some security (i.e., from being fired from job, losing friends, children, etc.), but there may also be increased fear that one's secret may be discovered by others.

Moses (1978) found that passing had an effect on one's self perception because one becomes dishonest and devious in attempts to hide an essential part of oneself. There was a negative relationship between self acceptance and the necessity felt for passing. Others may view the person who is passing as shallow and unemotional because she is not sharing much personal information. Lesbians in Brook's (1981) study found that their social acceptance depended on either hiding their lesbian identity or relating solely on the basis of it. Leading such a double life in the heterosexual and gay worlds can make it difficult to maintain an integrated sense of self. She also found a positive correlation between identification with lesbians as a reference group and reduced stress. She concludes that lesbians are each other's most important external resource. Ponse's (1978) data supports the theory that leading a double life can escalate a sense of alienation and fear of discovery. Strain is experienced in trying to keep friends who know about the lesbian identity from those who do not know.

In a study of gay men, Jacobs and Tedford (1980) found those who were members of a homophile group had higher self-esteem. Lesbians also tend to prefer to socialize with and feel more comfortable with other gays (Moses, 1978; Brooks, 1981). Brooks found many lesbians were unwilling to sacrifice their psychic well-being by routinely behaving according to heterosexual expectations and therefore socialized mostly with other gay people. Having a major affiliation with other lesbians and a positive identification with this group can serve to buffer the threats to self-esteem that come from more socially distant groups where heterosexuality is the norm (Brooks, 1981).

The importance of social networks can be seen when therapy issues for lesbians are explored. Krestan and Bepko (1980) found that because of the general lack of societal support, lesbian couples may have difficulties psychologically merging with each other and not having enough self-differentiation. It is important for their social networks to validate the relationship and diffuse its intensity. In therapy with

Hispanic lesbians, De Monteflores (1981) found the need to explore the importance of ethnic and sexual orientation identities for the individual and see how this relates to the resources in one's social network.

Thus, lesbian research to date has provided knowledge that refutes the notion of lesbianism as a mental illness and explores the management of this identity, including passing and coming out. There has also been some work relating management strategies to psychological well-being. Although there are references to the importance of relationships with others, there have not been detailed qunatitative studies examining the qualities of lesbian social networks or the relationship of these qualities to well-being.

Chronic Illness Experience

Chronic Illness and the Sick Role--Conceptual Problems

There is ambiguity in the literature in relation to the concepts of disability and chronic illness. Often the terms are used interchangeably or one finds such terms as "disabling illness" and "invisible disability" used. Perhaps this lack of clarity stems from lack of clear conceptual definitions and theoretical development. Often distinctions are not made between acute and chronic illness. Although most patients in hospitals are there because of acute exacerbations of chronic illnesses, they are treated mainly as acutely ill. Parson's conceptualization of the sick role is consistent with how people are often viewed whether their illness is acute or chronic (DeJong, 1979).

According to Parsons (1957) and DeJong (1979), the sick person is exempted from "normal" social activities and responsibilities and from any responsibility for his or her illness. The sick person is not considered morally accountable for his/her condition and is not expected to become better by sheer will. In return, the sick person is obligated to define the state of being sick as aberrant and undesirable and to do everything possible to facilitate her/his recovery. It is expected that this will occur by cooperating with the physician in getting well. Perhaps the most important distinction is that the sick role is intended to be a temporary one.

The complementary role ascribed to the physician is the "Medical Model:" 1) The doctor is the technically competent expert; 2) medical care should be administered through a chain of authority where the physician is the principal decision maker. Accountability for the care of the patient is centered on the attending physician; 3) the patient is expected to assume the "sick role", which requires him/her to cooperate with the doctor; 4) the main purpose of medicine is to provide acute/restorative care; 5) illness is treated mainly by use of clinical procedures, i.e., surgery, drugs, laying-on of hands; and 6) illness can be diagnosed, certified, and treated only by trained practitioners.

A major criticism of Parson's early work on the sick role was that it applied only to acute temporary illness and disability and not chronic illness or permanent disability (Twaddle & Hessler, 1977). In his later work, Parsons (1975) incorporates Gallagher's conception (1974) of health as capacity and acknowledges that, while many conditions are incurable, tendencies toward deterioration can be held in check by proper medically prescribed measures. He concludes that the fact that such conditions are incurable does not put them in a totally different category from acute illness. Recovery and management become different points on the same continuum of movement away from deterioration.

Although these expansions of the sick role are useful theoretically, the original sick role conceptualization still describes central tendencies in people's attitudes toward sickness (Gordon, 1966). A review of literature on chronic illness reflects the trend toward specialization and medicalization. Since the 1950s-1960s, when there were several studies of chronic illness, much study has been done of specific illnesses and their medical treatment (Strauss & Glaser, 1975, p. 6). There has been relatively little systematic research that explores the social and psychological impact of chronic illness on the daily lives of the people who have these illnesses (Strauss & Glaser, 1975, p. 7). Beyond the impact of chronic illness, there is also little written about strategies by which the chronically ill might manage their lives or how health care providers might help them with problems such as stigmatization, isolation, etc. The work of Strauss and Glaser is outstanding in its articulation of problems of living with chronic illnesses. Areas of discussion include: Preventing and managing medical crises, management of regimens, control of symptoms, reordering of time, managing the trajectory, social isolation, normalizing, and the role of family. These dimensions of chronic illness cross over the lines of medical diagnosis to offer a beginning framework with which to understand people involved with a variety of specific chronic diseases. As health care providers better understand these processes, they may be able to offer help that really helps.

Twaddle (1979) offers a particularly salient and comprehensive critique and defense of Parson's sick role conceptualization. He finds it a useful analytical concept if taken within the scope of its intended meaning, which he claims many of Parson's critics fail to do. The sick role is more useful for analysis of the sickness behavior of societies rather than of smaller units of study (Twaddle, 1979).

A major omission from this body of literature is an overarching framework that includes both perspectives of able-bodied and disabled, one that examines the processes involved in social interactions where chronic illness/disability is present, and one that acknowledges the continually shifting position everyone holds on the disability-ability continuum. Further, there is need to explore the forces in play that perpetuate this dichotomous thinking. What are the consequences of such a system where one is defined by self and others as either able-bodied or disabled, well or sick?

A concrete example of how dichotomous thinking is incorporated into the social structure is the structure of Social Security Insurance benefits. It is based on an "all or nothing" theory; either one is disabled or well. When one becomes employed, one generally loses Medicare benefits.

From the researcher's experience, there seems to be a significant gap between the clinical labelling of certain medical diagnoses and the individual who has these illnesses defining oneself as chronically ill. For example, one can find many people who will acknowledge that they are diabetic, but they often do not see themselves as being chronically ill or having a chronic illness. This may perhaps be related to the stigmatizing effect of such a label. If one associated being chronically ill with Parson's sick role, one may have difficulty claiming the label. When ambiguity and uncertainty are high, as they may be with chronic illnesses, there is more room for opinion, values, negative stereotyping, and stigmatization to take place.

Chronic Illness as Deviance

The impact of chronic illness/disability on the self-image and self-esteem of the ill or disabled frequently focus on helping the ill individual to change or overcome limitations and adapt to an unyielding society (Off Our Backs, 1981). The disabled are often viewed as totally dependent children to be protected. They are seen as asexual, emotionally unstable, pathetic, needy, and fragile people who are not worth educating (Campling, 1981). Others want to fix the disabled person. Off Our Backs (1981) points out the societal bias of the able-bodied as evidenced by the few images of disabled existing in the media. Often, the images that do exist tend to show ill and disabled who either die noble deaths or who are able to overcome their limitations and be cured.

In a discussion of the views of emergency room physicians toward certain types of patients, Jeffery (1979) found that those patients described as rubbish and seen as deviant were those who tried to make illegitimate claims to be allowed entry into the sick role as defined by Parsons. Jeffery states that illness is normally an ambiguous condition where one is vulnerable to charges of deviance. The resolution of this ambiguous state depends on negotiation and is contextually specific. With the only available categories of sick role and well role, it is unclear where someone with a chronic illness fits, except perhaps during acute exacerbation, requiring hospitalization.

Ambiguity evolves as an important concept in Zahn's study of invisible impairment (1973). Those with impairments that clearly indicated sickness or disability were more secure and had better interpersonal relationships than those whose health condition was in doubt.

Although chronic illness is not conceived consistently as stigmatizing, there is literature that supports the stigmatization process among chronically ill people who may not be viewed by self or others as "disabled."

Marcella Davis (1973), in her study of people with multiple sclerosis, found that they felt set apart from normal people but did not totally identify with the severely ill or disabled. People with multiple sclerosis and other chronic illnesses may devote large amounts of time doing work related to taking care of their illnesses. Davis states that "the condition of oneself as a person who is doing work that is not generally acknowledged as productive, can help create a devalued self concept" (Davis, 1973).

Eisenberg (1982) states that those who are chronically ill/disabled are different than others by the nature of their physical needs. Although invisible disabilities can be covered up by the individual, it is at great personal cost.

Safilias-Rothschild (1982), in discussing the stigma of a variety of conditions, focuses on the most stigmatizing conditions as described by Tringo (1979), i.e., the most visible ones. She acknowledges that we know little about the nonvisible conditions and the impact on interpersonal relationships once such a disability becomes known.

Drawing from Goffman's work (1959, 1971), Romano describes the constant stress that one with an invisible disability (e.g., heart disease, diabetes, cancer) experiences in mediating between the disease and social presentation of self. The issue of passing or telling is a constant one. For example, the dinner guest with high blood pressure who requires a salt-free diet or the diabetic who needs a sugar-free diet, are hard pressed not to define themselves and be defined as "problems" in social interaction (Romano, 1982).

In her study on low income clinic patients with diabetes, Hopper (1982) describes the factors that lead to stigmatization of the diabetic person. Diabetes can bring dramatic, often negative life changes. Although the most dire complications are blindness and amputations, others include heart disease, stroke, and kidney disease. Diabetics must adjust to a precarious balance between diet, exercise, and sometimes medicine (insulin or oral hypoglycemic agents). They may have to take shots and have dramatic symptoms associated with low and high blood sugar. Economically, acquisition of money is a major problem. There is employment discrimination because of the fact that diabetes is often not covered by health insurance policies. Being diabetic can have a major impact on self esteem. Depression and loss of friends and independence are common.

In summary, there is more discussion of deviance and stigma in relation to visible than invisible illness/disability although there is beginning exploration of stigma and chronic illness. There is also little self-reflective literature about health professionals' views of the chronically ill, although there is evidence from accounts of the chronically ill that they experience stigmatization.

The Chronically Ill--Social Networks and Psychological Well-Being

Relationships between the chronically ill and disabled and their friends and families can have an important impact on their lives. A major impact of chronic illness and disability is the social isolation experienced by the individual (Davis, 1973). Both physical and social accessibility may be problematic and limited (Campling, 1981). Social isolation is a process wherein the person is increasingly socially and psychologically separated from former relationships and social activities with decreased opportunities for adequate replacement with new relationships and activities (Davis, 1973).

In studying the impact of disability on interpersonal relationships, Zahn (1973) found that interpersonal relationships were more disrupted when the health condition was in doubt. Those who had severe functional limitations, were unable to work, and whose sexual impairment had been established, were seen to legitimately fit the "sick" or "disabled" role and this facilitated unimpaired interpersonal function. When there was more ambiguity about the health status of the individual, there were more interpersonal problems. In all cases, the visually impaired experienced more disruption than the nonvisually impaired, but with the younger age group the visibly impaired tended to get along better in interpersonal relationships than the nonvisually impaired.

Fred Davis (1961), in his study of social interactions of visibly handicapped people, discussed the process by which they manage strained interactions with others. The visible handicap is a threat to social interaction because the visibly handicapped are not viewed by others as normal, but as deviant. The handicap may become the exclusive focus of the interaction. Others may not act in their usual way, because they are afraid to hurt the feelings of the handicapped. It may be difficult to predict what joint activities are possible. The handicap may be seen as not fitting in with the other attributes of the person. He found that one strategy the disabled developed for feeling normal was to associate with like people, closing out those who were not similarly disabled.

Singer (1974) has provided a study that links psychological well-being with chronic illness and social relationships. While studying people who had Parkinson's disease, she found that younger patients (in their 50s), although they had less physical limitation, were also less likely to know others their age who also had the disease. They tended to feel more stigmatized than older people with Parkinsonism, withdrew more from social interactions, even though not required by the disability to do so, and frequently experienced depression. Singer concludes that well-being was related to comparisons, in this case with chronological peers. One implication here is that social networks, including peers with similar health problems, might increase one's sense of well-being.

Gaylene Becker (1981) found that self-esteem increased when people were members of a deaf community that used American sign language and shared experiences. Being deaf, for these people, was the single most important factor in their lives. Being part of a group increased feelings of belonging and decreased feelings of deviance. She observed that the deaf lived double lives: Their associations with hearing people, which were superficial, and their relationships with deaf

persons,. which were more intimate. Over time, the intimate relationships became more important to their self-concepts and they tended to limit interactions with the hearing.

In discussing the intimate environment of the disabled, DeJong (1979) mentions the importance of physical and emotional security--the need to have control in situations where vulnerability is high. The desire to avoid difficult situations may cause the disabled person to spend more time at home than they desire. There must be a balance between security and social isolation. People who have become chronically ill/disabled report changes in the reciprocity of their social relationships. Often a person may not be able to sustain friendships with old patterns, Issues of dependence and independence become salient (Davis, M., 1975).

Linkowski (1974) studied the relationship between self-concept and acceptance of disability. Self-concept was defined as self-esteem and satisfaction with social relationships. Acceptance of disability was defined as a perceptual process where individuals change values. These changes included enlarged scope of values, subordination of physique, containment of disability effects, and transformation from comparative values to asset values. A high correlation was found among the three variables: Self-esteem, satisfaction with social relationships, and acceptance of disability.

In summary, major issues that arise for the ill/disabled are relationships with others and maintenance of a sense of well-being. Association with other ill/disabled can help decrease isolation and feelings of alienation. Although stigma is discussed, it is not viewed as an interactive process and there is no examination of specific behaviors of others that affect feelings of well-being. Questions remaining to be considered are: What are the components of a supportive relationship, specifically for a person with a disability? What types of relationships enhance or diminish the general well-being? What is the role of social networks in maintaining well-being of the chronically ill/disabled?

Studies of Potential Relevance to the Chronically Ill Lesbian

Social Network and Well-Being

The concept of social network is a way of understanding a person's social field in a way that cuts across formal boundaries, and may represent an important reference group for the individual (Barnes, 1977). Social network is closely associated with social support in the literature, and is often assumed to be the route through which social support is delivered. There is growing evidence of the positive relationship between social support and health.

Since there are no studies at this time that specifically examine social network characteristics of chronically ill lesbians and their impact on the general psychological well-being, it is necessary to look at other groups. Groups that may be of particular relevance include women who are not conforming to sex-role stereotypes, people with chronic health problems, and those who are generally devalued by society, such as the elderly and schizophrenics. Findings will be summarized according to the network characteristics studied.

Types of network members. Sokolovsky and Cohen (1978), studying personal networks of former mental patients living in single room occupancy hotels, found that the healthier women had less contact with kin. Linn and McGranaham (1980) found that greater contact with close friends decreased the effect of personal disruptions on individual well-being. Litwok's (1969) work points out that relatives, friends, and neighbors are differentially suited for providing different types of support. For instance, family is particularly good for chronic stresses since we keep them over time and they are highly committed to their members. Neighbors are good for helping with urgent needs since they are readily available. Friends do not have the permanency of kin or the face-to-face contact of neighbors, but are held together by affectivity. Friendships best handle matters involving continuous fluctuations because when affect is there, they are more apt to accommodate each other. The friendship network has the advantage of being made up of people we actively choose to be part of our lives. Thus, although family is generally good for long-term problems, this might not be true for areas where the individual has rejected values that may be held very strongly by the group.

Hirsch's work (1980) found that, for women in transition from the traditional to nontraditional roles, the critical variable affecting mental health was the amount of interaction between kin and non-kin networks. Lower interaction was associated with higher mental health.

These findings do not provide clear directions for the types of network members most likely to be found in the networks of chronically ill lesbians. Although kin may be highly committed and helpful with long-term problems related to chronic illness, they may also be less than supportive of the lesbian identity. Many able-bodied lesbians seem to turn to friendship networks supportive of their lesbianism as their chosen "family." However, the affectivity that holds friendships together may not be sufficient to meet the continuing material needs related to the chronic illness. The chronically ill lesbian may be forced to interact with kin who reject her lesbianism in order to meet basic survival needs. Hirsch's study suggests that if they use different parts of their networks for different needs, these parts may be best kept separate from each other.

Network size. Although larger networks are generally associated with less hospitalization, both Hammer (1963), in studying mental patients, and Lally (1979) and Cohen and Sokolovsky (1979), studying older women, found that women with small networks were not necessarily unhealthy. Both quantity and quality of relationships may be more important for chronically ill lesbians.

Confidantes. Research by Lowenthal (1968) and others supports the idea that the most crucial characteristic of social networks for maintaining mental health is the presence of a confidante. With chronic problems, however, there is risk of overburdening a confidante. If the confidante is lost and the remaining network is too small or not supportive, once could be at high risk for health problems.

Reciprocity. Reciprocity has been found important for preventing hospitalization of mental patients (Hammer, 1963) as well as maintaining the stability and functioning of networks (Unger & Powell, 1980). This issue of balance or give-and-take in relationships could be particularly relevant for the woman with on-going special physical needs. What she needs may be more obvious than what she has to give, creating strain in relationships. Unger and Powell (1980) mention the stress of reciprocal costs and changes in reciprocity brought about by illness and disability.

Social Support and Well-Being

There has been little consistency in the conceptualization and measurement of social support across studies. Nurse researchers are currently testing tools designed to measure various dimensions of social support (Norbeck, 1981; Weinert & Brandt, 1981).

Norbeck's tool (1981) is based on Kahn's conceptualization of social support as affect, affirmation, and aid. Weinert and Brandt (1981) base their tool on Weiss' dimensions (1974) of social support: Attachment, reassurance of worth, social interaction, opportunity for nurturance, and availability of informational, emotional, and material help.

Evans and Northwood (1979) provide a general theoretical model to explain the process by which supportive relationships develop. The development of social support systems is viewed as similar to small group development where people test each other and may learn through their interactions to trust and have high levels of intimacy.

Heller (1979) addresses social competence as a competing hypothesis for effects associated with social support. Murawski, Penman, and Schmitt (1978) suggest further study of the dynamic aspects of support, especially in chronic and progressive illnesses through the use of multiple measurements. This work does not adequately address the specific support that may be needed in relation to potentially stigmatizing identities. Is a general sense of support from one's network possible if the members are unaware or unaccepting of a core identity like being lesbian? Here the issue of nonsupport or conflicted support becomes salient. Because these tools have been designed to measure support, they do not examine how much nonsupport one may be experiencing within one's personal network.

Studies of Relevance to the Chronically Ill Lesbian

There has been recent exploration within the lesbian/feminist community of the issues of disabled women. Resisting stereotypes of disability, women are inventing new labels like "physically challenged" and "differently abled." Ableism, the assumption of able-bodiedness and its superiority to disability, has been discussed. In acknowledgement of the fact that illness and disability are experiences from which no one is protected and that most people will experience in their lifetimes, some women have come to label able-bodied women as temporarily able-bodied. Extensive disability workshops have been held among able-bodied and disabled women at gatherings of lesbians and feminists such as women's studies conferences, and music and cultural festivals. One outgrowth of such conferences was the development of a national disabled lesbians network (Off Our Backs, 1981).

There have been attempts within the feminist subculture, unlike any in the dominant culture, to be accessible and sensitive to the needs of disabled women. Providing sign language and wheelchair accessibility are now common practice at many feminist events. As in the male-dominated heterosexual world, disability has been defined largely in terms of visible or readily apparent physical limitations. There is a beginning exploration of issues for women whose physical and emotional disabilities are less visible and less apparent. This has created tensions between disabled and able-bodied women with accusations from able-bodied persons that disabled women are asking for special privileges, and from the disabled that they are being misunderstood and discriminated against (personal observation by author). It is apparent that the lesbian/feminist community has begun to struggle openly with issues of disabled and chronically ill women and their relationships with the able-bodied.

Ricki Boden, a feminist therapist, has addressed issues relevant to this study in discussing her work with disabled lesbians (Rubin, 1981). Group therapy with these women is based on the assumption that disabled women would be extremely isolated from each other and perhaps from the disabled and lesbian communities also. A major value of the meetings was the opportunity to be in a supportive environment where disability, rather than able-bodiedness, was an assumption. These women could feel less alienated, feel like they belonged, and were in a safe place to express their anger toward the able-bodied world that, for the most part, denied them access.

It was very difficult for many of the women to take the first step of coming to the group, because this involved coming out as being disabled, a step some had never taken before. It was very important for these women to have social support concerning their disabilities, and there was some discussion of behaviors that were and were not viewed as supportive.

Several issues arose in these groups that are particularly relevant to this study. Many of these women were separated from their families of origin and had no relationships supported by social institutions like marriage. Family often viewed lesbianism as the outcome of the disability rather than a valid choice. For this group, coming out to their families as lesbians was very complex. For those whose disabilities were causing progressively greater dependency, coming out was seen as very risky. They could not risk alienation from their families by revealing their lesbianism.

This information brings into question the applicability of some previous research findings on social networks to this doubly stigmatized population. Most studies relating social networks to chronic illnesses have found that kin relationships are most beneficial for dealing with long-term problems. Because many families are not accepting of lesbianism, this avenue of support may not be available to the chronically ill/disabled women who are open about their lesbianism. Another option, as mentioned, would be to get the support from family needed for the disability or illness while subjecting oneself to a less than supportive environment concerning the lesbian identity.

Boden (Rubin, 1981) also describes several variables that are important for understanding any individual disabled woman. Although these variables may be generalizable to other groups besides disabled lesbians, it is important to note that these dimensions have evolved from experience with this group, and, therefore, may be of particular significance to them. They include: Age of onset of the disability; visibility of the disability; race and class background; interference with mobility; levels of dependence and independence; and whether the disability is fixed or progressive. The differential impact of these variables on disabled lesbians may be particularly important. In her work, Boden has begun to identify useful variables for understanding and helping disabled lesbians. She stresses the importance of social networks and social support for the maintenance of well-being.

With a general interest in the health issues of lesbians, this author (Browne, 1983) completed a small exploratory study of clients and health care providers in a clinic created especially to meet the health needs of lesbians. This study revealed important dimensions of health care that were then incorporated in an extensive questionnaire. The questionnaire was administered to volunteer women at a women's festival. Of the 109 women who completed it, 75% were self-defined lesbians. The specific findings provided direction for this research project. Results reported here refer to the lesbian sample (n=81).

Psychological Well-Being

In general, this group perceived themselves to be physically and emotionally healthy and satisfied with their lives. This, in itself, is striking considering the large amount of stigma and discrimination as well as non-recognition of lesbians in our society. Contrary to the myths that lesbians are mentally ill, this group seems not to have internalized this belief.

Chronic Illness/Disability

Another striking finding was that 49% of the lesbians indicated that they had a chronic health condition or disability. Some conditions identified were peptic ulcer, hypoglycemia, epilepsy, chronic lung disease, allergies, herpes, back problems, alcoholism, hearing loss, lupus, chronic pain, varicose veins, and pituitary tumor. Fifty-three percent reported special needs related to diet, medications, mobility, or communication. Alcohol was a personal problem for 23% and other drugs for another 14% of these women. One possible explanation for this high rate of chronic illness/disability is that great effort was made by festival organizers to be responsive to the health and disability needs of festival participants, therefore attracting women with special needs to the festival and creating a safe environment for revealing related needs. Beyond the amount of chronic illness is the fact that presence of such a condition did not correlate significantly with such variables as physical and emotional health or life satisfaction. If these findings are valid, it could mean that those with chronic illness have been able to maintain emotional well-being as well as the able-bodied.

Social Networks and Social Support

The third area of interest was related to the social network characteristics of these lesbian women. Respondents were asked to list as many as four people who were most important to them in their lives at the time. Data analysis revealed that 92% of their networks were composed of partners and friends, and 93% female. Over half of the networks knew and responded favorably to the subject's lesbian identity, and roughly 50% were homosexual themselves. These findings point toward sexual orientation as an important variable in the formation of social networks. The sex of network members may also be quite important.

In another exploratory study (Browne, 1983), issues that emerged as important to chronically ill/disabled lesbians included stigma, discrimination, frustration with health care providers, dependency/independency issues, and managing intimate relationships.

These studies along with other related research provided support for further exploration of the social networks, social support, and psychological well-being of lesbians with chronic illness/hidden disability.

Assumptions Underlying This Study

1. Lesbianism is a valid lifestyle alternative, not a pathological state in need of treatment. Lesbians are not inherently less mentally well than heterosexual women or people in general
2. Heterosexuality is the norm in our society, and lesbianism is seen by many as a deviance.
3. Women are devalued in our society and are generally seen as less important and less valuable than men.
4. Labels can serve as a means of social control
5. The assumptions of symbolic interactionism are compatible with the discipline of nursing and with the study of deviance and stigma.
6. The interactional process between person and environment is a crucial area of study for nursing.
7. Some degree of social support is necessary for mental health and psychological well-being.
8. Self-perceptions provide valid and useful information about a person's world.
9. The participant in this study has accepted on some level her lesbianism and chronic illness.
10. The participant has had some experience in sharing these identities with others (at least this investigator) and not sharing these identities.
11. Being lesbian and chronically ill are two potentially stigmatizing identities, <u>potentially</u> because others are often not aware of them unless specifically told, and <u>stigmatizing</u> because when this is known the person may be devalued.

Conceptual Framework

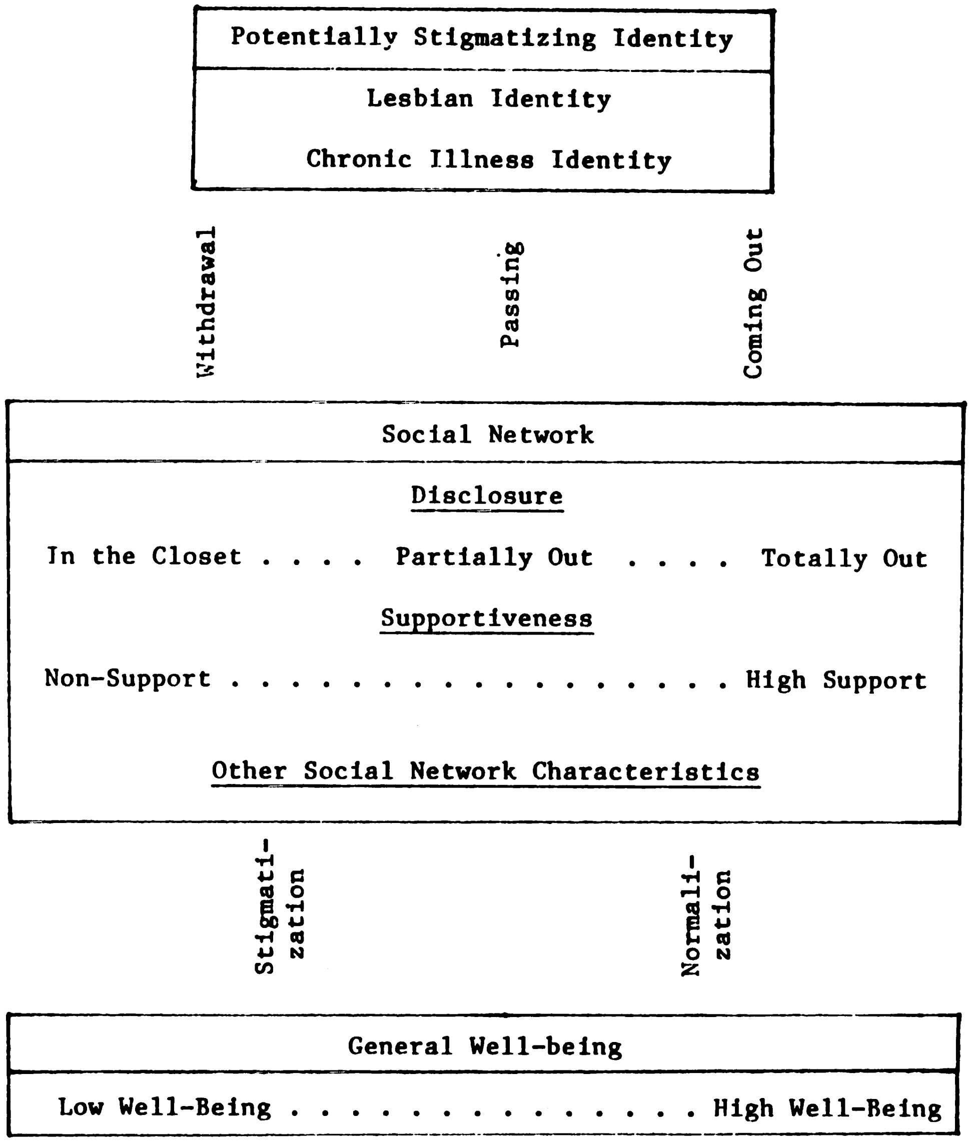
This study examined the following concepts: Lesbian identity, chronic illness identity, social network including social support and non-support, and general psychological well-being. Although not a major focus of this study, the processes of withdrawal, passing, coming out, stigmatization, normalization, and integration are acknowledged as part of the overall framework. A diagram is offered as a model for the interaction of these variables and processes (Figure 1).

The lesbian and chronic illness identities make up part of one's entire identity. For each of these identities, a wide range of information may be shared with one's social network, ranging from no information to a great deal of information about how this identity affects one's life. Withdrawal, passing, and coming out are on-going processes that reflect amounts of self-disclosure between the individual and her social network.

Social network characteristics may vary according to the amount and quality of disclosure concerning each of these identities. Special emphasis is placed on supportiveness of the social network in relation to these identities. Supportive interactions lead to a normalization process whereas non-supportive interactions feed into the stigmatization process. It is assumed that the interactional processes between the individual and her social network will be related to her general psychological well-being. For example, there is theoretical and empirical evidence of particular psychological outcomes associated with passing. Women who pass a great deal may be subject to confusion about their own identity; they may feel alienated with no sense of belonging

Figure 1

CONCEPTUAL FRAMEWORK



when they are in situations where their lesbian identity is not known and heterosexuality is assumed. They may experience high stress because of the potential that at any time their cover might be blown and their lesbianism revealed. They may experience fear that once their lesbianism is revealed, they will experience open discrimination. On the more positive side, they may be able to meet some of their needs such as retaining a job or custody of their children. There is some evidence that these processes are applicable to chronic illness identity also.

Definitions of Processes

Withdrawal. Withdrawal involves decreasing or stopping social contact with a person. This is protection from threatening situations where a person thinks she will be viewed negatively, where there is a threat to valued conceptions of self. The world is viewed as unyielding, uncaring and unfamiliar with one's plight, feeling that no one can know what one is experiencing or have sympathetic imagination (Davis, M. 1973, p. 20).

An example is a person with problems with incontinence (something that is capable of offending, being seen as offensive) who withdraws because this feels safer than finding out that a friend's view of her has changed. Another example is of someone who cut off contact with friends rather than tell them about her lesbianism because she feared they would think her evil, immoral, or crazy.

Withdrawal can lead to social isolation wherein the person becomes increasingly socially and psychologically separated from former relationships and social activities with decreasing opportunities for adequate replacement with new relationships and activities. This process may be vague, erratic, and imperceptible.

Passing. Passing is attempting to conceal an aspect of oneself (i.e., lesbian or chronic illness identity) viewed to be of lesser value than what one is trying to be seen as; trying to avoid being seen by self and others as different. Passing occurs when valued conceptions of self are threatened and alternate conceptions are alien and devalued by self and others.

Coming out. Coming out is the sharing with others in one's social network that one is a lesbian or chronically ill person and the specific implications of possessing these identities. This process is in contrast to passing, where the devalued conception is hidden from others. People who are passing are often referred to as being "in the closet." Although this metaphor captures some of the feelings of being shut off and isolated in a dark, confined place, it implies that there are two dichotomous states, that of being out of the closet and that of being in the closet. In reality one is always in the process of making decisions about how much to reveal about oneself to others, how "out" or "closeted" to be.

For the purpose of this work, coming out can be conceptualized on two levels. The first level of coming out is sharing with another person that one is "lesbian" or one is "chronically ill," the sharing with someone that the person accepts for themselves this label. The second level of coming out refers to the sharing of the implications of this identity for one's life. For example, one may decide to share with someone that being a lesbian means that one has not been allowed to visit a sick lover in the hospital, or that one's chronic illness causes chronic pain. Once one has begun the coming out process in a relationship, there are two possible processes that may occur: normalization or stigmatization.

Stigmatization. This is the process by which one person possessing a particular attribute (identifying as lesbian and/or chronically ill) believes, and another person agrees on some level, that this attribute is shameful, bad, etc., justifying treatment of the person possessing it as less than fully human.

Normalization/Deviance Disavowal. This is the process through which a person's needs and identity come to be viewed as normal, where the person is viewed as a whole human being rather than as one attribute overriding all others. The devalued person attempts to be seen as capable and to guide others to other aspects of the self than the devalued identity (i.e., lesbianism, chronic illness).

Table 1

Major Variables of This Study

The Lesbian Identity
The Chronic Illness Identity
Social Network Characteristics
Social Support Characteristics
General Well-Being

Research Questions

1. What are the characteristics of the social networks of chronically ill lesbians?
2. What is the general psychological well-being of chronically ill lesbians?
3. What are the relationships between social network characteristics and general psychological well-being of chronically ill lesbians?
4. What do chronically ill lesbians view as supportive and non-supportive to their identities as lesbians and as chronically ill people?

CHAPTER III

METHODOLOGY

Study Design

This study of the social networks, social support, and general psychological well-being of lesbians with chronic illness/hidden disability was conducted using a survey approach. Data was collected through structured questionnaires and interviews. Data analysis included descriptive and correlational statistical analysis as well as content analysis of interview data. Structured questionnaires were used to obtain data about the lesbian and chronic illness identities, socio-demographic characteristics, social networks, and general well-being of participants.

Operational Definitions

Socio-demographic Information

Socio-demographic data was collected through the General Information questionnaire developed by the investigator (Appendix A-1). The rationale for collecting basic socio-demographic data was twofold. The first was to compare the findings of the current study with data from other studies and the second to determine the extent to which the findings are generalizable to other studies. These rationale are of particular importance because of the issue of disclosure for this sample. Information included age, race, education, occupation, income, religion, marital and relationship status.

Questionnaires from other studies of lesbians were reviewed before development of questionnaires for this study (Tanner, 1978; Brooks, 1981; Ettorre, 1980; Moses, 1978). Care was taken in the development of the General Information questionnaire to eliminate heterosexual bias and to acknowledge common realities of some lesbians' lives. For example, it was not assumed that the participant had a spouse (Question #14). Also there was acknowledgment of woman-centered feminist religion (WICCA*) in the questions about religion (Question #11). Legal marital status was not assumed to be the same as current relationships (Questions 13,14). It was acknowledged that lesbians may be single, or have female or male primary partners (Question #14), and may have a variety of living arrangements (Question #15). There were 39 questions in the General Information Questionnaire. It took approximately 20 minutes to complete. Pre-testing resulted in minor revisions to increase clarity of some questions.

Reliability and Validity. The General Information questionnaire was developed using standard questions as well as questions found in other surveys of lesbians including the investigators previous research. It was pre-tested with lesbians with chronic illnesses and a few modifications were made to decrease ambiguity.

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[1] Wicca means to bend or shape and referred originally to covens that practice witchcraft, perhaps the oldest religion in the western world. Close in spirit to the Native American traditions and shamanism, its teachings come from nature, the movements of the sun, moon, and stars, and the cycles of the seasons (Starhawk, 1979). Today there is a revival of this religion that creates an image of "the legitimacy and beneficance of female power" (Christ, 1979).

The Lesbian Identity

Quantitative data about the lesbian identity was obtained through the Initial Contact Questions and the General Information questionnaire as well as qualitative data that emerged from the interviews. Lesbian Identity variables included in the Initial Contact Questions were:

1. Self-definition as a lesbian (Question #1);
2. Length of time one has been lesbian (Question #2);
3. Length of time one expects to be lesbian (Question #3), e.g., rest life, not sure;
4. Whether being a lesbian has a impact on how one lives her life (Question #4), e.g. yes or no.

(See Appendix A-2)

Additional lesbian identity variables in the General Information questionnaire included;

5. Sexual Preference - behavior and activities ranging from exclusively heterosexual to exclusively homosexual (Kinsey, 1965), (Question #22);
6. Sexual Preference - feelings, fantasies, and desires ranging from exclusively heterosexual to exclusively homosexual (Question #23);
7. Satisfaction with sexual preference from very to not-at-all on five (5) point Likert scale (Question #25);
8. Belief about health of one's sexual preference from very to not-at-all on five (5) point Likert scale (Question #26);
9. Importance to one's life that one is lesbian from very to not at all on five (5) point Likert scale (Question #28).

Lesbian identity composite variable. During the analysis of data, it was decided to create a composite variable for the lesbian identity. This variable was created by adding the scores on the following six variables and calculating a mean score:

1. Sexual preference - behavior and activities (Question #5)
2. Sexual preference - feelings, fantasies, and desires (Question #6);
3. Satisfaction with sexual preference (Question #7)
4. Belief about health of one's sexual preference (Question #8);
5. Importance of being lesbian (Question #9); and
6. Obviousness that one is lesbian (Question 10). The strongest lesbian identity was assumed to be one with exclusively lesbian behavior and feelings, high satisfaction, belief that it is very healthy, very important, and very obvious that one is lesbian.

The reasons for exclusion of the variables on the Initial Contact Questions are as follows. All participants were self-defined as lesbians and almost all (92%) expected to be lesbians for the rest of their lives. All stated that being lesbian had an impact on how they lived their lives. Thus, the sample was basically homogeneous on these variables. Although there was variation in how long one had been lesbian (1 - 70 years), it became obvious to the investigator that women were using different criteria for answering this question. Thus the meaning of the responses is not clear.

Reliability and validity. Since there was no one operational definition established to measure the complexities of the lesbian identity, variables repeatedly seen in the literature were selected by this investigator to create the composite variable. A multifactor lesbian identity variable was created for the purposes of this study. Reliability and validity have not been established. However, there is statistical evidence that it is a useful composite. The variables were correlated with each other and the composite variable using Kendall's Tau. The component variables were moderately positively correlated with the composite: lesbian behavior .62 (p=.000), lesbian feelings .50 (p=.000), satisfaction with lesbian identity .37 (p=.ooo), healthiness of lesbian identity .34 (p=.000), importance of being lesbian .60 (p=.000), and obviousness of being lesbian .67 (p=.000). Thus the component variables were related to the composite. There were some correlations among the component variables: lesbian behavior and importance .28 (p=.017), satisfaction .29 (p=.014), lesbian feelings .31 (p=.008), and importance and obviousness of the lesbian identity .31 (p=.006). None approached a 1:1 correlation that would have indicated that they were measuring the same concept. There were only four significant correlations among the component variables, all lower than correlations with the composite. This indicates that they were relatively independent of each other (see Appendix B-1).

The Chronic Illness Identity

Quantitative data about the chronic illness identity was obtained through the Initial Contact Questions and the General Information questionnaire as well as qualitative data emerging from the interviews. Chronic Illness Identity variables included in the Initial Contact Questions were:

1. Self-definition as having a chronic physical illness or physical condition that limits how one's body works, and specifying that illness/condition (Question #5);
2. Length of time one has had the illness/condition (Question #7);
3. Length of time one expects to have illness/condition, e.g., rest of life, a short time, not sure (Question #8);
4. Whether the illness/condition has an impact on how one lives her life (Question #9), (see Appendix A-2).

Additional chronic illness identity variables in the General Information questionnaire included:

1. Physical health from excellent to very poor on a five (5) point Likert scale (Question #31);
2. Importance to one's life that one is chronically ill/disabled from very to not-at-all on a five (5) point Likert scale (Question #34);
3. Seriousness of one's chronic illness/disability from very to not-at-all on a five (5) point Likert scale (Question #35);
4. Obviousness to others that one is chronically ill/disabled from very to not-at-all on a five (5) point Likert scale (Question #36).

Chronic illness composite variable. The chronic illness variable was created by adding the scores on the following four variables and calculating a mean score: Physical health (Question #31), importance of being chronically ill (Question #34), seriousness of one's chronic illness (Question #35), and obviousness to others that one is chronically ill (Question #36).

The reasons for exclusion of the other variables are as follows. All participants defined themselves as having a chronic physical illness or condition that had an impact on how they lived their lives. Thus the sample was homogeneous on these variables. Although two-thirds expected to be chronically ill the rest of their lives, and one-third was not sure how long they would be chronically ill, it was decided that this variable was not measured precisely enough to warrant including a composite score. The length of time one had been chronically ill was ruled out for similar reasons. Participants used different criteria to answer this including time since symptoms started, time since diagnosis, etc. Statistical analysis revealed that length of time with a chronic illness was only correlated with physical health, and not the other chronic illness variables (see Appendix B-2).

Reliability and validity. Since this composite variable was created during this study, its reliability has not been tested. However, statistical analysis supported that these component variables are moderately correlated with the composite chronic illness identity variable with a few weaker correlations among themselves. Thus they all contribute to the concept without totally representing it, and are somewhat independent of each other.Because of the diversity of diagnoses and lack of readily available topologies to categorize them, the author resorted to a simple descriptive classification.

Social Network

The social network was defined as the individuals listed by the participant in response to this direction: "Please list each person who is important in your life. Consider all people who are important whether you like them or not." There is space to list as many as 24 names. A list of examples of types of relationships is provided on the questionnaire (partner, family, friends, housemates, work/school associates, neighbors, health care providers, counselors, therapist, etc.) so the respondent can identify the relationship of each person to her (see Appendix A-3).

This definition of social network was designed to elicit the personal network perceived by the participant as important to her. It was assumed that the network elicited would not be only a social <u>support</u> network, but a more comprehensive network including elements of nonsupport, since the participants were asked to list all imporant people, not only supportive people.

Since a wide variety of characteristics have been studied with little consensus about their specific contributions, the investigator attempted to continue to measure characteristics typically used. This increases the knowledge base about social networks by examining them in this particular context. Several dimensions of the elicited network were investigated: size, relationship to subject, sex, duration of relationship, frequency of contact, availability of person, satisfaction with relationship, density, reciprocity, importance of relationship, and support from the relationship (see Appendix A-4 for the relationships between dimensions, constructs, components, and specific questionnaire items).

A unique feature of this questionnaire was the collection of information related to the specific identities of lesbian and chronically ill. In relation to the lesbian identity, it was asked if network members knew the participant's sexual preference, how they responded to her sexual preference (supportive/non-supportive), and what the sexual preference was of each network member. Similar questions were asked in relation to the chronic illness: Whether the network members knew the participant had a chronic illness/hidden disability, how they responded to this (supportive/non-supportive), and the health status of the network members. By collecting this information the author acknowledged that support might vary in relation to the each participant's different identities. This format also spoke to the issue of potential stigma by not assuming that network members would necessarily know that the participant was lesbian or chronically ill. Although relationships may be supportive in other ways, network members may be either unaware of or not supportive of these specific identities.

An attempt to avoid heterosexual assumptions was made by not using such words as spouse. Rather the word partner was used because this term describes an intimate relationship without assuming heterosexual marriage.

Reliability and validity. The requirements for a social network-social support tool for this study included: Ability to be self-administered; measurement of a broad range of social network characteristics; measurement of nonsupport as well as support within the context of specific relationships in the social network; and measurement of characteristics related to the potentially stigmatizing identities of lesbian and chronically ill.

Because of this last requirement, it was immediately apparent that there were no such established tools that would be appropriate. In examining instruments to determine if they could be used in a modified form for this study, further incapatabilities were found. Two self-administered instruments currently enjoying popularity in nursing research were evaluated--the Personal Resource Questionnaire (PRQ) (Brandt and Weinert, 1981) and the Norbeck Social Support Questionnaire (NSSQ) (Norbeck, 1981, 1983).

The PRQ, Part I, obtains a description of one's support resources by identifying eight life situations in which one might need help and by asking the respondent to identity whom she could turn to for help. Options included no one, spouse, child, relative, friend, spiritual advisor, professional person, agency, books, prayer. It then asks if one had had that particular life situation within the past 3-4 months and, if so, how satisfied they were with the assistance they received. The PRQ, Part II, has 25 items with which one can agree or disagree on a 7-point Likert scale. They address the components of social support identified by Weiss (1974). There is also a question about having a confidante and five self-help ideology questions.

This instrument does not measure most social network characteristics but rather provides a global measure of social support. The life situations identified do not relate to the identities of interest in this study. Because the questions are global it is unclear from where and when support comes. For example, one of the statements reads, "Sometimes I can't count on my relatives and friends to help me with important problems." Such a statement does not provide a context and confounds support from friends with that from relatives, a distinction important to make for the current study.

Norbeck's NSSQ provides a less global look at social support by having respondents answer questions about specific people listed. The format was used in the questionnaire for this study with the permission of Dr. Norbeck. Size of network, duration, and frequency were the only network characteristics measured, which were considered insufficient for this study.

As a social support tool, the NSSQ focuses on eliciting only a support network, not one that also includes nonsupport. There is also an assumption in eliciting network membership that important others are supportive. People are asked to list all significant people in their lives, those who provide personal support or who are important. Concurrently the tool is labelled a social support questionnaire.

The questions that relate to Kahn's dimensions of affect, affirmation, and aid were judged by this author to be too general to be able to be answered by someone who has two potentially stigmatizing identities.

Since there were no standardized tools measuring social network that met the requirements of this study, the investigator developed the Social Network Questionnaire. It was pre-tested with lesbians with chronic illnesses. Feedback was solicited and incorporated into the final version. Consultation with Norbeck supported asking specific questions related to the lesbian and chronic illness identities. The basic structure and several questions were retained from the NSSQ (Norbeck, 1981).

The validity of the total questionnaire is yet to be established, but there is support in the lesbian and chronic illness literature as well as interview data from the study for including questions that acknowledge the potential stigma and disclosure issues associated with being lesbian and/or chronically ill (see Chapter II). The availability question caused some problems, with some participants unsure of how to respond without a more specific context. There were some errors of omission in completing the density question that were easily corrected by the investigator.

Components of Social Support and Non-Support

There is no systematic research known to this investigator examining the components of support and non-support for people with these potentially stigmatizing identities. Boden's work (Rubin, 1981) touches upon issues of alienation, safety, a disabled assumption, etc., that need further exploration. Therefore, this investigator did not attempt to define support qualitatively before conducting the study. The amount of support for the identities was quantified as the percent of network members rated as supportive by the participant. The interview was designed to collect data for the development of a construct of social support and non-support for the lesbian and chronic illness identities.

Interview guidelines. The following were used as interview guidelines:

1. I would like to learn more about what you find supportive and nonsupportive to you as a chronically ill lesbian.
2. Tell me what kind of things feel supportive, times when you have felt particularly supported about being a lesbian, about being chronically ill.
3. How about some examples of feeling not supported as a lesbian, as someone with a chronic illness.

It was anticipated that it might be difficult for participants to articulate the specifics of what was supportive to them because of the general nature of the question. Some women were able to give examples without hesitation while for others certain strategies helped to make it easier to discuss specific examples of support and non-support. One strategy for making this easier was to have them complete the social network questionnaire before the time of the interview. Then specific relationships could be discussed. For example, "I notice that you have rated this person as very supportive. Can you tell me a little more about that? Can you describe a time you interacted with this person and felt particularly supported?," etc. This same strategy was used for those rated as not at all supportive.

Another interview strategy was to have the participant first discuss one's daily life in relation to each identity. This provided a context in which one might recall specific supportive and non-supportive interactions.

General Psychological Well-Being

The General Well-Being Schedule Research Edition was used as the main measurement of this variable (Appendix A-5). The original General Well-being schedule (GWB) was developed at the National Center for Health Statistics as part of a national health survey provided for by the National Health Survey Act of 1956. Its general purpose is to provide information about the health status of the population of the United States. Psychological components were included to provide a better assessment of health and well-being. The GWB was pretested on 373 adults and then administered to 6,900 adults as part of the national study of the Health and Nutrition Examination Survey that took place from April, 1971 to October, 1975 (Fazio, 1977).

The GWB is a self-report instrument designed to assess selected aspects of self-representations of subjective well-being and distress. Symptoms that are generally considered important to well-being and distress are assessed for presence, severity, and frequency. The original GWB is an 18 item schedule, and has been extensively tested for reliability and validity (Fazio, 1977).

For purposes of this tool, the term "general psychological well-being" refers to the net impact of the many forces that affect the individual's emotional or feeling states. It is assumed that people are able to differentiate feelings both qualitatively and quantitatively. "Psychological" is used here to mean how the inner states are seen by the individual. Psychological well-being is a selective aspect of the general concept of well-being. Self-reports of the psychological state, etc., are used as the source of observations about conditions rather than ratings by others, behaviors, etc. The affective state is determined by measurement of several different subjective states. Affective and cognitive processes are involved. Observations are of inner, personal nature, but these observations require a level of conscious awareness for verbal expression. The net impact of many psychological forces bearing on the individual is referred to as well-being. This impact is seen as being measured along a bi-polar dimension ranging from negative through neutral to a positive sense of subjective well-being.

The Research Edition the General Psychological Well-Being Schedule

Since the original questionnaire was developed, a more complete research edition has been created after extensive review of personality tests, structured clinical interview schedules mental health and adjustment inventories, etc.

The Research Edition was developed to provide for more comprehensive measure of psychological well-being. This edition has 58 items to measure components of general psychological well-being, nine items to assess mental health and one global assessment of well-being at three different points in time. Concepts measured in the 58 well-being items are organized into seven subscales.

Table 2

Frequency Distribution of Items in Each Sub-Scale of the Original and Research Edition of the General Well-Being Schedule

		# Items in Research Edition	# Items in Original GWB
I.	Positive well-being or intrinsic life satisfaction	8	4
II.	Health worry, concern or conditions	5	3
III.	Depressed mood	6	3
IV.	Behavioral, mental, and emotional control or "self-control"	10	3
V.	(a) Adjustment: Person-Environment fit	4	0
	(b) Adjustment: Coping	10	0
VI.	Energy level or vitality	7	4
VII.	Tension-Anxiety-Stress	8	5
	Total	58	22

The number of items was increased for each of the original concepts and two new adjustment subscales were added, person-environment fit and coping. The addition of the adjustment subscales is particularly important to the current study because chronically ill lesbians might have additional difficulties matching their needs to a society that devalues them and might need to develop additional coping skills to deal with having two potentially stigmatizing identities.

Harold Dupuy, who constructed the research edition, states that the variation in number of items per concept reflects that the items were constructed to fit the concept, represent a range of content related to the concept, and were of psycho-social interest (Dupuy, unpublished paper, undated).

Selection of the General Psychological Well-Being Schedule--Research Edition. There are several reasons why this schedule was deemed the most appropriate for this study of chronically ill lesbians. First, the concept of psychological well-being is chosen rather than a limited measurement of psychiatric pathology. This reflects a definition of health that goes beyond absence of disease. Nurses are interested in the maintenance of a high quality of life regardless of the presence of physical ill health. This study assumed that lesbianism and physical illness do not automatically lead to ill-being or psychological distress. This tool is appropriate for examining how women who are lesbians and have a chronic illness may be able to maintain a sense of psychological well-being.

The use of the participants' self-perceptions of general psychological well-being was also considered to be an advantage. According to symbolic interactionism, the perception is of critical importance in explaining outcomes and processes. One serious problem in the study of both lesbianism and disability has been the tendency to make assumptions about the pathology of these conditions without serious consideration of the perspective of the people who are living with these identities. In this study, self-perceptions were selected as a way to begin to fill this void.

Another important advantage to this schedule was its comprehensiveness. This is reflected in the development of more comprehensive subscales that measure more components of general psychological well-being than the original GWB.

Setting

The setting for this study was predominantly the San Francisco Bay area. This geographical area was selected because of the relatively high number of openly lesbian women and the great number of resources available for lesbians. These include social groups, support groups, and health services specifically for lesbians, many lesbian cultural events, businesses, etc. Such a setting provided for relatively easy access to this highly stigmatized population. It also allowed for face-to-face interviews with the investigator rather than obtaining only questionnaire data.

Procedure for Obtaining the Sample

Because of the potential for stigma of this population, it was anticipated that it might be hard to find participants without a personal connection to or knowledge of the investigator. By using informal connections that the investigator had established through previous research, she was able to reach people who might otherwise not have responded to requests for participation in a study of such sensitive topics. The investigator's position as an insider, both chronically ill and lesbian, was indicated on advertising materials to provide a safe atmosphere in which women would feel comfortable in discussing these identities (see flyer, Appendix A-6). The following is a partial list of places where the study was advertised: Friendship and professional networks of the investigator; the American Diabetes Association where the investigator is active in facilitating support groups; organizations and facilities addressing the needs of lesbians, such as Operation Concern, Center for Special Problems, Lyon-Martin Clinic, The Women's Building, the Artemis Society Cafe, Pacific Center, Berkeley Women's Health Collective, Clinic for Women of Color, Shanti Project, and Oakland Women's Feminist Health Center. Advertisements were placed in Plexus and Coming Up, local newspapers with a gay and lesbian focus. Interested women were asked to contact the investigator. Once contacted, the investigator explained the purpose of the study, the research process, and measures taken to protect the rights of participants, including informed consent and maintenance of confidentiality (see information sheet, Appendix A-7).

Selection Criteria

For those who were interested, the following Initial Contact Questions were asked to determine their eligibility for the study:

1. Do you define yourself as an lesbian?

2. Does being a lesbian have an impact on how you live your life?
3. Do you have any chronic physical illnesses or physical conditions that limit how your body works? What are they?
4. Does this illness/condition have an impact on how you live your life?

To be selected, women must have defined themselves as lesbian and chronically ill with both of these identities having an impact on how they lived their lives. The investigator had initially planned to select only women who had defined themselves as lesbian and chronically ill for at least five years and anticipated possessing each of the identities for at least five years. This criterion was dropped to assure an adequate sample size. Potential participants were also asked "Is this condition visible or obvious to others?" The chronic illness/disability must have had at least some features that the participant considered to be of low visibility or obviousness. A few women with more obvious disabilities, as well as hidden disabilities, were included to provide the opportunity to explore the concept of visibility. There were no specific diagnostic criteria for illness/disability.

The following exclusions were established in advance, but it was not necessary to exclude anyone on the basis of any of them.

1. Those with illness or conditions known or suspected of being contagious were excluded because of the potential impact of this on interpersonal relationships;
2. A medical diagnostic label was not sufficient or necessary. For example, if a woman had emphysema but did not consider herself to be chronically ill, and did not perceive this as

having any impact on her life, was not receiving treatment, etc., she would be excluded from the study. Women with undiagnosed chronic illness were included.

3. For the purposes of this study, the participant must have viewed the central problem as being a physical rather than an emotional one. Anorexia nervosa, alcoholism, drug addiction, depression, manic-depressive illness, schizophrenia, etc., would be excluded unless there was also a qualifying chronic illness present.

Data Collection Procedures

The Information Sheet and package of three questionnaires was sent to women expressing an interest. When the questionnaires were returned, the investigator reviewed the responses in order to formulate more specific questions for the interview. A mutually convenient time and place were set for the interview. At the interview the investigator asked for feedback about the questionnaires. She inquired about any special needs the participant might have during the process of the interview and shared her own. Because the interviewer anticipated that she might need to check her blood sugar, eat a snack, or take a break during some of the interviews, she informed the participant before the interview about this so that the participant would not feel undue concern or responsibility if a break were necessary. Hopefully, this also created an atmosphere wherein the participant would feel free to share her special needs with the investigator. All interviews were taped with permission of the participants. The investigator also took some notes during the interview. At the beginning of each interview the investigator acknowledged the sensitivity of the subject matter and allowed the participant to choose whether she had a preference about discussing her lesbianism or chronic illness first.

Obtaining the Interview Sample

Initially everyone who was eligible for the study and willing was interviewed. Once a core group of ten interviews were completed and analyzed, an additional twelve interviewees were selected from the total sample of 66 completing the questionnaires on the basis of how much support they had for their lesbian and chronic illness identities. The procedure was modified so that participants returned questionnaires to the investigator by mail and understood that she might call them in the future to request permission to do an interview. Thirty percent of the 47 participants queried learned of the study from the flyer, 30% from another person, and 32% from newspaper advertisements.

Protection of Participants

Safeguards were included throughout the study to assure the voluntary participation, informed consent, and confidentiality of all participants. The protocol was approved by the Committee for Human Research at the University of California, San Francisco (see Appendix A-8).

The most outstanding ethical issue for the study was the strict maintenance of confidentiality. This was because of the high possibility of stigmatization and discrimination that could be incurred by potential participants if their identities as lesbians and chronically ill became known to others. Specific measures that were taken to secure confidentiality included:

1. No signed consent form was used. Instead, participants were given a written information sheet and had ample time to discuss any questions with the investigator. Participants were asked to refrain from putting their names or the names of anyone in their network on any forms that were given to the investigator.
2. Each participant was given a code number that was the only identification on all data collected including tapes and written information. A code sheet identifying names with code numbers was kept in a locked file box in the home of the investigator and was destroyed when all data had been collected and analyzed. Names and addresses were kept separately under lock and destroyed upon completion of data collection. Audio tapes were erased as soon as they were transcribed and any identifying information from the taping was removed from the transcriptions.
3. Whenever someone spoke of another woman who might be interested in participating, she was told to have that woman contact the investigator directly rather than the investigator initiating the contact herself. In this way, the investigator was assured of not intruding on the privacy of these women or inadvertently increasing their anxiety by the realization that a stranger was aware of their lesbian and chronic illness identities.

4. Topics to be covered in the interview and questionnaires were shared with the potential participants in advance so that they could choose not to participate if they were uncomfortable with the topics being addressed.
5. Participants were informed that they might become upset, tired, or uncomfortable while participating. They were free to end their participation at any time for any reason without negative repercussions.
6. Participants were informed of the approximate time needed to complete questionnaires and the interview. If easily fatigued, participants could arrange to have interviews broken up into shorter segments. Questionnaires could be filled out at any time convenient for the participant. Interviews were held in a location most convenient and comfortable for the participants.

Quantitative Analysis Procedures

Preliminary Analysis for Each Study Variable

Lesbian identity. As discussed in the previous section, lesbian identity was calculated by adding the scores for sexual feelings, sexual behavior, importance of being lesbian, how healthy it was to be lesbian, how obvious it was that they were lesbian, and how satisfied they were with being lesbian. Recoding was done as necessary based on the assumption that the strongest lesbian identity would be one where behavior and feelings were exclusively lesbian, and being lesbian was considered to be highly important, healthy, obvious, and satisfying.

After this variable was calculated, Pearson's correlations were done among the subvariables and the lesbian identity variable to see how they were related to each other.

Chronic illness identity. As discussed before, the chronic illness identity was then calculated by adding the scores for how obvious, serious, and important the chronic illness was as well as the degree of physical health. Individual variables were recoded as necessary based on the assumption that the strongest chronic illness identity would be one in which the illness was considered to be highly obvious, serious, and important, and where physical health was considered to be poor.

After this variable was calculated, Pearson's correlations were done among the subvariables and the chronic illness identity variable to determine how they were related to each other.

Combined identity support was calculated as an ordinal variable with three levels: 1) High support for both identities; 2) high support for one and not the other; and 3) low support for both. Identity support was then correlated with other variables.

Analysis Related to the Research Questions

Describing the social networks of chronically ill lesbians. First a count was done for each category of response on each question of the social network questionnaire. These counts were then divided by the number listed to get a percent of network score. Scores were first calculated for each respondent and then for the overall sample. Frequencies, means, and standard deviations were done for each variable.

Network support for lesbian identity. To create a score for network support for the lesbian identity a count was done of all the network members listed who were rated as positive/supportive of the respondent's sexual preference. This score was also divided by the number listed in the network to get the percent of the network supportive to the identity.

Network support for chronic illness identity. To create a score for network support for the chronic illness identity, a count was done of all the network members listed who were rated as positive/supportive of the respondent's sexual preference. This score was divided by the number listed in the network to get the percent of the network supportive to the identity.

Network members' knowledge of the identities. For both the lesbian and chronic illness identities, a count was made of network members who knew the respondent possessed this identity, whether they had told them themselves or they had found out another way. These scores were then divided by number listed in the network to get a percent of the network who knew about each of the identities.

Relationship of network members to respondent. Twenty-eight categories were established from those listed by respondents. These were then reduced to four major categories:

Non-kin included partners, lovers, friends, housemates, ex-lovers, ex-friends, children (other than own), and other intimates;

Kin included mother, father, sister, brother, step-parent, grandparent, own children, partner's relatives, and other relatives;

Health care providers included therapists, other health care providers, sponsors (from Alcoholics' Anonymous and Al-Anon), and ex-health care providers;

Others included co-workers, clients, bosses-supervisors, teachers, other professionals, landlords, and neighbors.

General Well-Being of Chronically Ill Lesbians

The General Well-Being Schedule. After response order was corrected according to the Dupuy's directions, total scores for the whole schedule as well as the subscales were calculated. Means and standards for each were calculated. Pearson's correlations were done among the subscales and the total score, and an internal reliability analysis was done of the subscales as well as of the total instrument.

In order to allow comparison with other studies that have used other versions of the GWB, the sample means and standard deviations per item as well as the total score were done for the 18 and 22 item versions of the GWB. A lability scale was calculated by counting the number of responses made indicating lability. Items 1, 6, 9, 29, 30 had such options according to Dupuy. This scale was used in some of the further analysis.

Other Well-Being Questions. Frequencies, means, and standard deviations were done on other items reflecting well-being. Correlations using Kendall's Tau were done among the GWB scores and those other variables that address well-being to see how they were related to each other.

This findings could have implications for additional and perhaps shorter ways to measure the concept of well-being. The variables included were overall health, emotional health, physical health, GWB item number 68B (considering your whole life, how ar things going at present?). In further analyses the scores from the GWB were used to represent the concept of general well-being.

What Chronically Ill Lesbians Find Supportive and Non-supportive to These Identities

Four subgroups of the sample were created according to how much support they received for each identity. The groups were 1) high support for both the lesbian and chronic illness identities (HH), 2) high lesbian and low chronic illness support (HL), 3) low lesbian and high chronic illness support (LH), and 4) low support for both identities (LL). High and low support for each identity were determined as above and below the mean of percent of the network that supported the identity.

Analysis of variance and Scheffe's test were done to detect if there were significant differences between any two of these groups at the .05 level on social network, lesbian identity, and chronic illness identity and socio-demographic variables. For ordinal variables, the Kruskal-Wallis one-way anova was done, and for nominal data, cross tabulations were done. No cross-tabulations were interpretable because of the small numbers of subjects per cell. Ordinal variables included were education, socio-economic status, religiousness, and level of debt.

The Relationships Between Social Network Characteristics and General Well-Being

Pearson's correlations were done between social network variables (the general ones as well as those specific to the lesbian and chronic illness identities) and the General Well-Being scores and subscale scores. In addition an anova was done to see if there were significant differences in the GWB scores among the four groups, HH, HL, LH, and LL. Further analysis included correlations among the identity variables and the GWB.

Qualitative Analysis Procedures

Most of the qualitative data in this study was obtained through interviews and addressed the research question: What do chronically ill lesbians find supportive and non-supportive to their identities as lesbian and chronically ill? The data was used to develop a construct of support and non-support for chronically ill lesbians. Constant comparative method of data analysis was used. Qualitative data consisted of notes made during and immediately after interviews as well as transcriptions of audio tapes of the interviews. The following steps were taken in analyzing the data.

Analysis was done in two sections. The first twelve interviews were analyzed first to establish basic categories and themes. The the last ten interviews were analyzed using the same basic process. Categories emerging from each of these separate analyses were compared and contrasted to check for completeness and validity of the construction of support and non-support.

The analysis process for each group was as follows. Each interview was carefully examined for specific examples of support and non-support as classified by the participant. All examples were color coded into four categories: Support for the lesbian identity, non-support for the lesbian identity, support for the chronic illness identity and non-support for the chronic illness identity. A list was then made of all the examples for each of these categories. Content analysis was done on these examples (Polit and Hungler, 1978). They were compared to each other to determine similarities and differences in the type of support and non-support described. Based on these comparisons, the examples were reduced into the smallest number of categories needed to include all examples.

Examples of support and non-support as classified by participants were analyzed for similarities and differences. It was discovered that similar behaviors might be classified as supportive at one time and non-supportive at another by the same person, or supportive by one person and non-supportive by another. The contexts, including characteristics of the participant, the identity of interest, the potential supporter and the interaction were compared to see what might have accounted for the difference in interpretation of behavior. Conditions affecting the interpretation of behaviors as supportive or non-supportive also emerged from this analysis. Comparison of the support experience among sub-groups of high and low support for each identity was also done.

Specific interview strategies varied with interviews. When asked what they found supportive/non-supportive, some responded spontaneously with specific examples without further probing. For others this was more difficult. Sometimes asking what one's daily life was like in relation to the identity seemed to help clarify identity-related needs for the participant and to bring to mind experiences of support and non-support. As the typology for support began to develop, when a participant described a specific incident, the researcher would repeat it back at a slightly higher conceptual level and check with the interviewee to see if this conceptualization made sense to her. For example, "It sounds like ... was having a hard time believing that you are chronically ill. Is that so?"

Types of support and non-support were ordered into an approximate continuum from least to most supportive. This was based on the idea that certain types of support were prerequisites for others. Those with the most prerequisites were considered the most supportive and generally involved more intimate interaction and involvement with the participant. This proposed continuum is a theoretical construct that needs empirical testing.

Selection of the second group of ten interviewees was done as follows. After the first twelve interviews with the first people who had responded to the study and were available and willing to be interviewed, there was a decision to use theoretical sampling to choose the others from the total group who had completed questionnaires. This sampling was done on the basis of how much support the person was receiving for each identity as calculated from responses on the social network questionnaire. When over half of the network supported the identity, it was classified as high support with below half considered low support. Selections were made to try to equalize the number of participants in each of the categories: High support for both identities, high support of lesbian and low for chronic illness, low support for lesbian and high for chronic illness, and low support for both identities. This was done to maximize the possibility of getting sufficient examples of both support and non-support for each identity.

The Sample

Socio-Demographic Characteristics

The sample for this study was 66 lesbians with chronic physical illness/disability. They ranged in age from 19-73 years with a mean of

34 years and a standard deviation of 9.05 (see Appendix B-3 for all tables of sample characteristics). Eighty-three percent were Caucasian, 3% Black, 13% of other races. All but one were California residents with 89% from the San Francisco Bay area. The highest education level attained: high school, 5%; partial college, 29%; a college degree, 32%; and post-baccalaureate work,35%.

Twenty-nine percent were employed full-time, 39% part-time, and 14% were unemployed. Twenty-nine percent were attending school. Three-quarters of the sample were employed at their main occupation. A wide range of occupations were represented.

Sources of income included: work, 62%; disability insurance, 21%; investments, 20%; and family 21%. Annual income for 69% was below $15,000 and below $10,000 for 45%. Two percent considered themselves to be upper class, 51% middle class, 29% working class, and 19% poor. Thirty-seven percent were in at least moderate debt.

The sample was moderately religious. In comparing the religion in which they were raised and their current religion, there was a trend away from Catholic and Protestant religions. Twenty-three percent were currently practicing a feminist spirituality, 33% other, and 16% no religion.

Seventy-seven of these women had never married while 21% were divorced. Ninety-two percent had no children. Forty-six percent were currently single, while 49% had a female primary partner. Thirty-six percent lived alone while 29% lived with a primary partner and 20% with friends.

Lesbian Identity Characteristics

These women had defined themselves as lesbian for 1-70 years with a mean of 14 years and standard deviation of 12.3. Ninety-two percent expected to be lesbians for the rest of their lives. Sexual behavior was exclusively lesbian for 85% while 50% had exclusively lesbian feelings, fantasies, and dreams. Eighty percent were very satisfied with their sexual preference, 92% believed their sexual preference to be very healthy, and 76% saw being lesbian as very important to their lives. The obviousness of their lesbianism varied across the sample.

The mean lesbian identity score was 1.55 with a range of 1-2.67 and with standard deviation of .41. This variable had a potential range of 1-30 with 1 indicating the strongest lesbian identity. A score of 30 would indicate someone whose sexual behavior and feelings were primarily heterosexual with substantial lesbian activity and feeling, who believed their lesbian identity was very unhealthy, unimportant, and not obvious.

Chronic Illness Identity Characteristics

These women had been chronically ill for 1-54 years with a mean of 15 years and standard deviation of 10.8. Sixty-nine percent expected to be chronically ill for the rest of their lives while 31% were not sure. While their physical health varied, 57% saw being chronically ill as very important. The obviousness and seriousness of their chronic illnesses also varied.

The mean chronic illness identity score was 2.63 with a range of 1-4.67. This variable has a potential range of 1-20 with 1 indicating the strongest chronic illness identity. A score of 20 would indicate someone who is in very good health and viewed their chronic illness not at all important, obvious, or serious. These women had a wide variety of chronic illness and hidden disabilities with about 50% listing more than one.

Table 3

Frequency Distribution of Chronic Illnesses/Disabilities

Immunological		24
Allergies	(14)	
Environmental Illness	(8)	
Lupus	(2)	
Orthopedic		15
Respiratory		13
Endocrine		9
Neurological		9
Arthritis		9
Digestive		8
Cardiac/Circulatory		6
Sensory		5
Pain		5
Alcohol, Drug Abuse		4
Skin		3
Obesity		2
Excretory		2
TOTAL		114
Undiagnosed		2

Now that this sample of chronically ill lesbians has been described, the findings related to each research question will be presented in the following chapter.

CHAPTER IV

FINDINGS

The findings of this study are presented in two major sections. The first section presents quantitative data related to research questions 1, 2, and 3. Findings related to Question 1 include a description of the social networks of chronically ill lesbians, findings related to Question 2 include a description of the general well-being of chronically ill lesbians. And results related to Question 3 include the relationship between social networks and general well-being of chronically ill lesbians. In addition, the third part includes results of further analyses examining the relationships between socio-demographic and lesbian and chronic illness identity and general well-being.

The second major section presents data related to research Question 4 and is a description of what these women found supportive and non-supportive to their lesbian and chronically ill identities. The first part presents statistical findings of variables associated with support for the lesbian identity, chronic illness identity, and both identities. The second part presents descriptions and examples of types of non-support and support for the chronic illness and lesbian identities and conditions affecting the interpretation of behaviors as supportive or non-supportive.

Research Question 1: What are the Characteristics of the Social Networks of Chronically Ill Lesbians

These women listed an average of 16 people in their social networks, 80% of those listed were female. On the average, 61% of the network members were non-kin with 47% of these being friends. Twenty percent were kin while 9% were health care providers and 10% other. The average duration of the relationships in the networks was 2-3 years, and participants were in contact with network members about every 2 weeks. In general, network members were viewed as being quite important and at least moderately available and supportive. Relationships with network members were at least moderately satisfying. The balance in relationships leaned toward the participants doing a little more for network members than members did for them (see Appendix B-4).

In the average network, each network member had an ongoing relationship with between one and two other people in the network besides the participant. Density ranged from having only one relationship among network members for every seven people listed to having six relationships among network members for every person listed

Characteristics Related to Lesbianism

The sexual preference of participants was known to 84% of the network members, 72% of whom the participants told themselves. Sixty-four percent of the network members responded positively to the lesbian identity, 10% had a neutral response, 8% a mixed response, and 5% a negative response. The sexual preference of network members was nearly evenly divided between heterosexuals (40%) and homosexuals (46%).

Forty-three percent were lesbian, 5% bisexual, and 4% undecided (see Appendix B-5).

Characteristics Related to Chronic Illness

The chronic illness of participants was known to 84% of the network members. For 77% of these the participants had disclosed this identity themselves. Fifty-nine percent of the network members responded positively to the chronic illness identity, 12% had a neutral response, 11% a mixed response, and 5% a negative response. While 52% of network members had no chronic illness or disability, 21% did have a chronic illness or hidden disability and 4% had a visible illness or disability (Appendix B-6). Thirty percent of the participants had high network support for both identities, 21% had high lesbian and low chronic illness support, 20% (13) had low lesbian and high chronic illness support, and 24% had low support for both identities.

Research Question 2: What is the General Psychological Well-Being of Chronically Ill Lesbians

The mean per item score on the General Well-Being Schedule (GWB)was 2.78, with sub-scale mean scores ranging from 2.19 for person-environment fit to 3.38 for depression. All of these scores are less than those obtained in a national sample (n = 6.913), indicating that these women had generally lower well-being (Table 4).

Table 4

Comparisons of Mean Per Item Scores on the GWB for Two Independent Samples

		n = 65		n = 815	
		This Study		Rand (Dayton)	
Total GWB Schedule					
I.	POSITIVE WELL-BEING (8 items)	X	S.D.	X	S.D.
1	General spirits	2.78	1.19	3.21	1.04
9	Happy, satisfied with personal life	2.69	1.21	3.35	1.06
17	Interest in people	3.14	1.17	3.88	.75
24	Change from usual in well-being, distress	2.94	1.74	2.96	.91
30	Satisfaction with self	2.90	1.39	----	----
37	Interesting daily life	2.98	1.18	3.15	1.23
43	Felt cheerful, lighthearted	2.18	1.11	3.36	1.15
57	Felt loved, wanted	3.37	1.50	3.86	1.25
II.	HEALTH WORRY CONCERN OR CONDITION (5 items)				
2	Bodily distress	1.45	1.42	3.59	1.26
10	Healthy enough to do things	3.55	.91	4.51	.75
19	Concern, worry about health	2.04	1.31	4.03	1.11
25	Physical shape, condition	2.67	1.09	3.74	.85
31	Appetite	3.51	1.19	----	----
III.	DEPRESSED MOOD (6 items)				
3	Felt depressed	3.14	1.38	4.03	.83
11	Sad, discouraged, hopeless	3.57	1.49	4.30	1.08
18	Others better off if I were dead	4.43	1.10	----	----
38	Felt downhearted, blue	3.24	1.07	3.97	1.01
45	Felt lonely	3.22	1.18	4.22	1.09
49	Moody, brooded	3.24	1.09	3.90	1.07
IV.	BEHAVIORAL-EMOTIONAL CONTROL (10 items)				
4	Firm control	3.18	1.17	4.16	.96
12	Self confident	2.69	1.06	3.57	1.16
20	Afraid losing control	3.59	1.44	4.68	.78
26	Socio-behavioral control	3.62	1.76	4.49	1.12
32	Crying	2.41	1.43	----	----
34	Doubts about ability to succeed in life	2.59	1.35	----	----
39	Felt calm, peaceful	2.33	1.03	3.27	1.25
47	Emotionally stable, sure of self	2.69	1.19	4.06	1.12
50	Angry, bitter, frustrated	2.84	1.36	4.01	.90
53	Others saw as strange	4.22	1.12	4.73	.67

Table 4 (cont.)

V.	ADJUSTMENT (14 items)	X	S.D.	X	S.D.
A.	Person-environment fit (4 items)				
5	Made changes in self or life situation	1.82	1.60	----	----
13	Felt need for change in routine	2.90	1.26	4.13	1.25
44	Full life situation	2.18	1.33	3.16	1.30
56	Felt well adjusted to life	2.76	1.50	3.64	1.20
B.	Coping (10 items)				
8	Needs satisfaction	3.53	.92	4.15	1.03
16	Took care of things needed to do	4.12	1.59	4.63	1.03
21	Meeting physical, mental, social demands	3.22	.96	4.12	1.03
27	Things turned out the way wanted	3.03	1.15	----	----
35	Enjoyed life	3.06	1.16	3.83	1.16
40	Love/sex life full, complete	2.16	1.68	3.15	1.70
48	Eager to tackle tasks, make decisions	2.49	1.26	3.11	1.34
51	Lived life wanted to	2.57	1.41	3.44	1.37
54	Felt proud about some things	2.98	1.18	3.25	1.16
58	Could cope with or handle problems	2.20	1.60	3.77	1.19
VI.	ENERGY LEVEL (7 items)				
6	Energy, pep, vitality	3.04	.98	3.58	1.06
14	Trouble sleeping	3.43	1.43	4.40	.95
22	Active, vigorous vs. dull, sluggish	2.73	.67	3.39	.94
28	Inertia	3.16	1.20	----	----
41	Tired, worn out	2.65	1.15	3.61	1.06
46	Fast tempo or pace	2.22	1.48	2.99	1.35
52	Waked fresh, rested	2.45	1.23	2.92	1.41
VII.	TENSION-ANXIETY (8 items)				
7	Nervousness	3.18	1.39	3.93	1.11
15	Strain, stress, pressure	1.80	1.40	3.29	1.32
23	Anxious, worried, upset	2.55	1.43	3.68	1.08
29	Relaxed vs. high strung	2.76	.90	3.58	1.02
33	General tension	1.96	.93	3.32	1.19
36	Drove, pushed self hard	2.92	1.22	3.54	1.28
42	Jittery, irritable, on edge	3.29	1.15	3.79	1.03
55	Restless, fidgety, impatient	3.57	.96	3.74	1.13

Mental Health Section of the GWB

Findings from the mental health section of the GWB indicated that a majority of these women had sought professional help for mental health problems within the last year and found it helpful. Most (73%) have never had a "nervous breakdown" or been an in-patient or out-patient in a mental hospital, mental health ward of a hospital, or a mental health clinic (70%).

While 37% are seeing a psychiatrist, psychologist, or psychoanalyst, the professional sources with whom they discussed emotional concerns included regular medical doctors (27%), group therapy (23%), marriage or family counselors (22%), occupational or educational counselors (20%), nurses (15%), and "other" formal mental health assistance (46%). Almost all of these women (96%) discussed problems with family or friends, with 59% finding it very helpful and 37% finding it somewhat helpful (Appendix B-7). In rating their lives as a whole, they found it to be equally positive and negative during the last year, a little more positive now, and expecting it to be quite good next year (Appendix B-8). This sample had lower well-being than the women in O'Rourke's study (1982) or the HANES study (Ware, 1979). O'Rourke studied the relationships between self-reports of menstrual and nonmenstrual symptoms and psychological well-being in university employed women. The HANES (Health and Nutrition Examination Survey, 1971) was a survey of a general population of 6.000 adults (3,743 females).

The mean total score for this sample on the 22 item version was 71.67 (s.d. = 5.21). O'Rourke's study, also using the 22 item version, had mean totals of 78.12 (s.d. = 15.09) for her entire sample and 77.53 (s.d. = 14.95) for her select sample, while the HANES study had a mean total of 77.7 (s.d. = 18.3) (Table 5).

Table 5

Comparison of Mean Total Scores on 22 Item GWB in Three Studies

	n	Mean	s.d.
This Study	66	71.67	5.21
O'Rourke (entire sample)	1110	78.12	15.09
O'Rourke (select sample)	601	77.53	14.95
HANES Study (entire sample)	3743	77.70	18.30

This sample had lower mean total scores on the GWB with less variation than these other samples. There were no significant differences in the GWB among the sub-groups of those having high support for both identities (HH), high support for lesbian and low support for chronic illness (HL), low support for lesbian and high support for chronic illness (LH), and low support for both identities (LL).

Research Question 3: What are the Relationships Between Social Network Characteristics and the General Well-Being of Chronically Ill Lesbians

Reliability and Validity of the GWB

The overall reliability for all 58 items of the GWB-Research Edition was .97 (using Cronbach's Alpha test for internal consistency), while sub-scales I, III, IV, VB, VI, and VII had reliability coefficients of at least .8. Sub-scale II (Health Worry, Conditions) was .73 while VA (Coping - Person - Environment Fit) was only .21 (Table 6). The correlational matrix of total and sub-scale scores revealed numerous significant correlations, indicating that these scales are not independent of each other (Table 7).

Table 6

Internal Reliability of General Well-Being Schedule--Research Edition

			Number of Items	Reliability Coefficient
Total	GWB		58	.9681
Subscales	I	Positive Well-being or Intrinsic Life Satisfaction		.8898
	II	Health Worry, Concerns or Conditions	5	.7349
	III	Depressed Mood	6	.8644
	IV	Behavioral, Mental, Emotional Control or "Self-Control"	10	.8899
	V	Adjustment		
		A. Person-Environment Fit	4	.2130
		B. Coping	10	.8640
	VI	Energy Level or Vitality	7	.8071
	VII	Tension-Anxiety-Stress	8	.8864

Table 7

Correlations Among Total GWB Scores and All Sub-Scales (N = 65)

	GWB I	GWB II	GWB III	GWB IV	GWB VA	GWB VB	GWB VI	GWB VII
GWB I	.76 p=.000							
GWB II	.40 p=.000	.24 p=.007						
GWB III	.69 p=.000	.69 p=.000	.27 p=.003					
GWB IV	.73 p=.000	.66 p=.000	.29 p=.001	.60 p=.000				
GWB VA	.60 p=000	.51 p=.000	.26 p=005	.50 p=.000	.31 p=.000			
GWB VB	.76 p=.094	.70 p=.048	.33 p=.672	.63 p=.575	.54 p=.256	.57 p=.371		
GWB VI	.60 p=.000	.45 p=.000	.50 p=.005	.48 p=.000	.43 p=.000	.45 p=.000	.58 p=.000	
GWB VII	.54 p=000	.47 p=.000	.22 p=.005	.36 p=.000	.53 p=.000	.40 p=.000	.38 p=.000	.34 p=.000

Kendall's Tau

In examining the relationships among the GWB total and other measures of well-being, significant positive correlations were found between the GWB and life satisfaction (r=.52), emotional (r=.52), physical (r=.32), and overall health (r=.41) (Table 8).

Table 8

Correlations Among the GWB and Overall Physical and Emotional Health

Overall Health	.41 p=.001 (66)*			
Physical Health	.32 p=.009 (66)	-.87 p=.000 (66)		
Emotional Health	.52 p=.000 (66)	.26 p=.036 (66)	-.10 p=.436 (66)	
GWB Total	.52 p=.000 (65	.15 p=.226 (65)	.15 p=.221 (65)	.45 p=.000 (65)
	Life Satisfaction	Overall Health	Emotional Health	Physical Health

Pearson's Correlations

*Number in parentheses equals N value

Life satisfaction was associated with greater physical health (r = .30), emotional health (r = .42), and overall health (r = .36). While overall health was more strongly associated with physical health (r = .83), life satisfaction was more strongly associated with emotional health. Physical health was not significantly related to emotional health for these women inspite of the presence of chronic illness (Table 9).

Table 9

Correlations Among Well-Being Variables

	Life Satisfaction	Overall Health	Emotional Health	Physical Health
Overall Health	.36 p=.001 (66)*			
Emotional Health	.42 p=.000 (66)	.25 p=.020 (66)		
Physical Health	.30 p=.004 (66)	.83 p=.000 (66)	.11 p=.281 (66)	
GWB 68B (Life Satisfaction)	.48 p=.000 (65)	.23 p=.025 (65)	.43 p=.000 (65)	.18 p=.070 (65)

Kendall's Tau

*Number in parentheses equals N value

For all items on the GWB, low scores indicate low well-being while high scores indicate high well-being. The higher the total score the greater the well-being. Most of the subscales have either neutral or positive labels, for example, positive well-being or behavioral-emotional control. A high score on these subscales means more well-being or control. However for three of the subscales the label reflects the negative end of the scale. For the subscales health worry (II), depressed mood (III), and tension-anxiety (VII), a high score reflects <u>less</u> of these characteristics. In order to eliminate confusion for the reader, directional signs on the table subscales (II, III, VII) have been reversed so that it will not be necessary for the reader to make this reversal. Thus a positive correlation between depressed mood and importance of being lesbian on Table 33 means that more depression is associated with more importance of being lesbian.

Social Network Characteristics and General Well-Being

The total GWB score was positively correlated with the duration of relationships and the satisfaction with relationships (Table 10). Positive well-being (I) was positively associated with chronic illness support (r=.27, duration of relationships (r=.34, availability of network members (r=.29), general supportiveness (r=.27), and satisfaction with relationships. Health worry, concern or conditions (II) was negatively associated with duration of relationships and positively associated with the percent of health care providers in the network (r=.36). Depression was negatively associated with density of the network and duration of relationships. Self-control (IV) was positively associated with chronic illness support, duration of relationships, and satisfaction with relationships. Person-environment fit (VA), found very unreliable for this sample, was positively associated with duration of relationships and satisfaction with relationships.

Coping (VB) was positively associated with density of network, duration of relationships, and satisfaction with relationships, and negatively associated with the percent of health care providers in the network. Energy level (VI) was positively associated with satisfaction with relationships, and negatively associated with percent of health care providers in the network. Tension-anxiety-stress (VII) was not correlated with any social network variables.

Table 10

Correlations Between Social Network Variables and General Well-Being Schedule (n = 64)

	% Health Care Providers	% Kin	Duration of Relationships	Availability Network Members	General Support of Network Members	Satisfaction with Network Members	Density	Chronic Illness Support
Total GWB			.35 p=.005 (64)			.33 p=.008 (64)		
I Positive Well-Being			.34 p=.006 (64)	.29 p=.022 (64)	.27 p=.034 (64)	.38 p=.002 (64)		.27 p=.032 (62)
II Health Worry	-.36 p=.004 (62)		.27 p=.029 (64)					
III Depressed Mood			.35 p=.005 (64)				.29 p=.022 (60)	
IV Self- Control			.30 p=.016 (64)			.27 p=.032 (64)		.25 p=.047 (62)
VA Person- Environment Fit		.26 p=.040 (62)	.34 p=.006 (64)			.33 p=.007 (64)		
VB Coping	-.27 p=.033 (62)		.27 p=.030 (64)			.31 p=.013 (64)	.27 p=.037 (60)	
VI Energy Level	-.38 p=.003 (62)				.25 p=.042 (64)	.32 p=.011 (64)		
VII Tension-Anxiety								

Social network variables not correlated with the total GWB or any of the sub-scales were: Network size, support for lesbian identity, knowledge of lesbian or chronic illness identity, sex of network members, lesbianism of network members, frequency of contact, reciprocity of relationships, combined identity support, or percent of non-kin or others in the network.

Additional Analyses of Variables Related to the GWB

After examining the relationships between social network characteristics and general well-being, furher analysis was done to see if there were significant correlations between the socio-demographic, lesbian identity or chronic illenss identity variables and the general well-being of chronically ill lesbians.

Relationships Between Socio-Demographic Variables and the General Well-Being of Chronically Ill Lesbians

Greater age showed small-to moderate positive correlations (Pearson's correlation) with the GWB total (r=.29, p=.019), positive well-being (r=.29, p=.02), self-control (r=.35, p=.004), and less stress (r=.30, p=.014). Socio-conomic status was associated with well-being for two measures. Higher debt was associated with lower well-being on three subscales: depression (r=.21, p=.028), person-environment fit (r=.24, p=.013), coping (r=.21, p=.021), and energy level (r=.22, p=.019) (Kendall's Tau).

Higher social class was associated with higher well-being on the total and on five subscales: the total GWB (r=.21, p=.036), positive well-being (r=.20, p=.044), health worry (r=.21, p=.047), depression

(r=.20, p-.046), coping (r=.30, p=.003), and energy level (r=.21, p=.-35). There were no significant correlations between education or religiousness and the GWB.

Relationships Between Lesbian Identity Variables and the GWB

The composite lesbian identity variable was positively correlated with health worry (r=.34)--the stronger the identity, the more health worry. Satisfaction with being lesbian was associated with more well-being (r=.23) and less depression (r=.21). More exclusively lesbian sexual behavior was associated with more health worry (r=.23) and lower energy (r=.20).

The more important being lesbian was to one's life the more apt she was to be worried about health (r=.23), depressed (r=.28), and have less fit with the environment (r=.34), less coping (r=.24), lower energy (r=.24), and lower total well-being (r=.21). The longer she had been lesbian, the more self-control (r=.27) and less tension she had (r=.25) (Table 11).

Relationships Between Chronic Illness Identity Variables and the GWB

The composite Chronic Illness Identity Variable was negatively correlated with the total GWB (r=-.24). In other words, as the strength of this identity increased, well-being decreased. Health worry increased (r=.55) and coping (r=-.25) and energy level (r=-.41) decreased as the chronic illness identity became stronger.

The sub-variables of the chronic illness identity showed the following relationships with the GWB. Seriousness was negatively associated with total well-being (r=-.22), coping (r=-.20), and energy

Table 11

Correlations Between Lesbian Variables and General Well-Being Schedule (n = 64)

	Satisfaction with Being Lesbian	Importance of Being Lesbian	Obviousness of of Being Lesbian	Length of Time One Has Been Lesbian	Composite Lesbian Identity Variable	Lesbian Behavior
Total GWB		-.21 sig=.035 (64)				
I Positive Well-Being	.23 sig=.025 (65)					
II Health Worry		.23 .031 (64)	.26 p=.009 (64)		.34 p=.006 (65)	.23 sig=.028 (65)
III Depressed Mood	-.21 sig=.045 (65)	.28 sig=.006 (64)				
IV Self- Control				.27 p=.032 (62)		
VA Person- Environment Fit		-.34 sig=.001 (64)				
VB Coping		-.24 sig=.017 (64)				
VI Energy Level		-.24 sig=.019 (64)				-.20 sig=.047 (65)
VII Tension- Anxiety				-.25		

Pearson's Correlation

level (r=-.35), and positively associated with health worry (r=.39). Poorer physical health was associated with more health worry (r=-.41) and lower energy level (r=.33). More importance of the chronic illness was associated with lower total well-being (r=-.24), and more health worry (r=.30), and less self-control (r=.21) (Table 12).

Research Question 4: What Do Chronically Ill Lesbians Find Supportive and Non-Supportive to Their Identities as Lesbians and Chronically Ill People

Quantitative Findings

The first section will describe the significant statistical relationships between social network variables and lesbian support, chronic illness support, and combined identity support.

Support for lesbian identity. Lesbian support was significantly positively correlated with knowledge of lesbian identity (r = .59), chronic illness support (r = .36), females in the network (.46), lesbians in the network (r=.72), and non-kin in the network (.37) (Table 13). The percentages of kin and others in the network were negatively correlated with lesbian support (.29 and .26 respectively).

Results of analysis of variance among groups according to identity support (HH, HL, LH, LL) also associated numbers of females with lesbian support. Duration was negatively associated with lesbian support.

Support for Chronic Illness Identity. Chronic illness support was significantly positively correlated with knowledge of the chronic illness identity (r = .61), lesbian support (r = .36), general support

Table 12

Correlations Between Chronic Illness Identity Variables and the General Well-Being Schedule (n = 64)

	Physical Health	Importance of Being Chronically Ill	Seriousness of Chronic Illness	Length of Time Chronically Ill
Total GWB		-.24 sig=.017 (64)	-.22 sig=.024 (63)	
I Positive Well-Being				
II Health Worry	-.41 sig=.000 (65)	.30 sig=.003 (64)	.39 sig=.000 (63)	-.27 p=.043 (57)
III Depressed Mood				
IV Self-Control		-.21 sig=.041 (64)		
VA Person-Environment Fit				
VB Coping			-.20 sig=.042 (63)	
VI Energy Level	.33 sig=.001 (65)		-.35 sig=.000 (63)	
VII Tension-Anxiety				

p = Pearson's Correlation   sig = Kendal's Tau

Table 13

Social Network Variables Correlated with Support for the Lesbian Identity (n = 63)

Support for Chronic Illness	.36 p=.004
Knowledge of Lesbian Identity	.59 p=.000
Percent of Females in Network	.46 p=.000
Percent of Non-Kin in Network	.37 p=.000
Percent of Lesbians in Network	.72 p=.000

Pearson's Correlation

(r = .32), satisfaction (r = .25), and availability (.27) (Table 14). The only between group differences (HH, HL, LH, LL) were on degree of physical health.

Combined identity support (support for both identities was positively associated with knowledge of the identity) for both identities (r = .29) and negatively associated with density (r = .21) (Table 15).

The variables statistically related to lesbian support were knowledge of the identity, sex of network members, lesbianism of network members, relationship of members to the participant, duration of the relationships, and support for the chronic illness identity. Chronic illness support was statistically associated with identity disclosure, general supportiveness and availability of network members, participants satisfaction with the relationship, and support for the lesbian identity.

Table 14

Social Network Variables Correlated with Support for the Chronic Illness Identity (N=63)

Support for Lesbian Identity	.36 p=.004
Knowledge of Chronic Illness Identity	.61 p=.000
Availability	.27 p=.033
General Support	.32 p=.010
Satisfaction with Relationship	.25 p=.048

Pearson's Correlation

Between group difference among the HH, HL, LH, and LL groups revealed that the number of females in the network was associated with lesbian, but no chronic illness support. Shorter duration of network was associated with more lesbian support but not related to chronic illness support. In analysis of variance, stronger lesbian identity of the participant was associated with more lesbian support, while chronic illness identity was not associated with chronic illness support.

Qualitative Findings

In the next section, types of non-support and support for each identity will be described and examples of each will be given. Presentation will begin with the chronic illness identity and non-support since this was where the data were most comprehensive and because types of support flow logically from those of non-support.

Table 15

Correlations Between Social Network Variables and Support for Both Identities (N=63)

	Knowledge of Lesbian Identity	Support for Lesbian Identity	Knowledge of Chronic Illness Identity	Support for Chronic Illness Identity	Density
Support for Both Identities	.29 p=.004	.56 p=.000	.27 p=.011	.56 p=.000	-.21 p=.039

Kendall's Tau

Types of support for chronic illness will follow moving from least to most supportive. Next will be types of non-support and support for the lesbian identity following a similar progression. Finally there will be a presentation of conditions affecting whether behaviors are interpreted as supportive or non-supportive (see Table 16 for Frequency Distribution of Types of Non-Support and Support for Lesbian and Chronic Illness Identities).

Chronic Illness Non-Support

There were eight categories of non-support for chronic illness mentioned by participants.

Physical Abuse

There were three examples of physical abuse reported by two participants. Physical abuse is defined as direct physical action that could be generally known to cause physical harm to the recipient. The abuse occurred in response to the chronic illness/disability needs of the participant. Although there were not many examples given in the sample, it is included as a category because of its danger to the chronically ill lesbian.

One woman with a severe allergy to cigarette smoke reported being beaten by a man on a bus when she asked him to put out his cigarette. Another example was a woman traumatized by a massage offered by a drunken acquaintance at a party. A third example of physical abuse is where one participant's mother secretly fed the participant food to which she was known to be allergic.

Table 16

Frequency Distribution of Types of Non-Support and Support for Lesbian and Chronic Illness Identities

Chronic Illness Non-Support

	Number of Incidents	Number of Participants
Physical Abuse	3	2
Avoiding Interaction	19	11
Disbelief	28	13
Being Blamed	23	11
Minimizing	47	18
Maximizing	31	16
Lack of Collaboration	35	14
Unsolicited Advice	13	8
(Non-support from other chronically ill)	4	3

Chronic Illness Support

	Number of Incidents	Number of Participants
Belief in Existence	2	2
Willingness to Interact	6	4
Acceptance of Physical Basis	13	6
Normalizing		
Accepting Limits	21	16
Collaboration with usual needs	51	21
Collaboration with emergency needs	10	9
Checking In	6	6
Offering Information	4	3
Soliciting help of others	7	6
Support from other chronically ill	24	18

Table 16 (cont.)

Frequency Distribution of Types of Non-Support and Support for Lesbian and Chronic Illness Identities

Lesbian Non-Support	Number of Incidents	Number of Participants
Physical/Verbal Abuse	14	8
Avoiding Interaction	23	12
Disbelief	24	14
Lesbian as sin	19	9
Minimizing	9	6
Maximizing	2	2
(Non-support from other chronically ill)	9	8
Lesbian Support		
Acceptance of Lesbianism	16	10
Normalizing		
Encouragement to be self, develop as a whole person	17	10
Acknowledging importance of significant others	14	10
Collaboration with lesbian needs		
Discussing implications of being lesbian	10	8
Expressing feelings	3	3
Participating in gay activities	7	4
Protection from abuse	2	2
Support from other lesbians	20	12

Although no examples of ongoing battering relationships emerged in this study, it is not safe to assume that this is not a problem. The interviewer did not inquire specifically about it and the high stigma and frequency of battering in lesbian relationships is just beginning to emerge in the Bay Area lesbian community.

Avoiding Interaction

There were 19 examples from 11 participants of others avoiding interaction related to the chronic illness/disability. Avoiding interaction was defined as others communicating non-verbally or verbally that they were not willing to talk or to listen to the participant talk about the chronic illness. There were a variety of ways in which interaction about the illness were avoided.

> When I try to talk with my friend about the things that frighten or upset me, she changes the subject, has to go somewhere else, cuts me off or tells me what she thinks is the problem.
>
> I can't talk about [my disability] without my mother getting up and leaving the room.
>
> None of my well friends want to hear about the nitty gritty.
>
> When I asked my physician what was the matter with me, he never answered me. That is poor interaction.
>
> On a day-to-day basis, when it is not a crisis, people don't want to hear too much about it. I know by they're being kind of quiet until I finish up, not continuing the conversation, just letting me finish what I am saying. Sometimes people won't begin by asking me how I am right now. It is up to me to bring it up and then I have to be real careful about how much I go into it."
>
> I haven't heard from my family since I have written them about this disability stuff.
>
> When I tried to get more information from my family about when I was sick as a child, they got strange. My sister flipped out 'what are you doing, writing an autobiography?' I felt like she wanted to direct me away from it. My father pooh-poohed it.

Disbelief

There were 28 examples from 13 participants of disbelief in the existence of the chronic illness/disability. Disbelief is defined as verbal or non-verbal behaviors that indicate that one does not accept that the illness/disability exists. It may take the form of rejecting that the condition exists at all, that it has a physical basis, or that it is chronic.

Some women reported examples of others just not believing that the illness or disability existed. One woman with a hearing loss said: "When people say, 'You just hear what you want to hear,' it is a real put down, real condescending." A woman with a neurological disorder found doctors that did not believe her diagnosis. "I had to retell the whole story, all the symptoms I had when I was diagnosed. The doctor called a couple of neurologists to see if I really did."

Another woman found that doctors did not believe her symptoms had any physical basis.

> On and off for the last ten years, the doctors I have seen have told me that there is nothing wrong, that nobody has chronic headaches, that these things don't exist. They said there was nothing wrong with my joints and no reason why they should hurt. There was nothing they could to because there was nothing wrong.

One woman with a severe allergy to cats said: "People, no matter how many times I would say, 'I can't be in the house because of the cats,' they would wonder where I was. They would say I wasn't doing my part." Another hard-of-hearing woman told of how her behavior had been misinterpreted and how it was assumed that her disability did not exist.

> A lot of times people will think I can hear more than I can, and they don't realize that my hearing fluctuates. One time my cousin and I were having a fight. I yelled back at her through a closed door, although I hadn't understood what she

> had said. Later that evening in the car, she said something to me from the front seat. I was sitting in the back and said 'What?' because I didn't understand her. She said, 'You heard me this morning, why can't you hear me now. You don't want to hear.'

A woman with arthritis was not allowed to pay the disabled rate at a swimming pool although she had a doctor's pass, and had been going to that pool and doing water exercises for some time. Because she did not appear disabled, the person in charge did not believe that she was. "They figured I was trying to get by. I have to take these challenges all the time. It is real hard."

Another woman with epilepsy found herself accused of being manipulative. "I have been accused of asking for special things to be manipulative, to get attention. That is ridiculous to think that someone would be willing to do something that makes them the center of that kind of attention.:

A woman with a smoke allergy had the following experience when trying to participate in a political event. "Before the event began, we were asked if we had any disabilities that would cause us to have special physical needs. I put down extreme allergy to tobacco smoke. This guy working there laughed and handed it back and said 'Oh, no, we mean real disabilities.'"

Thus women may be disbelieved even in an atmosphere where there is sensitivity to some disabilities. One's woman's mother doubted her daughter's dietary restrictions to the point of secretly testing them. "When I was visiting my mother and explained that I couldn't eat wheat, she would use it in cooking and try to act as if she hadn't, to test me out. I got sick and confronted her with it and of course she lied. I have got to <u>prove</u> to her that I am allergic to wheat."

One area of disbelief was lack of acceptance of the chronic nature of one's condition.

> When my balance problems first started, I called people. They said 'You'll get over it,' or 'go to the hospital.'
>
> I would like a more truthful response. I keep trying to hammer it into their heads that it bothers me because of this reason or that and it isn't as easy as they see it. They say, 'get over it,' but you can't get over it cause you just can't.
>
> From the first time I went to [a theatre], my friend keeps pushing. Why don't you accept your disability. You haven't accepted your disability. She is a therapist too.
>
> They are constantly trying to get you to go to doctors, and 'Oh, I know they have a cure for that over at ---, Dr. --- is the best. And I know about Dr. ---.
>
> [Re children] It has been difficult for them to accept that this is an on-going, permanent sort of thing. They sort of saw me as sick and then well again.
>
> Once the cat was out, there was nothing anyone could do. [Still bothered her to be in there] There wasn't anything to do about the space, but in terms of me they could remember. Once they had put the cat out and done the cleaning, there was a total--we don't want to deal with it any more. While everyone else would be inside, I would just be sitting outside with all the dogs--me and the dogs. The lack of awareness bothered me more than the cat.
>
> I can't get on my lover's health care insurance. I can't afford health insurance, I didn't have any savings when I got sick. My father was afraid to get too involved with my support. They are afraid that if I am completely disabled I will end up on their doorstep, can't depend on the institution of heterosexuality. He lent me $1000 and gave me $1000. I didn't get well and he freaked out that he could be responsible for my care. He said, 'That is it. I can't give you any more.'
>
> My parents won't deal with the problems, because they are afraid they don't have any solutions, or they see the adaptations as less than perfect.
>
> People around me get sick of chronic pain, get sick of hearing one say, 'I can't do that. I am in pain.'
>
> When you have a broken leg people know it is going to end. They are more likely to support you while you are in a cast.

Some women have found that they received the most support during acute phases of their illness/disability.

> [Re friends] Whenever I have been sick they have always been there. When I had neurosurgery, my friends came to the hospital very night and I didn't ask them.

> The main thing where I have had almost 100% support is with surgery. I have been bombarded with people calling me and helping me, bringing me flowers. The week after I came home from the hospital, I stayed at a friend's house and people would come and do my laundry.

Being Blamed for the Illness/Disability

There were 23 examples from 11 participants of being blamed for the illness/disability. Being blamed is defined as verbal or non-verbal behaviors that assume that chronic illness is something bad or wrong and that put full responsibility for its existence on the participant. Often these behaviors are based on disbelief in the existence of physical limitations.

As a child, one woman learned to associate being sick with having been bad. "My mother always asked me, when I got sick, what I did wrong. And I was always sick as a kid." As an adult it is hard for her to discontinue this association.

The most common way in which women reported being blamed for their illnesses was by being told that their illnesses were psychological in nature and that they could make themselves well if they would just deal with their emotions. "With allergies there is this attitude--why don't you get yourself together and you won't have allergies. Obviously you wouldn't have this allergy if you had your head together."

Another reported,

> I have been teased for years, told that I am a hypochondriac. People would say, 'You sound like a little old lady, you are such a hypochondriac.' It is hard for me to tell what people

> are putting down. Is it the fact of having these things, not being healthy, or is some of it talking about it and allowing it to effect your life?
>
> People say, 'You must want to be sick,' and I want to kill. Then my lover accuses me of being obsessed with my illness. These are real hard issues. What is the level at which a person is responsible for their own health? People have the idea that you brought it on yourself, that you want to be sick.

The woman with some undiagnosed illness had this experience.

> Because the tests were negative, they wouldn't validate that I was still sick. They told me it must be psychological, depression. They asked me if I was depressed. 'I am still sick, yes I am depressed.' They wanted to turn it around and say that I was really sick <u>because</u> I was depressed. That was the worst in my health care experiences.

Another woman found her friends' judgments unsupportive. "With friends it is hard. Some of them have judgments that I have come up against. They believe that we create our own realities. They ask what it is about my emotions that I got this illness. It is an insidious blaming of the victim."

When trying to get the medication she needed for her neurological disorder, one woman got this response: "He kept asking, would you like me to put you down for a psychiatric consult?" A woman with chronic back pain suggested that the role of emotions could be considered without blaming the ill person for causing the illness/disability.

> Things said in an accusatory way could have been said differently. A woman who said I was delaying healing by holding in feelings could have said, 'you can help the healing process by finding a way to process your feelings about it.' Then I would have told her about my isolation. What she was saying was that I was having trouble because I was bad.

A diabetic woman said:

> I get blamed a lot when I have bad insulin reactions--when I am out of control, and I don't like it. At diabetic camp, the attitude was, you can control this disease. Those who were losers then are dead now. Lots died of self-hate because they

> couldn't live up to that image. They believed they were bad people, and they were only little kids.

Minimizing the Illness/Disability

There were 47 examples from 18 participants of minimizing the illness/disability. Minimizing is defined as verbal or non-verbal behaviors that indicate that one views the chronic illness/disability as having less impact, being of less importance than the participant believes it to be. Comments that fail to recognize the pervasiveness or seriousness of the condition or that fail to validate the limitations imposed by the illness/disability were classified as minimizing the illness/disability.

There were examples of people minimizing the impact of an illness or disability. When discussing the illness that had led up to her disability, one woman found that "my father was really trying to minimize my having the disease. He said, 'Well, you were out of school a couple of weeks and that's all there was to it.' I know they drove me 80 miles a day to therapy. That was a big deal!"

A hearing impaired woman found that her parents tried to minimize her disability. "They have a lot of trouble dealing with it, that they have a hard-of-hearing daughter, and that I have problems because of it. They would much rather believe that everything is perfect. 'You can hear on the telephone, so you can do _anything_ you want.'"

A woman with rheumatoid arthritis also found her family had a difficult time appreciating her illness. "My parents don't take it seriously, they can't. They want to deny it because they can't deal with it. My brother doesn't take it too seriously either. He doesn't know what to do." A woman with lupus found her mother saying, "It is just arthritis." She doesn't see it as an important thing in my life."

The tendency to minimize is not limited to parents however. Relationships of friends, lovers, and health care providers are also affected. A hearing impaired woman found it disturbing when friends minimized the importance of what they were saying. "A lot of times when I know someone is saying something that is not very important, and they have already repeated it three times, I will smile and say, 'forget it.' But if somebody else says forget it, I am not going to forget it. You repeat it. My hackles rise."

Another woman said, "My old lover viewed my disability as an inconvenience." A woman with food allergies had difficulty with roommates respecting her needs for special foods. "I finally found a margarine without whey or milk solids. My roommates are always using my margarine and putting theirs on my shelf or they bake something for all of us using their margarine."

"When people find out I am diabetic they say 'I am trying to give up sugar,' but they miss the point. It is not that I want to give it up, it is that I have to give it up." One woman who had been seriously ill for several years and had tried many types of treatment without success had this experience of non-support.

A woman whose skin reaction is a symptom of her systemic disease found that "my doctor like to write on my skin and watch it turn red. He thinks it is fun." A woman with several diagnosed and undiagnosed health problems felt discounted when her doctor said "You look like the picture of health" after she had just spent a half hour telling her all of her symptoms.

In contrast, another woman with a relatively visible partial paralysis on one side felt unsupported when her friends told her to just not worry about it when people stared at her on the street. "To walk down the street and have people look at me funny, I go nuts inside. I wish I could explain to them how it felt. I was told growing up to have a smile on my face and be courageous. I hate that. I was also told that if you had two hands you wouldn't do any more. You can do anything you want."

A woman with diabetes found being told "you can lead a normal life" was not supportive to her as someone who had to remember her insulin, carry extra sugar for insulin reactions, etc.

Sometimes the minimizing took the form of joking about behaviors related to the illness/disability. A woman with chronic back and leg pain from an injury told this story. "One woman whom I have known for a long time teases me about my shoes. I wear one kind of sneakers. She says, 'Why don't you get cowboy boots. You would look so great in cowboy boots.' I <u>can't</u> wear cowboy boots because they cause me pain. No matter how many times I say that it doesn't get heard."

A woman with allergies said, "I got a lot of chiding because of my allergies and doing different diets. People always make fun of me."

"I was worried about going someplace because I couldn't wear a dress because I can only wear running shoes and they would look funny with a dress. I was told to stop talking like that, that I was being ridiculous. That was not supportive."

"The jokes get to me--about me being a klutz, being forgetful, not being able to talk right. It depends on my medications, what I've eaten, whether I am tired."

Maximizing the Illness

There were 31 examples of maximizing the illness from 16 participants. Maximizing is defined as verbal or non-verbal behavior that makes the illness/disability the major focus of attention or the most important attribute of the participant. This attention is viewed by the participant as more than is necessary or as inappropriate to meet current illness needs.

Non-supportive behavior can also be a method of maximizing the illness. Rather than avoiding, not believing, or minimizing the illness and its impact on one's life, the illness can become the major focus of attention.

> In social situations [it is not supportive] to be making a big deal about the fact that I am having a hard time hearing.
>
> Diabetes is a small part of who I am. Don't take it and magnify it. People grab on to what is different--they introduce me 'She is a diabetic.' That is all people see. People say, 'am I going to catch it?'
>
> The two or three times I have gotten very ill and become the center of everyone's attention instead of the 13 years I have had this disease. They don't seem to realize we could live our lives in the hospital but we choose not to.

One woman with asthma found it non-supportive to have people constantly watching over her, trying to anticipate an attack. "It is too much sometimes. I say when I feel it coming on I'll tell you. If I cough or use an inhalant, they say, 'Is something the matter?' No, I'll tell you. I can tell when it is going to happen."

For a woman with a neurological illness, her illness became a way for others to discount what she had to say. "This woman has explained away some of my sincerest attempts at communication by my having this disease. Because I have this bizarre neurological condition and I take strange drugs, I have no credibility."

The same woman, when applying for a job, told her potential employers she had a neurological condition. The woman's response was, "Great, we can use you to fill our quota for hiring the handicapped."

Sometimes seriousness was overestimated. "[My friend] got really panicky the first time I told her what was wrong because she had another friend with lupus who was terribly, horribly, seriously ill.

Lack of Willingness to Collaborate in Meeting Illness-Related Needs

There were 35 examples from 14 participants of lack of willingness to collaborate in meeting illness-related needs. Lack of willingness to collaborate is defined as verbal or non-verbal behaviors that indicate that one is not willing to change their usual ways of behaving to accommodate the illness/disability needs of the participant inspite of being aware of these needs.

Illness and disability needs exist within a social context. The meeting of needs often requires cooperation of others. Lack of willingness to change one's behavior in order to help accommodate needs was seen as non-supportive. A woman with lupus said this lack of responsiveness is "one of the biggest problems I have with friends. When I say I need to take pills now, if I need their cooperation to get at them, they will say 'in just a minute,' and 30 minutes later they still haven't done anything. I have tried to explain this, yes, but they mostly don't listen very well."

A woman with a severe cat allergy spoke of when friends excluded her from a special celebration by deciding to have it in an inaccessible space. "I was in tears for two days over the whole thing. Something finally came through, but I had to go through these feelings alone." A woman who had recently had surgery for her disability had this experience. "My parents were talking about whether to bring a wheelchair and said, 'Oh no, we don't need it, why bother.' They would leave me in the car when they would go shopping rather than get the wheelchair out. I felt completely alienated at that point. That was probably the worst thing that has happened in my whole life with them.

Non-support was experienced when people required frequent reminders of the need for their cooperation in meeting disability needs. "I am constantly telling people what I need because they will forget from one minute to the next. I am constantly trying to keep my temper down. I have been working with these people for two years. They should know."

Refusal to help was experienced by a diabetic woman who wanted others to learn to give her a shot so they would be able to give her emergency drugs if she was unable. "People who have never learned to give me a shot are not supportive. I _have_ to do it and you cringe and won't learn."

Another hearing-impaired woman brings up the question of whether some people lack understanding or if the issue is unwillingness to change their own behavior. "A lot of people will realize that I am hard of hearing, but they don't realize what that entails. A lot of people just sort of never get it, they just never understand it or they are just not willing to put out the effort."

A woman with smoke allergies was told by a smoker, "Why don't _you_ sit by the window. _You_ are the one that needs air."

When asked for examples of 'neutral' behavior in relation to support around the chronic illness (versus supportive or non-supportive), women told of people who were helpful only after being asked.

> I don't feel like some people have an overview of what my needs are and they don't spontaneously remember it. They are basically willing to accommodate, but I have to ask for it.
>
> I tell friends what I go through but they don't have too much response. They don't treat me any differently or offer anything. I am puzzled by that and sometimes feel betrayed.
>
> They never check in with me. If you ask them to speak up, they will do it pretty often.

Unsolicited Advice

There were 13 examples from 8 participants of unsolicited advice. Unsolicited advice is defined as suggestions one makes concerning the illness/disability without being asked and without a complete or accurate appraisal of the entire situation. It is often seen as a taking-over of the situation based on the assumption that the chronically ill/disabled woman is incapable of making her own responsible decisions.

> People say, why don't you learn sign [language]. I say if I sign will you understand what I am saying?
>
> One friend was of the opinion I shouldn't take the drug I do because her mother had my illness, took the drug, and died of a stroke. Only she didn't really have the same illness I do.
>
> They are not believing me that I am a responsible adult and that I am actively trying to deal with my health. I appreciate new information, and they can suggest something new, but don't push, like you <u>have</u> to go. You <u>have</u> to get a hearing aid. It is funny how hearing aids don't help in nervous disorders, they make it worse.
>
> The biggest problem is people's attitudes--assuming what I need and don't need--that they know better than I. They assume what I can and cannot do.
>
> If someone takes away my responsibility for what I need and don't need, I get very angry. Or they decide what I should do rather than letting me take my chances.
>
> Your are eating candy? You aren't supposed to do that [while having an insulin reaction]. It makes me very, very angry that they don't take into consideration that I am thinking

> about what I am doing. People assume I don't know the facts when I start to eat something.
>
> I don't want somebody jumping in all the time. A lot of time parents would do that at a party. I would be talking to a friend of theirs and my father would stand near by and make remarks to me. Oh, he said. . ., he said. . ., annoying.
>
> Judging--trying to take over my life, because I have to be taken care of. I hide my disability because I don't want someone to take over my life.

Two disabled women gave examples of times when they had tried to take over responsibility for another disabled woman. They realized later how on-supportive these behaviors had been.

> I tried to get my diabetic friend to eat just one small piece of birthday cake--'it won't hurt you. I have known other times you have eaten it. Why not this piece now?' I was tying to be nice.
>
> My lover is in a wheelchair. When she is transferring sometimes I get afraid she will fall, so I give her a shove. She doesn't like it. I have to learn to keep my hands off even if it makes me anxious. I understand it is a very touchy subject helping the disabled because I am disabled <u>and</u> I have tried to help.

Chronic Illness Support

Four major categories of support emerged from interview data in response to the question "What do you find supportive of your chronic illness/disability in your relationships with other people?" They are presented below with definitions, frequencies, and examples.

Belief in Existence in Chronic Illness

There were two examples from two participants of belief in the existence of the chronic illness/disability. Although this is a small number, it is included as a category because higher levels of support may be predicated on this belief. Further research should be done to see if this belief is a taken-for-granted assumption for someone judged by the participant to be supportive.

Support for a person's chronic illness begins with an acknowledgment that one does have a chronic illness. In examples of support, there was generally an unspoken assumption that supportive others did not question the existence of the illness or disability.

Willingness to Interact

There were six examples from four participants of willingness to interact. This is defined as verbal or non-verbal behavior indicating that the person is interested in talking with the participant about the illness/disability with the intent of learning more about the participant's experience with illness/disability. Such interaction can provide a beginning of development of a supportive relationships.

People who were supportive were those who demonstrated a willingness to discuss illness/disability issues. Although it may have been only a beginning of developing a supportive relationship, interaction itself seemed to be a basic beginning. "There is one woman friend I feel doesn't help me enough. She is questioning how able-bodied she is herself. But thank God we are talking about these issues."

An openness to learning more about her disability was seen as supportive by one woman. "One guy initiated it by saying 'I notice you wear a hearing aid. What is it from? How did you lose your hearing?' I told him. I am very happy to talk about it."

Acceptence of the Physical Basis of the Illness

There were 13 examples from 6 participants of acceptance of the physical basis of the illness/disability. Acceptance of the physical basis is acknowledgement of physical causation of the illness rather than assuming that one's problems are caused by psychological or other limitations.

There appear to be a variety of ways in which supportive others demonstrate that they have an understanding and acceptance of the chronically ill woman. "She supports me by saying that I do have arthritis. She won't say that I am just lazy."

Normalizing

Normalizing the experience of living with a chronic illness/disability is a major category of support. There were a total of 87 examples of such behaviors. Sub-categories of normalizing are encouragement to accept one's illness-related limitations and associated feelings and collaboration with the participant in meeting illness-related needs.

Encouragement to Accept One's Limitations and Associated Feelings.

There were 21 examples from 16 participants of encouragement to accept one's illness-related limitations. Encouragement to accept limitations is verbal or non-verbal behavior that allows the participant to acknowledge the full extent to which the illness has an impact on her life. This category includes the expression of feelings related to being ill.

> I live with a nurse who says to me that it is time to take a nap, and I do.

> I was talking with a friend about passing as non-Jewish. I said, 'You know, I have been passing as able-bodied in my community for a long time.' She said, 'Yeah, you know you are not able-bodied.' I am getting a lot more validation for saying that.
>
> If I have a severe migraine, my boss will say 'You poor baby, go and lie down and put warm compresses on your eyes and neck, darken the room, and if you don't feel better tomorrow don't come to work,' because she gets them too.
>
> My friends don't care how I walk or what I can't do. They are more accepting of me than I am.
>
> It is real easy for people to expect me to be able-bodied and do certain things. In the past I would go ahead and do those things and hurt myself. Now I say 'No, I can't do that,' because of the influence of my friends.
>
> [My lover] is real matter of fact. Your limitations are what they are.
>
> I talked with other disabled women at a workshop on sex and disability. We talked about having limitations to our physical being, accepting them and asking for help around them. It has been really nice.
>
> When I visit them, there is no expectation that I am an able-bodied person able to do everything. There is an expectation that I help, but if I need to rest, that is O.K.

Allowing for the expression of one's feelings about being chronically ill was viewed as supportive.

> She [lover] is supportive of me being maudlin about it.
>
> When my hearing is so bad I can hardly hear, she'll let me call up and cry and moan and tell her all my worst fears that I am never going to hear again, I will lose my job, I am never going to get a girlfriend. She won't challenge it, she will just listen, she won't push it. She will say, I am not even aware of what she says, she just makes me feel better. It is not threatening to her. She knows that only part of me believes these things. She still has faith in me without pushing. That is why she is #1.

Collaboration in Meeting Illness-Related Needs Non-Emergency Situations. There were 72 examples of collaboration in meeting health-related needs. Collaboration is defined as working with the participant to help meet illness-related needs. One way is by taking some responsibility for changing one's own behavior to facilitate the meeting of needs. There were 51 examples from 21 participants of collaboration in routine situations and 10 examples from 9 participants of collaboration in illness-related emergency situations.

Going beyond understanding and acceptance of limitations was demonstrated by willingness to work with the ill woman around her limitations and seemed to require an absence of minimizing or denying limitations. At the same time there was no maximizing them so that they became the central focus of interactions. This appeared to be a normalizing process.

> If I say, 'I can't go to the beach because I can't walk on the sand,' she says, 'We can go anyway, we can just stay on the blanket.' This feels supportive, that we have his consideration but we don't have to treat it like a limitation. Come on, let's go to the beach anyway. Sometimes people have been really willing to do that.
>
> In a restaurant where I couldn't hear the waitress three items, she would quietly repeat the menu to me without making a big scene out of it. She would interpret for me. She and her husband were very easy going and did not make a big deal of it, yet they weren't patronizing.
>
> When I have been struggling all day with pain, sometimes I just don't want to have sex. Some women have felt really rejected. My current lover now says, 'Of course you don't.' We might not have sex or do it in a way that's easiest on my body.
>
> Around my illness, what I really want and expect from people is that they put up with my limitations. There are so many things I can't do, places I can't be. I don't stay out late, I have dietary restrictions, I can't be around cigarette smoke.

> My lover is willing to go to the movies because it is low output, when she really wants to do something more energetic--take a walk instead of play tennis--watch TV instead of going out on the town.
>
> It's supportive when people are willing not to smoke around me.

A woman whose back problems make it impossible for her to sit tells of this example of normalizing.

> I have a date for dinner tomorrow night. We are going to do it at one of our houses rather than a restaurant so I can stand up.
>
> She is willing to accept responsibility for things if I can't do them, or let them slide and have that be O.K.
>
> She always speaks clearly and she will repeat things 100 times for me without making faces or exasperated sighs. She will always buy into my world view of it. She has lots of hidden disabilities too, like allergies. She is always there.
>
> When people call me up on the phone and want to see me and make plans. I want people to call me up, say they miss me, let's make plans.
>
> If we are going on a long car trip, before we leave, she will ask if I remembered my meds, makes me check. She always has a quart jar of water so we don't have to stop, but because the doctor says I should stop every 100 miles and walk around, she stops. It was the least painful trip I have taken. They are supportive in some ways that are obvious and some that aren't. She will throw an extra pillow in to help me with posture. She yells if I don't take my pills and stops at a drug store for aspirin--remembers it before we leave. She is good about it if I tell her I have to do something, there is immediate action.
>
> Some of the others depend on what the problem is and whether it can be fixed without any real strain to them.
>
> People have to be willing to do things for me sometimes--like ask someone not to smoke, to wash dishes, to listen to me complain.
>
> A woman with dietary restrictions:
>
> Some people go out of their way and have vegetables instead of chips.
>
> If people want me in their life a lot they have to be willing to learn.

Providing Material or Physical Support. Sometimes collaboration involves physical or material support.

> When I need help with physical work, some people will help and I will feel no subtle judgments that I am not doing enough.

> My partner is paying for room and board. She is most supportive of me in physical ways.

> She is sympathetic to my condition and she helps if something is too heavy. She'll help carry the heavy things or open things for me.

> My ankles sometimes give out. I get a little warning. I really appreciate it for someone to take me by the elbow when we're walking.

> When my muscles are weak, sometimes just sitting down or walking along helps more.

Emergency situations. Being willing to participate in helping one meet special needs becomes particularly important when situations are potentially life threatening. "My co-workers know exactly what to do for me when I have a bad asthma attack."

A woman who could need emergency injections if she becomes unconscious:

> Supportive people are those who are willing to learn how to give me a shot.

> When I am at an event I almost always have someone there who knows exactly what my medical problems are. I believe in safety.

> I ask people what I looked like during a reaction. If they can give me feedback, they are paying attention.

> The nurse takes command of the situation. When I was sick in the hospital, she came in and would check. She always made me feel like everything was going to be O.K.. 'It's O.K. honey, everything is going to be fine.'

> I need to do things with someone who knows about the treatment I am on, so if I get dizzy and collapse, she will say stop and rest now not later.

Other examples of collaboration fall under the subcategories of checking in, offering illness-related information or feedback, and the soliciting of other's help in meeting illness-related needs.

Checking in. There were six examples from six participants of checking in. Checking in is the active seeking of current illness-related information from the participant. In contrast to making incorrect assumptions about what one needs, the process of checking in was seen as supportive. A woman with arthritis told:

> I need for people to make sure I can keep up with them if I am doing something active.
>
> People who don't make assumptions about what I can and can't do on a particular day are supportive. She asks and then follows through with it.
>
> Sometimes it is helpful when my partner reminds me to take a pill. I don't really need that, but find it endearing.
>
> The supportive will check in, like is this a bad day for you, or oh, it must be hard for you.

Offering illness-related information. There were four examples from three participants of offering information. Offering information is the sharing of knowledge that one can use in the management of the illness.It was found supportive at times to offer women new information or even advice, if it is done without negative judgments.

> You can make suggestions and not say that the person is fucked up for not having thought of it themselves--or assume that the person has not thought of it themselves.
>
> It helps if people check in to see if you want to hear ideas.
>
> A close friend said, 'I notice you aren't getting a lot of the jokes because you have trouble hearing voice inflection.' [The same friend] would give me positive feedback, like 'I thought you dealt with that well.' When I had problems, she was available to point things out.

> [My partner] has really helped me understand some of the ways [my illness] affects the way I feel and behave and think. It is sort of an intimate thing since I have always been so private about having ([my illness]. I wouldn't let anyone tell me it was time to take a pill, leave me alone about it. I feel less lonely because somebody else knows and understands, sometimes a lot better than I do. When I am being affected, I am so busy being affected that I don't have much self-observation. She can objectify it later, by putting it into words rather than the gray, hazy, fuzzy feeling I had awhile ago. Her describing my behavior brings to my consciousness how that felt and helps me understand how that behavior or feeling is a discreet effect of my illness.

Soliciting the help of others to meet illness-related needs. There were seven examples from six participants of soliciting the help of others. This involves being an advocate for the participant by asking others to change their behaviors in order to better meet the participants illness-related needs. Women have found it supportive to have others act as their spokesperson in getting help from others.

> My friend was right there letting them know that they have to understand that this is a permanent thing, that I am not getting sick and getting well again, but that I am disabled and they need to help me in ways they haven't before.

> When I was in a wheelchair my partner would drag my chair all over and just get other people to do all sorts of things.

> I love it when somebody else brings it up. I am sick and tired of always being the one. I love it when someone who has never had asthma, out of the sheer goodness of their heart, says, 'Why don't we not smoke at this meeting?'

Relationships with Other Chronically Ill/Disabled

There were 24 examples from 18 participants of the special support from others who are also ill/disabled. Some of this data emerged spontaneously while some was in response to asking "Do you know others who have this illness? What is that like for you?"

Support

With others who are ill/disabled there is more interest in discussing the details of day-to-day life with the illness, symptoms, fears, and experiences with treatments and coping strategies.

> I have one friend who is disabled and has trouble with her feet--is housebound in a wheelchair. I have had this real sense of indulgence because we can just sit and talk for hours. The operation I was supposed to have and didn't get was the same one she had. She got out her surgical reports and we went over them. It was so indulgent, really a pleasure. I would like to have more friends who have disability issues.

> There may be little questioning of the reality of the illness.

> [My friend] is sympathetic because she has some of her own arthritis. If I talk about it, she will listen and we share symptoms. She recognizes that it exists and supports that it does.

> I have a close friend who is asthmatic. She is very supportive on not being down on yourself.

> This one friend I have who has allergies has been validating to me.

> I get to places where I wonder if it is worth it. I need to be around other differently abled people. They can tell me it is worth it, that struggling is O.K., and that there are other people who feel like I do.

> I have one friend who has been very emotionally supportive, because she also has allergies. I talk to her on the phone quite a bit [talks re difference between talking on phone once a week and living with someone].

> There is a woman who lives in the apartment [where she is staying now] who has a similar disability. Here I feel supported.

> I feel a comraderie with people I see on the streets who have arthritis.

> Attending a disability group can be supportive.

> It was very uplifting to go to the group at first. Just the sense of identification, and that was very comforting.

> In the group we are able to share things with each other. I don't know if the group will always be something I need but right now it is a growth process for me.

Association with others who are ill/disabled can provide a normalizing atmosphere where special needs are taken for granted and disability loses its meaning.

> I am beginning to want to reach out to more people with epilepsy. There are more epileptics in my life now. We talk about our fears, history, what we have heard as children, what we can and cannot do. It's a real supportive thing. We had a campout for disabled with able-bodied as attendants. Everything was set up for us. All of a sudden our disabilities weren't disabilities anymore. I realized how many things I enjoy and can still do. I just need a little extra help.

Contact with similar others can offer an opportunity to share what one has learned about dealing with disability.

> [During an interaction with a woman becoming deaf, she had forgotten that this was true.] Talking in the car in front with the other woman, I realized she wasn't participating in the conversation. I started to lean over so she could see me, and she started to participate. O.K. I know what she needs. I told her you have to be really assertive about it, because this is a new thing for her. It was a long time before she got a hearing aid. I talked to her for about an hour. I have found that ___ works, you might find that something else works better.
>
> I felt really good, that I was able to help her. Later I thought maybe I was being a know-it-all, but a mutual friend said she really like it. It was helpful to know other people were dealing with it, it made it easier for her. I felt real good that I was able to pass that on, helping someone else in ways I had been helped before.

This woman expresses some positive and negative aspects of her association with others with her same neurological disease.

> The illness support group has been a source of frustration, but I must get some support because I have been going for two years. Maybe I give more than I get. A lot of people call me for support. Maybe in giving that I get something back that is supportive to me.
>
> If someone really wants information it is useful for me to be someplace visible. I can share information about things I had to figure out myself.

For some, contact with more visibly disabled women has proven to be a source of unexpected support. Coming to the interaction with the expectation that they might not <u>really</u> be disabled or disabled enough, they seem surprised to find validation for their own less visible problems.

> [At a women's music festival] I found that disabled women had no problem validating me as disabled. They are in chairs! If I say I am disabled, they say, oh. That made it a lot easier for me. If a woman in a chair doesn't have a problem saying that I am disabled, it is easier to validate myself. It certainly is a different issue being in a chair.

Non-Support

However, it cannot be taken for granted that contact with similar others will be experienced as supportive. It may provide increased awareness of one's vulnerability or negative role models.

> I get frustrated when I see others with the same disease and it has gone to their head--affected their mental function. I hope that doesn't happen to me.
>
> Everybody else in the disability group was a mess, all very depressed, having tremendous problems with the material world because of their disabilities.
>
> One friend is diabetic too. Sometimes I don't feel very supported by her. She doesn't take very good care of herself.

Lesbian Non-Support

Six categories of non-support emerged from data in response to the question "What do you find non-supportive of you being lesbian in your relationships with others?" There was a total of 91 examples of non-support given.

Physical and Verbal Abuse

There were 14 examples of physical or verbal abuse from 8 participants. Two of these incidents were physical while 12 were verbal abuse. Physical abuse is defined here as physical action that causes or has the potential to cause physical harm to the participant. Such physical action is provoked by the lesbian identity. Verbal abuse is defined as comments that devalue the lesbian identity. They may be made to the participant directly or in reference to other lesbians or homosexuals.

> [An ex-boyfriend] had a bad reaction because I was involved with a woman. He got very angry. He didn't direct it at me but at my stuff--threw a bottle and broke the glass on the painting.
>
> [Straight male house mate] tried to kill me, threw a coffee cup at me. I feel like the attack was partly because I am a lesbian. He called me a 'fucking dyke!'

Women had also experienced verbal abuse.

> People yell out of cars at us, but nobody has beaten us with a bat for holding hands in the street.
>
> Being called a dyke on the bus.
>
> If they say homophobic jokes in front of me.
>
> My boss[female] says, 'That's why I hate hanging around lesbians. All they ever do is talk about women. I want to talk about men.'
>
> My landlord says gay people bored him, he didn't want dykes renting from him because they were unavailable [sexually].
>
> One person at work came back from a meeting complaining about all the flaming faggots.
>
> My son wishes I were straight. He takes shit for it out on the street.

> I have a fear of being on the streets, being attacked. It is really hard to tell what is because I am a woman and being lesbian. I think most of it is because of being a woman, but there are times I feel more vulnerable because of being lesbian.

> It is very different to be with someone when it is a woman instead of a man in terms of how safe it is to be out in the world--to find places we can go folkdancing and be able to dance together when we get there.

For some, these fears prevent full disclosure of their lesbian identity.

Avoiding Interaction

There were 23 examples from 12 participants of avoiding interaction. Being unwilling to engage in conversation about the lesbian identity was seen as non-supportive.

> My family doesn't want to talk about it. Straight friends don't want to talk about it either. They don't care. It is not important to them.

> When I came out to my mother, she didn't even want to talk about it.

> My sister is not thrilled about talking about me being a lesbian.

> My father is generally non-supportive of me. It is an absence of anything. I was in a 5-year relationships--as far as he knows, I still am. I think he sort of accepted that his daughter married another woman, but he won't say anything positive about it.

> I get my [writing] work rejected most of the time and get meaningless feedback--'You need not have spelled out these women's [lesbian] relationships.'

> One woman just doesn't want to hear about it.

> My sister doesn't want to be forced to have to deal with my gayness with her friends. She cut me off when I was asked why I moved to San Francisco.

> People say I tell too much about my problems. They wish I would be more private. [Old straight friends] really didn't want to hear about [me being a lesbian].

> [Straight friends] invited me over for my birthday. They talk about their lives, but don't ask me about mine, don't want to hear it, not the details.
>
> Now I'm not coming out so I don't lose my job.
>
> I think a lot of people [at work] are just denying the fact that we have been together so long--that it means anything other than buddies.
>
> My mother won't admit it's not O.K. with her. She doesn't tell people because it seems irrelevant. It wasn't irrelevant to tell people when I had a boyfriend.
>
> My mother had no reaction to me going to the gay parade. They dismiss it, are very uptight about it.

Disbelief in Lesbian Identity

There were 24 examples from 14 participants of disbelief. Disbelief is defined as verbal or non-verbal behavior that indicates tht an individual views the lesbian identity as non-existent or rare, temporary or changeable. The belief in the non-existence or rarity of lesbianism is also known as the heterosexual assumption. Some examples are assuming that one is heterosexual or that lesbians do not exist or are rare was deemed non-supportive.

> New people in the office assume that any male picture setting on a females' desk is either her child, boyfriend, or husband. Sometimes it bothers me.
>
> When referring to a group of students, the teacher said, 'We don't have lesbians here. I have only seen two.'
>
> It is hard when people are shocked. How could you be a lesbian? I have known you all my life, you are too feminine, you are not the stereotype.

Belief that the lesbian identity is temporary, a passing phase, is shown in the following examples.

> People say it's O.K. to have these feelings if you don't keep on being consistent that way. They think these are teenage crushes, not stable, just a phase. I think they are homophobic.

> My ex-boyfriend says, 'It's a passing phase. She doesn't know what she wants.'

> [Parents] say it is a phase, she has not excluded men yet so there is nothing to worry about. [A woman who identifies as lesbian and as bisexual.]

> Parents think 'It's O.K. for her to be depraved and fool around with women as long as she eventually gets married and settles down.'

> My father stepped in to make an excuse for me when the family was teasing me about not being married, like I haven't met a man who was rich enough.

Attempts to change the lesbian to heterosexuality are seen in the following examples.

> My parents would always say 'You need to find the right man.'

> My father read psychology books about it. When I would be in trouble with my lovers, he would say 'Maybe you should try men.'

> My friend has to grill me every time she sees me, 'Maybe you haven't found the right man.'

> People pick up that I am going through a relationships crisis and say, 'Well, maybe you should try men.'

> People think it is because no man is interested in me, or I had a bad experience with a man, or I am afraid of rape. That is what my mother thinks.

Lesbianism as a Sin

There were 19 examples from 9 participants of lesbianism being viewed as smoething bad, immoral, sinful. Viewing lesbianism as morally wrong was considered non-supportive.

> My parents are fundamentalist Baptists and [they believe] I am going to hell.

> With straight friends there is the issue that we are lesbians and whether that is bad.

The fear of this judgment was given by some as the reason for not revealing their lesbianism.

> I don't come out to my friends who have children. I wonder if they knew they would worry about us with their daughters. I don't want to raise their fears. It's a sin in the back of lots of people's minds. They think we are child molesters.
>
> She would not be able to comprehend that we are lovers. She thinks my lover is a good person, and for her gay equals bad.
>
> I have a super straight friend who hasn't been able to deal with my illness. She is Catholic and says she will pray for me. I think if I told her I was gay, she would say the same thing.

Minimizing the Consequences of Being Lesbian

There were nine examples from six participants of minimizing the lesbian identity. Minimizing is defined as a lack of appreciation of the impact of being lesbian. Verbal or non-verbal behaviors that indicate that one does not understand that lesbianism is disapproved of by many in our society (even in the Bay Area), or that being lesbian can affect many aspects of one's life are classified as minimizing. Rejection by significant others, especially one's lover, is an example of minimizing the scope of lesbianism by not accepting that lesbians, like everyone else, have close, intimate relationships with others.

> You just don't know what it is like until you are there. [Straight friends] say 'Why are you making such a big deal about it [about being a lesbian]. This is a real open community.' It is not. There are more gay people and public consciousness, but it doesn't mean people like it or want to deal with it.
>
> There are two friends we spend lots of time with we deliberately haven't come out to. We're afraid one, who is such a blabbermouth, that she would tell my boss just in passing conversation--not to be malicious.

Lack of Understanding. Demonstrating one's lack of understanding about the meaning of being lesbian was seen as non-supportive.

> Sometimes straight friends say something in ignorance, they don't get it. It's not homophobia so much as lack of education of what it is to be lesbian in this society.

Lack of understanding of how much being a lesbian may be a part of everything one does was non-supportive.

> I feel like in every conversation, everything I do, something is missing because I know that people aren't necessarily perceiving that I am a lesbian, even if they already know I am a lesbian.

> [My sister is good.] She talks about it, but there's a point where she doesn't understand it.

> When I tell straight friends, there is so much explaining.

Rejection of Lovers and Friends by Others. Women have experienced rejection of their lovers as non-supportive.

> My father said he didn't want my lover staying at his house.

> When my lover and I visited my father and sisters, they didn't deal with us, they talked around us. They didn't make much effort to include her--or me.

Maximizing the Lesbian Identity

There were two examples from two participants of maximizing the lesbian identity. Maximizing is defined as viewing the lesbian identity as the primary, inclusive identity that has specific proscriptions for many other areas of one's life.

> I want it to be okay for me to be who I am even if sometimes it is PI (politically incorrect). I don't want to be told how to be a good lesbian at all times.

Lesbian Support

Two major categories of lesbian support emerged from interviews in response to the question "What do you find supportive of being lesbian in your relationships with others?"

Accepting Lesbianism

There were 16 examples from 10 participants of accepting lesbianism. Accepting lesbianism is defined as verbal or non-verbal behavior that indicates a person takes for granted that one is lesbian rather than assuming heterosexuality, that one will remain lesbian rather than passing through a lesbian phase, or that lesbianism is no less desireable than heterosexualtiy rather than trying to convert one from lesbianism to heterosexuality. Acceptance of one's dress may also be seen as acceptance of one's lesbianism.

> Not giving me a hard time about being lesbian.
>
> I can talk to these people and they won't say, 'It's because you are gay that there are problems.'
>
> Not having to worry about dressing the way I want, not being made fun of for that.
>
> I like it when people look at me and smile when I wear my leather jacket. It is usually gay men.

Sometimes support was experienced without total acceptance by others of the lesbian identity.

> My family has been very accepting. My mother wrote a great letter. She didn't understand exactly, but she would be right there by my side.
>
> My father will be behind me no matter what I do. But he doesn't really want to talk about it or think about it.

Normalizing Lesbianism

Beyond basic acceptance of the existence and acceptability of the lesbian identity is interaction with the participant that normalizes this identity by acknowledging the realities of being lesbian without minimizing or maximizing this identity. Subcategories include encouragement to be oneself and develop as a whole, unique person, acknowledging the importance of relationships with significant others and collaborating in meeting lesbian-related needs.

Encouragement to be oneself and develop as a whole, unique person. One subcategory of normalizing is encouragement for the participant to be oneself and develop as a whole, unique person. There were 17 examples from 11 participants of encouragement to be oneself. This category is of behaviors that reflect understanding that one's lesbianism is important but not one's whole identity and encouragement to develop one's own unique self.

Some women associated lesbian support with encouragement to develop their own individuality with her lesbianism recognized as a part of who she is.

> The relationship I have with my partner has allowed me to find my strengths, to learn who I am, become who I want to be.
>
> I get encouragement for being independent, figuring out what I want.
>
> There are a lot of roles, but there is a lot more chance for people who are willing to question them and come out of them.
>
> My children support me for being who I am. I think there times when they consider themselves (at least the two living with me) quite lucky having the mother they do. They like me as a person.
>
> People who are supportive of me whichever way I go [re sexual orientation].
>
> I have the space, permission I created and has been created for me to be myself, to find myself, and become myself.
>
> I guess the need I have, that is fulfilled, is for the people closest to me to know, and not just to know but to accept that that is a part of me.
>
> She has treated me like her own kids. She is real supportive of me, period. No matter who I am involved with.

> When I was having a relationship crisis, I came out to a co-worker. He is supportive in that he cares about me as a whole person. I feel safe. It is clear there is no stigma about me being lesbian. He say, 'I am sorry. I still care about you, and if I can be in your life, I will.'

Acknowledging importance of relationships with significant others. There were 14 examples from 10 participants of acknowledging the importance of relationships with significant others. Acknowledging importance is defined as verbal and non-verbal behaviors that include sigificant others of the participant. Most examples dealt specifically with participant's lovers.

> With parents we never really talk about it, but they know. When my partner called my parents while I was visiting them, they told her 'You know, --- loves you very much.
>
> [Mother] would ask me about [my relationships with my lover].
>
> If I am talking with someone straight, she can talk about her boyfriend and I can talk about my girlfriend--that we can talk about love relationships.
>
> Being able to talk about lovers, relationships, political things.
>
> If I meet someone and they are really happy--O.K., it's wonderful.
>
> People supporting the idea of me having a lover--being excited if I say there is someone I am interested in (rather than saying 'oh,' or 'that's nice,' and changing the subject. I have gotten those responses too.
>
> My mother would ask about my relationship with my lover.
>
> She would invited my lover over with me.
>
> My family accepting friends as part of the family.
>
> My kids now call my partner's parents grandma and grandpa sometimes. They take the kids on their own little trips.

Collaboration in meeting lesbian-related needs. There were 20 examples of collaboration. Collaboration in meeting lesbian-related needs is defined as behaviors where one takes an active role in helping meet lesbian-related needs. Such needs include opportunities to discuss positive and negative aspects of lesbian relationships and feelings related to being lesbians, participation in gay rights activities, and protection from abuse.

Opportunity to discuss implications of being lesbian. There were 10 examples from 8 participants of this type of support. One woman found it supportive "being able to talk about lovers, relationships, political things." Another woman finds being able to discuss the issues of coming out and other's negative stereotypes of gays helpful. "It is such a tough area. We talk a lot about it. It helps. We talk together a lot."

Expressing feelings about being lesbian. There were three examples from three participants of expressing feelings about being lesbian. "When I had big anxiety attacks about going into women's bookstores, she helped me work through the anxiety.

Participating in gay rights activities. There were seven examples from four participants of participating in gay activities.

> When I told a straight woman I was working for, she showed no signs of dismay, went with me to see a lesbian show, and let my lover and I stay at her house when my father didn't want us staying there.
>
> My parents have gone on gay marches with us.
>
> Co-workers supported gay political work I was doing because it was important to me.

Protection from physical and verbal abuse. There were two examples from two participants of protection from physical and verbal abuse.

> My sister told me her husband was real homophobic. I could do what I wanted, but he would probably be really weird abut it and try to keep me from seeing her daughters--so I have never dealt with him.

Relationships with Other Lesbians

Support

There were 12 examples from 7 participants of others being supportive just the fact that the other person was lesbian. Creating a lesbian environment seems to provide a buffer between these women and the larger society.

> My world is so lesbian. Of course it is supportive because I mostly hang out with lesbians. I have chosen to live here because it is one of the places one can be a lesbian and not so afraid for their life.

> I am so used to feeling comfortable with my lesbianism, it is hard to identify a lesbian support system from just the life I have created.

> Where I live there is a social structure set up for you. There are always lesbians there on some level for you if you need them, if you need to talk.

> Most people in my network who are supportive are lesbians.

> I don't really have a problems because I shelter myself.

> They are all supportive of me being lesbian because they are all lesbian.

> I am real connected with the women's community so I am very sheltered. My therapist is a lesbian, so I am sheltered that way.

For two women contact with other lesbians has been so extensive as to begin to erase the larger societal stigma and the women have begun to perceive sharing this identity as an asset to their lives.

> As far as being lesbian, I am usually around lesbians in my social life. I make that choice a lot. I am not that aware of other sorts of attitudes.

> Here I either work for dykes or with dykes. It isn't even an issue. Housing hasn't been affected by it. I am out to my [health care provider]. It has worked for me, not against me.

There were another eight examples from seven participants that being lesbian in and of itself is not enough to be considered supportive. They must also feel positively about this identity.

> It is not that they have to do something for me to be supportive. Who they are is supportive because they are lesbians and they are out and they talk about positive stuff about lesbianisms.
>
> Lesbians who don't feel very ambivalent about it, who have very little hangups about being lesbian, who aren't embarrassed--they are supportive.
>
> We all [groups of lesbians] assume we through different stages of being in and out of live--the drama of being a lesbian.
>
> She has recommended me for jobs reviewing gay writing. I could talk from my heart about what I was reading in a school classroom [gay literature class]. I can't tell you what.
>
> It's supportive to have lesbian friends who are willing to try out fantasies of how things could be different. We were talking about eating alone--started a supper club--one person cooks once a week, others come over and eat, cleanup, and leave. We don't spend the evening together because we are all too busy. It is the beginning of forming a community that is really important to me.
>
> The kind of support I need from lesbians is permission to be politically incorrect sometimes. For example, with this questionnaire, I was really impressed. Although it was for women who identify as lesbians, it had questions about [heterosexual] fantasies. It was really good that you saw those questions could be relevant. I have been trying to allow myself to have fantasies about men when I want. I want it to be O.K. to be who I am even if sometimes it is P.I. [politically incorrect]. I don't want to be told how to be a good lesbian all the time.

Non-Support

There were two major areas mentioned where lesbians experienced non-support from other lesbians. It was non-supportive to think that one would reveal someone else's hidden lesbian identity. There were two examples from two participants.

> My supervisor was gay and very closeted. That's part of why I got fired. She was afraid I would blow her cover.

> Someone claimed I had told a big name professional that she was a dyke. Because of knowing I am a lesbian, and homophobia, she assumed it was true.

The other area of non-support was making judgments that there was just one correct way to be a lesbian, whether it be monogamous, uncomplacent, political, or separatist. There were six examples from five participants.

> I have been sleeping with strangers. I find myself with other lesbians who are condemning me.

> Some lesbians feel complacent, like they have already arrived and don't need to go any further.

> We can't seem to meet other lesbians. We're not quite as cause oriented as we're supposed to be.

> There was a group of lesbian separatists who outwardly hated men a lot where I was when I was trying to figure out what was going on with me. It wasn't permitted to be feminist unless you were a lesbian and agreed with their ideas. I left because I knew I couldn't figure it out with that pressure.

This could be particularly difficult for women just beginning to identify as lesbian.

> Initially I got a lot of non-support from lesbians who didn't think I was one--including my lover. That was massive enough that I wasn't sure I was until I broke up with her.

Relationships with Health Care Providers

Although information about support and non-support of health care providers was not elicited unless health care providers were listed in the network, some categories of support began to emerge from the limited data. For each category I will give examples of support followed by evidence that absence of that characteristic was perceived as non-supportive.

Holism

Health care providers who were perceived as having a holistic approach were seen as supportive. This included allowing time for discussion of emotional issues. There were six examples from five participants of holistic approaches.

> [Re therapist] When I talk about my disability, she is absolutely 100% supportive. She is another one that I can go on and on about it with. Sometimes I get embarrassed when I go on and on abut my feelings. If I tell her I am embarrassed, she says it is O.K., the embarrassment is my own thing.

> [Re health workers] I need someone to work with ongoing, someone who knows me, what I am going through, who I can tell what is coming up for me emotionally in my life so she can work with all that energy that is there more explicitly and consciously.

> We have spent a lot of time talking about my fee and she [the therapist] says that she feels really bad about it too. I am in pain. She has heating pads.

Also included was acceptance of lesbianism and of one's significant others.

> [Re health care provider] I was out with her from day one, identified myself as a lesbian and talked about my lover. She is not at all homophobic, didn't bat an eyelash, very understanding, compassionate.

> One time I was sick, in the ER for eight hours, and they wouldn't let [lover] in.

There were four examples from three participants that lack of a holistic approach was non-supportive.

> When I am blowing it, I need help right away--someone to sit down and say, 'What is going on in your life?' My doctor says if you don't take care of yourself, you will be dead in two

> years. I know that, but I don't know what to do for the moment. I need someone knowledgeable about diabetes as a way of life versus diabetes as a disease.
>
> The nurses took my wheelchair (and any hope for mobility) away from me. The bathroom was not accessible.

Respect for One's Knowledge

Respect for the woman's knowledge about her own body and needs was also seen as supportive. There were three examples from three participants of respect for one's knowledge.

> My doctor writes prescriptions ungrudgingly, he was always real helpful about suggesting new stuff and he was real encouraging for me adjusting the dose I took. 'If you think you need more I will write the Rx for more.'
>
> [Re doctor] He really stops to listen about what hurts and where it hurts and when it hurts, which is sometimes the most important thing of all.
>
> [Re doctor] I know what is going on inside my body and if I will tell him he will adjust the prescription. He is really good about that. Sometimes 50 mg. benedryl makes me sleepy at work, sometimes it doesn't, so he wrote it for 25 mg. caps and I can take 1, 2, 3, 4 at a throw.

Lack of respect for the woman's knowledge was seen as non-supportive. There were five examples from three participants.

> Once when my blood sugar was high because of an infection, the doctor gave me a dextrose IV. I needed salt water. I told him and he said I didn't know what I was talking about. On the next shift, they changed it and I got better. I could have been dead.
>
> Doctors think they are gods. They get two months about diabetes and think they can do it.
>
> I had 18 hours of severe pain and he wouldn't come to see me. Then my legs and hands stopped working. I said I need you to come see me, he said no and ordered more demerol. When I finally talked to him later, he said I was just depressed. You are a woman and you are depressed. That wasn't the case. I had a lot of pain and couldn't move my arms and legs. I guess it's just not recognizing the whole situation.

Availability

Availability of health care providers was seen as supportive. There were three examples from three participants of availability.

> My homeopathist is a sincere healer, she has studied my case. She doesn't get back to me in a few days after I call full apologies. One day I was in a crisis. It wasn't her day to work, she came in to treat me. I am paying low end of the scale.
>
> There was a time when I could make it near but not to her [therapist's] house. she came and not me. Now she is keeping my time open even though I can't get there. If I can find a ride over to --- she will do what she can to see me at another time.

Willingness to Admit Own Limitations and Encourage Use of Other Resources

There were seven examples from four participants of willingness to admit limitations.

> [Doctor] came out, told me it was a great mistake, he was very sorry he had ruined my arm. He was real good about it, about being honest.
>
> I am very honest with them and they have been really honest with me.
>
> [Re medical treatments] The results haven't been great, but the interaction has been good, and I still correspond with these people.
>
> [Re health care providers] I would really appreciate it when they would finally say, 'I don't think I can help you. I don't really understand what is going on.'
>
> [Health care providers are] supportive when they have a basic understanding that going after a problem from a lot of different approaches can give you a faster and more thorough solution--that different ways of healing have different virtues--you might as well get them all.
>
> Some of them have been respectful of the other disciplines. My chiropactor, who I love, he is really all for the surgery. He is against surgery in general, but he thinks that this one is a wonderful thing.

In contrast, doctors who are not receptive to seeing other practitioners may be seen as non-supportive. There were three examples from three participants of this.

> I have experienced professional jealousy because I have been to so many different kinds of practitioners. I think this osteopath was mad after I also went to see a chiropractor.

How Being Both Lesbian and Chronically Ill Affects Support and Non-Support

Increased Vulnerability to Non-Support

There were eight examples from seven participants of how these two potentially stigmatizing identities interact to increase one's potential or actual experiences of non-support. In six of these examples, disapproval of the lesbian identity seemed to provide the basis for non-support of the chronic illness. Because the woman was a lesbian, she was denied chronic illness support. In two examples, it is not clear which identity precipitates non-support for the other, only that being both increases the woman's vulnerability.

> I know I get more hassles on the street being a visible lesbian. I am worried about having to get into a fight--wrenching my back again. There is more vulnerability with the two going on.
>
> I was kicked out of nursing school because I was honest about my disability and about being gay. I was told that nurses have to be able-bodied and straight too.
>
> This guy [a co-worker] had the idea that he didn't want to be friends, he wanted to be lovers, and that wasn't going to work so he immediately started to use my hearing against me. He would be talking to someone else about work and I would come up and try to join the conversation, and he would immediately start talking in a soft voice and refuse to repeat things.
>
> Problems with the illness may be attributed to the lesbianism.
>
> When I say I can only hear higher voices, I invariably hear 'that's hysterical hearing loss, you just don't want to hear men 'cause you want to be a dyke.'

> My mother is convinced that if I were living with a man who had a lot of money I would have a bed that wasn't on the floor and then I would be a lot better off. They are not supporting me. As a matter of fact, when I asked for my piano from them because my hands were in pain, they wouldn't give me my piano because I am a lesbian.
>
> They are withholding support from me because of their lack of support of moral issues, and that is more important to them.

Increased Potential for Support

Ironically, although being lesbian increases vulnerability to non-support for one's chronic illness from some sources such as relatives, co-workers, and teachers, it may, at the same time, provide access to sensitive support from within the lesbian community. There were 16 examples from 11 participants of perceptions that the lesbian/women's/gay community was more sensitive to and supportive of disability issues than was the mainstream, heterosexual society.

> The community is attempting to have a consciousness about disability. It makes it a lot easier.
>
> I find lesbians to be a lot more sensitive [about disability]. Lesbian groups are now saying they will move meetings to wheelchair accessible places.
>
> In a group of lesbians, I would feel like it would be possible (not comfortable) for me to stand up and challenge, do what I need to do to get my needs met.
>
> I have found that in gay situations, mostly gay men and lesbians, people tend to be more accommodating for some reason. There is more of a recognition. 'Oh, you are hard of hearing. That means I have to do this and this.'
>
> There is something abut lesbians and disability that in general is quite important. I do experience the lesbian community as feeling a need to address issues of disability more than other general communities, in a way that is less humiliating and more helpful.
>
> There is a lesbian community. I am not sure there is such a cohesive straight feminist community. I have a lot of resources for support. All these women with political understandings of problems.

> The lesbian community is the only one that has done anything abut disability issues.
>
> When I first saw your ad, I thought somehow there has to be some consciousness come about in the feminist community in general about disability--hidden or otherwise.
>
> I know a lot of differently abled women who become lesbians first because they do love women, but who also prefer the support of the women's community which, shitty as it may be, is a hell of a lot better than it is in the straight world.

Standards for dress in the lesbian community have made it easier for a woman with environmental illness to accommodate her disability needs.

> It is more acceptable in the lesbian community to wear all cotton clothes, no make-up, no nylons--the kind of clothes I have to wear anyway. The part of the lesbian community I have contact with is generally more conscious. They don't use a lot of scents, whether for the same reason or not.

Because of her chemical sensitivities, she found not having to use birth control is an advantage of being lesbian.

> One thing that being a lesbian makes easier for having environmental illness, that has to do with sex. All birth control methods are intolerable for people with EI, except maybe some can tolerate skin condoms. All the rest are petroleum products. That was a major problem for me when I was in a straight relationship.

Although there was a definite sentiment that there was more support and potential support from the lesbian/gay/women's communities, there were limits to this support. Several social situations common to the lesbian community in the Bay Area were found to be inaccessible because of illness/disability needs. There were six examples from five participants of inaccessible lesbian activities.

> [Because of smoke allergy] for years I just couldn't go to the things dykes go to. I still can't go to bars. I couldn't go to places where you meet other lesbians. I was <u>very</u> isolated for many years.

> We had lots of potlucks, so there are lots of quiches. People don't have enough money to make something like a chicken dish, so they make something cheap, vegetable dishes with cheese sauce. I am allergic to cheese.

> At lesbian potlucks I get picked on because I eat a lot of lettuce.

> I can't go to the bars like lots of lesbians do because of the smoke.

Participating in vigorous physical activities for some was viewed as an expectation of a proper lesbian. Lack of understanding about chronic illness limitations was not supportive.

> You mean you don't climb mountains and swing across streams on ropes? What kind of a dyke are you? You are not on the softball team. Why don't you drive?

Conditions Affecting the Interpretation of Behaviors As Supportive or Non-Supportive

Participants had been asked to identify behaviors that were supportive and non-supportive to their identities. Typologies of non-supportive and supportive behaviors were developed from these examples.

Upon further examination of the typologies, it was discovered that similar behaviors had sometimes been classified as supportive and other times non-supportive. For example, reminding someone to take her medications was seen by one participant as a willingness to recognize her limitations and collaborate in meeting illness-related needs. Another woman saw such reminders as intrusive, maximizing her illness identity by taking over and treating her like an irresponsible child rather than a responsible adult.

In order to understand this phenomenon, the investigator examined the contexts of these similar behaviors and found that there were six conditions that seemed to affect the determination of support or non-support. These conditions include visibility/obviousness of identity, chronicity of the identity, the variability of the identity, the timing of the supportive/non-supportive behavior, the intimacy of the relationship, and characteristics of the participant and the potential supporter.

For the most part, no specific questions were asked in order to elicit information about these conditions. Rather, it emerged spontaneously within descriptions of supportive and non-supportive behaviors.

Visibility/Obviousness

One of the conditions that emerged was visibility. Although having a low visibility chronic illness or disability was a prerequisite for inclusion in the study, there was still variability in these dimensions. Thirty-one percent of the sample was not sure how long they would have their illness, and responses to the visibility question (How visible/ obvious is it that you are chronically ill) ranged from very to not at all. Three women wrote that there was high variability in the obviousness of their illness.

From interviewing two women who had experience with both visible and invisible illness/disability, it was apparent that they saw visibility affecting the amount of support they received.

> I get a lot more support for my legs when I am in a wheelchair because it is more obvious.

> People don't understand that I feel different inside. I don't look different. I get moody and forgetful from the medicines. With my chair it is obvious I have special needs and people accept it easier. They don't accept it when I am not in the chair. When I am on my feet, it is obvious I can move. The same people treat me differently.

> I would like to see a support group for hidden disabilities. I think my epilepsy affects my life more than my visible disability.

Six women with less visible conditions think they might receive more support if their conditions were more visible.

> They would be supportive if I was having something that was causing obvious pain. They would be supportive if it were visible.

> She has no empathy for the pain and struggles I have been through. She has lots of visibly disabled lesbian friends she hangs out with and then won't support me when I'm sick. Somehow I don't qualify--I am not disabled enough--not physically disabled.

> You don't have to come out about diabetes. No one has to know. Of course that might kill you.

> Lots of people question whether epilepsy is a disability.

> We need to stop separating visible and invisible disabilities and the feeling that invisible isn't real.

Chronicity

Although all participants stated they had a chronic illness or disability, one-third were unsure of how long they would be chronically ill. Four were enthusiastically involved in treatment regimens or spiritual belief systems that also helped them believe that they would get better.

> If you're born blind, by the time you are 30 you've accepted it. It's different if you're disabled from birth or get disabled or sick later on in life. That is much harder to accept. It takes years to accept physical limitations. I feel like it is not necessary for me to accept this. For some things there are no cures, but there is no reason for me not to get well that I can see. I don't know how long it is going to take. I haven't been diagnosed with something incurable.

> I keep thinking if I do the right thing long enough, I will get well. I am impatient to get on with it. It has bee 4½ years. I feel sorry for myself. Why do I have to be in such misery.

Variability

The symptoms of illnesses and, therefore, what the individual needs for support may vary greatly. There were eight examples from six participants of variability as a condition of support.

> The hardest thing about filling out these forms is that it changes with the day, week, month. It is hard to summarize.
>
> I have varying degrees of functioning depending on which set of symptoms is happening. That means I can't be depended upon to do what I say I am going to do, or be anywhere I say I am going to be. It can change. I can wake up fine and be sick at 5:00. I can't count on anything--make plans for sure.
>
> There are so many inherent difficulties in the relationship with my lover--me as a sick person and her as a well person. What we need to do to make it worthwhile is to have some good vacation time to play together. I build up a lot of stress about my ability to do that since I can never be sure how I will feel.
>
> I'm not social. I'm not really good at putting out all the time where I am and what I need.
>
> Variability in my condition is very real. If it varies at all there is a question of reality about it. Some days I go where lights (that can precipitate seizures) are, some days I don't. I used to get a lot of shit at school for using a chair some days and some days not. I can't tell you three days ahead if I will go dancing Friday. I don't know how I will feel, how tired, how my medicine is affecting me.

For one woman who is just beginning to define herself as both lesbian and bisexual, there is a similar need for understanding of the variability in her sexual orientation identity.

> For those I am close to, support is on the level of helping me deal with these things. Are they going to be supportive of me whichever way I go? What I define as supportive are people supportive of me working it out.

Timing of Support

Timing of support is another condition that effects whether a specific behavior is perceived as supportive or non-supportive. There were five example from four participants of timing affecting support.

> If my hearing is bad, we will try to communicate more non-verbally or write notes. Like a person in a wheelchair trying to walk, I am always trying to hear, so if I have that last resort, if it gets too uncomfortable for all of us, we can write it down. She seems to know when it is the right time, or when I ask, she will whip it out automatically.
>
> [Re friend] She is very sensitive to how much I can hear. Most of the time she is hands off. If we are in a group she sits back and lets me deal with it myself. That is good. I don't want somebody jumping in all the time.
>
> [Re a man with decreased vision] We talked about our disabilities. Just to be able to share that was really nice. In a situation where I was having a hard time understanding the boss, he finally interprets. Sometimes butting in is very inappropriate; other times it is very helpful. He is able to sense when it is helpful and when it is not.
>
> My friends know exactly what to do if I have an attack. It's great. They just take over.

Intimacy

There were four examples from four participants. Because of the complexities of being supportive of one chronically ill lesbian, the intimacy of relationships becomes important. It is within the context of close, open relationships that information related to conditions and the support needed are most likely to be understood, accepted, and accommodated.

> Unless I am really comfortable with a person, I won't ask for help. I will struggle to do something. It is a bigger struggle to ask for help.

Characteristics of Participant and Potential Supporter

Each person comes to the interaction with certain characteristics beyond those of the two identities of interest. Some of the relevant characteristics of the respondent as well as the potential supporter emerged spontaneously when examining data for conditions affection perception of support. One is each individual's ability to be supportive of herself. This may be affected by the amount of self-examination that the person has done of issues that arise from being lesbian and having a chronic illness/disability.

> I tend to devalue myself. My friends say I am too hard on myself. They are more supportive of me than I am.

Another is one's basic values concerning independence, dependence, and interdependence.

> My personality is that I don't need any help. I take charge. I have never been sick before. I realize how I am dependent on medications.

A complex picture of support emerges when one considers the actual behavior, the visibility, perceived chronicity, and variability of the condition and the timing of the offered support.

> It is hard to work out what comes from what. They [symptoms] are probably all interrelated.
>
> With diabetes people only see if you eat sugar or not. You can't correlate it. Some days I have to eat it and some days I don't. It is not that clear. It is real hard.
>
> If I am forgetful, have trouble walking, it could be my medicine, being tired, what I've eaten.
>
> People who haven't experienced it don't know what you can and cannot do. People in the elevator ask me what floor I want, like they can't imagine that I can push the button. On the other hand I have had people watch me struggle to do something over my head. People don't understand how complicated things are.

I never realized what a handicap diabetes is till I had a very good friend who was diabetic. There were lots of things we had to struggle through. I thought you just shot up and everything was O.K.

CHAPTER V

DISCUSSION

The purpose of this investigation was to describe the social networks and social support of chronically ill lesbians. Also, it was designed to explore the relationships between social network characteristics and the psychological well-being of that population.

Sixty-six chronically ill lesbians completed questionnaires about their social network and general well-being. Twenty-two of these women were also interviewed concerning what they found supportive to their identities as lesbians and chronically ill.

The discussion below is organized around five major themes:

1. The researcher, the chronically ill lesbian, and stigma;
2. Social network characteristics of chronically ill lesbians;
3. General well-being of chronically ill lesbians; and
4. Conceptualization of non-support and support for stigmatizing identities of chronically ill lesbians.
5. A conceptual model for identity support and general well-being of chronically ill lesbians.

The Researcher, the Chronically Ill Lesbian, and Stigma

Acknowledgment of the potential stigma of being lesbian and chronically ill was crucial from the very beginning of conceptualizing this research project. As the investigator was planning this research project, the most frequently raised question was how would she obtain her sample? It is a critical question for any research, for if participants cannot be found, the research cannot be done. For this study it was a particularly relevant question since potential participants were being sought because of two identities they possessed that they might want to keep hidden.

It is questionable whether this research could have been done by an outsider. There are many potential barriers to studying such a sensitive area. Women who have been misunderstood and mistreated because they are lesbians and/or chronically ill may be understandably reluctant to reveal these identities to a stranger and risk further non-support. Although the researcher did not routinely inquire about what difference, if any, it made to participants that she was also a chronically ill lesbian, several women commented that they would not have participated if that had not been the case. There were two dramatic examples of the importance of the researcher being an insider. Two potential participants interviewed the researcher extensively about her credentials. One woman was particularly interested in how findings would be presented both within and outside the lesbian community. She had participated in other research wherein she felt misrepresented. Another woman requested references for the researcher from the disabled lesbian community to assure herself that the researcher could be trusted to do fair and sensitive research.

Issues like these were manageable because the researcher was aware of problems with previous research done on lesbians and was well established within the lesbian and disabled/chronically ill lesbian community both professionally as a researcher and personally as a participant in a disabled lesbian group and numerous activities supportive of chronically ill/disabled lesbians.

As an insider, the researcher was able to advertise herself as such when soliciting volunteers to participate in the study. This may have provided a sense of safety through identification that allowed some women to choose to participate who might not have done so otherwise.

The development of questionnaires and interview questions for the study was influenced by the researcher's knowledge of lesbian life styles and by living with an invisible chronic illness. Options on multiple choice questions reflected knowledge of the diversity among chronically ill lesbians. Because of her sensitivity to the issue of stigma with chronic illness as well as lesbianism, the researcher was able to provide an interview atmosphere supportive to acknowledging needs that may have previously been unconscious or hidden. One strategy for providing this safe atmosphere was as follows: If a participant shared an incident that was similar to one the researcher had experienced, the researcher sometimes shared that she too had had a similar experience. This sharing was done only after the participant had raised the matter so as to not inadvertently force the data in certain directions. This strategy allowed some participants to become increasingly honest, self-reflective, and specific about support and non-support as the interview progressed.

Another strategy used both to maintain the well-being of the researcher and to increase the comfort of the participant was to reveal at the beginning of interview that the researcher might need to take time out during the interview process to deal with her own chronic illness. Although measures were taken to prevent researcher bias because of her insider status, it is possible that it had some unfavorable influence in addition to positive ones. A strategy for future, similar research might be for team research including people who are insiders and outsiders working closely together. It might still be necessary to have insiders conduct the interviews to assure participant ease of disclosure.

Because the investigator is an insider in the world of the chronically ill lesbian, being both lesbian and chronically ill, questions of objectivity of the findings were carefully examined. All interviews were transcribed in total including all comments made by the researcher as well as her thoughts, feelings, and reactions. The interview process was carefully critiqued to assure that the researcher was not biasing the type of information elicited.

By acknowledging and clarifying her own experiences, ideas, and biases related to support and non-support as a chronically ill lesbian, this researcher attempted to avoid forcing the data in directions that were congruent with her own experiences. Any time the researcher became psychologically uncomfortable during an interview, the situation was analyzed to determine if the discomfort was due to threats to her preconceived notions about support and non-support. Every effort was made to provide a safe atmosphere for participants to express any ideas without experiencing judgment from the researcher.

The researcher participated in ongoing discussions with experts in the area of social support as well as qualitative analysis to verify validity of emerging conceptualizations.

The Lesbian Identity

For this study, the lesbian identity was conceptualized as having several components. The selection of these components was based on

themes in the literature on lesbian identity. Components included the actual lesbian sexual behavior and feelings, belief about the healthiness of being lesbian, the importance to one's life of being lesbian, the obviousness of this identity, and satisfaction with being lesbian.

The average woman in this study found her lesbian identity to be a satisfying, healthy, and an important part of who she was. She was not exclusively lesbian in her sexual behavior or feelings within the last year. Half of the sample had exclusively homosexual feelings, while 85% were exclusively lesbian in their behaviors. This findings is similar to other research (e.g., Browne, 1983; Moses, 1978).

It is clear from the literature that there can be great variation among lesbians on each of these dimensions of their identity. Some lesbians have sexual fantasies and activity with men while others do not (Moses, 1978). Some believe being lesbian is a healthy choice while others believe they are sick because they are lesbian (Ettorre, 1980). While for some lesbians this identity is very central to who they are, others see it as relatively unimportant to their overall identity and their lives (Ettorre, 1980). Some go to great lengths to hide their lesbian identity by withdrawing or passing while others make it obvious that they are lesbian (Moses, 1978).

Some women have known they have been lesbians since a very early age, while others come to the identity late in life. Thus there can be great variation in the length of time one has been lesbian (Ettorre, 1980).

Women who fully accept their lesbianism as healthy and satisfying may be those least threatened by the idea of discussing it and, therefore, most apt to self-select into a study such as this one. This sample may represent a very small part of the range of existing attitudes toward one's lesbianism.

This group of women, because of the unusually supportive social environment of the Bay Area, may have available resources for developing positive beliefs about being lesbian to counter the negative attitudes pervasive in the society at large. Applying Goffman's analysis of stigma (1963), there may be less discrepancy between their actual social identities and the attributes that others ascribe to them.

This study brings into question Goffman's assumption that certain attributes, such as homosexuality, are inherently stigmatizing since these women find this trait to be both healthy and satisfying. Becker (1973) described deviance as a process that involves breaking a rule established by a group with power to enforce the rules. This analysis can be used to speculate about how it is that these women can possess such positive attitudes about a trait generally detested. Blacks are another devalued group, although more visible, who have broken rules by taking pride in their color. If a social network does not have rules against being lesbian and has some power to enforce this perspective, the lesbian identity can take on a more positive meaning.

An attempt was made in this study to create a composite variable to measure the concept of lesbian identity. This measure incorporated the previously mentioned dimensions. The length of time as a lesbian was considered for inclusion, but was omitted for the following reason. It was clear that women were using different criteria for answering the question when asked in the phone interview how long they had been lesbian. Some immediately answered "all my life," while others calculated from the time they realized they were lesbian. Others stated a number of years without indicating on what they were basing that response. Thus it was unclear what this variable was really measuring. The dimensions used were weighted equally. Other researchers have not used such a composite and, as a result, there is no data available to determine how much weight each component should have. Although there are many definitions of lesbian, perhaps more specific questions could be asked depending on the focus of the research. For this study of social networks and social support, knowing how long a woman had been disclosing her lesbian identity to others might have been more useful information since this is the time actual support and non-support for her as a lesbian would begin to be experienced. Since there are different ways and degrees of disclosure, this might need still further specification.

All of the dimensions used in the composite were more highly correlated with the composite variable than with each other, indicating that the composite may capture a new variable that is different from its component parts. Such a composite variable may prove useful for providing a more reliable measure of lesbian identity than single measures. This analysis may also be useful for future researchers in selection of which lesbian variables may be most appropriate to measure for a particular study.

Chronic Illness Identity

The chronic illness identity was conceptualized for the purpose of this study as including the degree of physical health, the seriousness

of the chronic illness, the importance to one's life that one was chronically ill, and the obviousness of the chronic illness. There is support for the importance of these dimensions in the chronic illness literature (Sexton, 1983; Zola, 1982).

There is evidence that chronic illness is a significant factor in the lives of these women. While their health status varied, most found being chronically ill important and the illness serious. Only 29% were employed full-time and 21% were collecting disability insurance.

Relatively low income as compared with O'Rourke's sample could be partially due to inability to work full-time because of illness/ disability as well as student status and other unknown factors. The unemployment rate of this sample was 14% as compared with a national rate of 7.2% reported on November 7, 1984 in the San Francisco Examiner.

These dimensions were combined to form the composite identity score. Although length of time was considered as a possible important variable, it was omitted from the positive score for the following reason. This measure, like the length of time one has been lesbian, may not have been specific enough to be a meaningful measure. For some women, there was no medical diagnosis for some of their health problems, making it more difficult for them to determine what condition they had or how long they had had it. Variability and fluctuation in symptoms resulted, for some, in a long process before they were officially diagnosed or came to believe that they had a chronic health condition. More specific questions of time since diagnosis or the onset of symptoms or the time since one has thought of their condition as chronic would provide more useful information. For this study it might have been particularly useful to know when participants first started telling others that they had a chronic illness, or first started telling others about their special needs related to the chronic illness. Again, the dimensions were weighted equally. There is no data available to determine how much weight each should have.

It was found that correlations of these dimensions with the composite variable were higher than correlations with each other. Thus this composite measured a new variable, called here chronic illness identity, that is different from its component parts.

The highest correlations among these variables were between seriousness and importance (r=.47, p=.000) and between seriousness and obviousness (r=.40, p=.000). The correlation between obviousness and importance was .23 (p=.034). Thus seriousness and obviousness relate to importance. Although causation cannot be inferred from these statistics, it is important to consider the implications of the correlations with obviousness. When an illness or disability is less obvious there is more room for ambiguity about the implications of the illness for one's life. Zahn (1973), Marcella Davis (1973), Jeffery (1979), Eisenberg (1982), and Romano (1982) all point up the greater risk for having a devalued self-concept when one possesses less visible and more ambiguous health conditions. Data from this study demonstrate that this sample may be in such an ambiguous position since seriousness and importance of the illness are not necessarily highly correlated with obviousness.

Chronic illness has many more components than a medical diagnosis. The composite variable used here, or modification of it, may prove useful to future researchers attempting to measure the complexity of the chronic illness identity.

Social Network Characteristics of Chronically Ill Lesbians

The social networks of these chronically ill lesbians were predominantly female and composed of friends. On the average, network members were evaluated as important, available, and supportive. For the most part, relationships were satisfying and balanced. Although relationships were basically balanced, participants tended to do a little more for network members than members did for them. Perhaps participants did more to compensate for feeling like they had less to give because of their illness. Another possible explanation is that women tried to do more for others most of the time so that when they needed support during a medical crisis, others would owe them. There also may be, in relationships where the other does not have a comprehensive understanding of the identity, less encouragement for the participant to share her life experiences. In sharing less she may feel as though she is giving more understanding than she is receiving.

This sample has larger social networks than Norbeck's (1981) with an average of 16 versus 12 people listed. The higher number in this study may have been because this study elicited supportive and non-supportive people while Norbeck's asked for only supportive others. The samples are similar in terms of frequency of contact with network members (This study 3.3, Norbeck, 3.6) but duration of relationships was shorter for this sample (3.9 versus 4.4).

There were important differences between the Norbeck sample (1981) and the present sample in terms of he relationship between network members and the participant. While the percent of friends in the network was similar (this study 47%, Norbeck, 43%), relatives accounted for 36% of Norbeck's sample and only 20% in this study. Therapists and other health care providers were more apt to be listed in this study than in Norbeck's (this study 4.3% and 4.3%, Norbeck's .8% and .9%).

There are several possible reasons for these differences. Relatives may represent less supportive relationships for lesbians with chronic illness and therefore be more apt to have been dropped from one's immediate network. Lewis' research (1979) indicated the trend for lesbians experiencing severe oppression to establish friendship networks that served as extended family. She also found that lesbians commonly experienced problems with their parents' understanding, acceptance and approval. Often parents view lesbianism as an illness.

The composition of friends and family is consistent with Albro and Tully's study (1979) wherein lesbians feeling isolated in the heterosexual macroculture turned to the homosexual microculture for social interactions, emotional support, and friends. There may be less involvement with relatives because this sample tended not to be married or have children. Health care providers may be more important to women who have chronic illnesses and therapists may be important for managing the stress of living with these stigmatizing identities.

General Well-Being of Chronically Ill Lesbians

When compared with the Rand samples (Ware, 1979), this group of chronically ill lesbians had lower psychological well-being. This was consistent for every item on the GWB schedule. The subscales wherein lay the greatest differences were health worry and concern, behavioral-emotional control, and tension-anxiety.

It is consistent with the chronic illness identity that health worry would be higher in this sample of chronically ill than in the healthy Rand sample. In comparison with O'Rourke's sample (1981), again the chronically ill lesbians had lower general well-being. High tension and anxiety could be related to living with two potentially stigmatizing identities or to other unknown factors. It cannot be determined from this study how much each identity contributed to lower well-being than in other samples. However, this finding does substantiate that this group may experience lower well-being than populations whose physical health is good and whose sexual orientation is unknown or assumed to be heterosexual.

Although there is no equivalent data available on the mental health of other lesbian/chronically ill women, the mental health of this sample as measured by Questions 59-67 of the General Well-Being Schedule appears good. These women actively use mental health services and their friends for help with emotional problems. Perhaps their willingness to seek such help explains why few have been in-patients on mental health units or had nervous breakdowns. It is reasonable to expect that these women, because of the stress of living with two stigmatizing identities might need the support of mental health professionals more than people who are able-bodied and heterosexual. The greater inner-direction and self-actualization that O'Leary found (1979) in lesbian versus heterosexual women, although not measured in this study, might be counteracted by the presence of chronic illness.

The psychological well-being of this sample may be higher than for women who are in the process of discovering their identities as lesbians and as chronically ill and, therefore, who may have not disclosed their identities. This group has disclosed their identities to 84% percent of their networks. There is evidence that other strategies for managing the lesbian identity, like withdrawal and passing, can be detrimental to one's mental health. Brooks (1981) found that withdrawal led to feelings of alienation and isolation while passing led to fear of exposure. Moses (1978) found that the need to pass was associated with lower self-acceptance.

Greater age and higher socio-economic status were associated with higher psychological well-being. There is much support in the literature for a positive relationship between social class and various health measures (Luft, 1981). It is unclear why increased age is related to greater well-being. Perhaps one develops lower expectations or more effective strategies for coping with life as one ages. Since this was a relatively young sample, higher age may represent increased job status or income. Another possible explanation is related to chronic illness. Singer (1974) found that young, chronically ill experienced more distress than older because they were more different than their peers than the older group where chronic illness was more common.

Lesbian Identity and General Psychological Well-Being

The lesbian variable most associated with general well-being was the importance to one's life of being lesbian. The more important one's lesbian identity was the more likely she was to be worried about health, depressed, low in energy, and the less likely she was to fit into the environment and to cope.

In contrast to these negative associations between importance and well-being. Satisfaction with being lesbian was positively correlated with positive well-being and negatively correlated with depression. If the lesbian identity is important, meeting one's lesbian needs would be more important. Because this society is so anti-lesbian, meeting these needs is difficult and may lead to lower well-being. When the lesbian identity is not central to the woman, she may have fewer perceived needs to meet, therefore less frustration in meeting them, and higher well-being. In interviews there was a possible trend for women newer to the lesbian identity to be more aware of their specific needs for support than established lesbians who already had a supportive lesbian network in place. Perhaps the identity is perceived as more important when identity support is least available and needs are not being met. This might also explain why high importance is associated with lower well-being. High satisfaction with the identity might reflect higher satisfaction of lesbian related needs. It would then follow that higher satisfaction is related to higher well-being.

Chronic Illness Variables and General Psychological Well-Being

The chronic illness variables most associated with general well-being were the importance of being chronically ill and the seriousness of the chronic illness. When importance was high, the woman had lower total well-being, more health worry, and less self-control. When the illness was more serious, she had lower total well-being, more health worry, less coping, and lower energy.

The composite chronic illness variable showed that the stronger the chronic illness identity, the lower the total well-being, coping, and energy level, and the more health worry. There were no significant correlations between obviousness of the chronic illness and well-being. Thus, the more important and serious one's illness, the lower one's well-being. It is important here to note that chronic illness has been conceptualized in this study as a more negative identity than being lesbian. Evidence of this is that there are no chronic illness questions parallel to the questions asked about satisfaction with and healthiness of the lesbian identity. There was an underlying assumption that being chronically ill is not healthy or satisfying. Perhaps this is a reflection of having available only the limited concepts of sick and well. These assumptions need to be questioned. Is it possible to be satisfied with being chronically ill? Is it possible to consider oneself healthy and chronically ill at the same time? It is not surprising that the present negative conceptualization of chronic illness is associated with lower well-being. Future exploration might look toward examining under what conditions, if any, the chronic illness identity is perceived more positively--as healthy and satisfying.

It is possible that the chronically ill lesbians have internalized more negative perceptions of themselves as chronically ill than as lesbian. There is not a concept of their illness that they can comfortably identity with since all illness is devalued. There is, in contrast, enough of a positive notion of lesbianism that women can view it as healthy. There is also not so common a perception that illness is stigmatizing. With less acknowledgment of the negative judgments made about someone who is chronically ill, that person may be more apt to internalize the judgments and devalue the identity.

Conceptualization of Non-Support and Support for Stigmatizing Identities of Chronically Ill Lesbians

It is evident in this study that chronically ill lesbians experienced both support and non-support for these identities from their social networks. Participants' lesbian identity was known to most network members and most who knew responded positively. However for 23% of the network members, the response was negative, mixed or neutral. There were about equal percentages of homosexuals and heterosexuals in the networks.

A similar pattern was true for the chronic illness identity, except there was less support for the chronic illness identity than for the lesbian identity and fewer other chronically ill/disabled in network than there were homosexuals.

Table 17

Comparison of Network Characteristics for Lesbian and Chronic Illness Identities

	Lesbian	CI
% of Network Who Know About Identity	84%	84%
% of Network Supportive of Identity	64%	59%
% of Network Who Have Same Identity	43%	25% (visible/ invisible)

Other research found a similar situation in relation to the lesbian identity. Ettorre (1980) found that 75-98% of her sample tended to be

out about their lesbianism. That sample found 65% of those they told to be supportive, 19% indifferent, 8.5% hostile, and 7% not applicable. There is no equivalent data on the chronic illness identity.

Thus about one third of the average network was evaluated by the participant as being less than supportive to both of these potentially stigmatizing identities. Inclusion of similar others was greater in relation to being a lesbian. These women experience less support for the chronic illness identity and are less apt to have other chronically ill people in their networks. It would be important in future work to quantify how much of the identity support comes from those possessing the same identity.

Similarities and differences will now be considered in the constructs of support and non-support for the chronic illness identity compared to that for the lesbian identity, category by category beginning with non-support and moving to increasingly more supportive behaviors.

Physical and Verbal Abuse

Physical and verbal abuse were experienced with both identities but were more likely to occur in relation to being lesbian. There are several possible explanations for this. First there is the issue of visibility. There may have been more ways in which lesbianism was made visible or obvious, especially nonverbal ways like dress, hair cuts, affectionate behavior with another woman, ignoring men on the street. There are certain symbols adopted by some lesbians that may communicate to outsiders as well as other lesbians that one is lesbian. Women wearing leather jackets, pants, ties, fedoras, short haircuts may be harassed on the street for being lesbians whether they are or not.

One who is chronically ill may have fewer non-verbal symbols of this identity that are understood by outsiders. Physical changes may be unnoticed or misinterpreted by people unknowledgeable about a specific chronic illness. For example, eyes that bulge may just be seen as unusual rather than a sign of hyperthyroidism. Often changes are in the function of internal systems. External manifestations of low blood sugar, for example, may be something as non-specific as a slower than usual pace when walking. This may be less likely to provoke abuse specifically toward illness/disability, although others may express annoyance.

Another possible explanation is that it is more socially acceptable to be openly prejudiced against lesbians than the chronically ill. The physically ill are more apt to be the recipients of pity and charity than lesbians who may be viewed as perverted sinners.

Avoiding Interaction

This form of non-support was found for both identities and expressed similarly.

Disbelief in the Identity

Disbelief in the identity was also experienced about equally for both identities. With chronic illness the disbelief was that the illness existed at all, that it had a physical basis, or that it was a chronic condition. For the lesbian identity there were similar examples of not believing that the identity existed, by making heterosexual assumptions. Parallel to not believing the chronicity of illness were examples of lack of belief in the "chronicity" of the lesbian identity believing that it was temporary, only a passing phase. Although lesbianism is not generally considered a chronic condition by those who accept it, by those who do not, it might be. The word "chronic" suggests long duration or frequent recurrence especially of a disease or habit that resists all efforts at eradication. The implication behind chronic is that it is something that is undesirable. Trying to convert one to heterosexuality also implies that the identity is not permanent but changeable.

There is no obvious parallel in the lesbian non-support for the lack of belief in the physical basis of chronic illness. This may represent a gap in the lesbian conceptualization. Perhaps the overarching category is lack of belief that the identity is grounded in actual real differences within the individual--physical or emotional.

Being Blamed

Being blamed for an identity is perhaps less non-supportive than disbelief because it at least acknowledges the existence of the identity. Blame does, however, imply guilt for being or having done something wrong. Being blamed for an illness and seeing lesbianism as a sin perhaps represent the same idea of non-supportive behavior based on a belief that the identity is "wrong" with an implication that one could change it if she only tried hard enough. With physical illness blame is often placed on the individual's psyche. If only one were emotionally well, she would not need to manifest physical illness. There is generally agreement that illness is something undesirable that the individual would like not to have. It may be more difficult to blame one for lesbianism when the lesbian is accepting and desirous of this identity.

Minimizing

Minimizing was the most common type of non-support mentioned for chronic illness. Forms of minimizing were perceptions that the illness was less important, pervasive, or serious than the participant experienced it to be. Although much less common, minimizing of the lesbian identity was also experienced. Here it took the form of lack of appreciation of the stigma or pervasiveness of being lesbian and rejection of one's lesbian lovers and friends.

There seemed to be more consciousness of the concept of stigma in relation to being lesbian. This is similar to what is found in the literature. Acknowledgement of pervasiveness was important for both identities.

Not viewing the chronic illness as serious may be a parallel category to rejection of lesbian lovers. Exclusion of lovers is a way of minimizing the seriousness of lesbian relationships.

Maximizing

Maximizing the chronic illness identity was much more common than maximizing the lesbian identity. Perhaps it is because there is generally less awareness or acknowledgement of the stigma of illness that people feel freer to make the illness the focus of interactions. There might also be a greater need for associates of the chronically ill to emphasize their separateness and difference from the chronically ill because they realize their vulnerability to also becoming ill. There is not the same degree of "danger" of unwillingly becoming lesbian.

Lack of Collaboration and Unsolicited Advise

These categories were found only in association with the chronic illness identity. Perhaps need for collaboration in relation to being lesbian is met through the supportive interactions with other lesbians (and therefore categorized elsewhere). If this need was being satisfied through lesbian interactions, participants' experience of this type of non-support may have been low. One example of advice about being lesbian (to find the right man) was classified under disbelief (trying to change the identity).

Perhaps the lesbian identity is perceived as less mutable, especially when the lesbian has no desire to change it than is a chronic illness where people having it would like not to. Such a state of dissatisfaction might encourage people to offer advice even when it is not asked for.

Belief in Existence of the Identity

There were only two examples of this category, both with chronic illness, but it is an important category to retain because it represents the basis on which more supportive behaviors are based. It stands in opposition to the non-supportive category of disbelief.

Willingness to Interact

Again there were only a few examples, all in relation to the chronic illness. This category is also important theoretically because it is through interaction that further support can occur. It is a critical prerequisite to more support that may often be assumed or taken for granted in established supportive relationships. In new relationships it may be clearer that willingness to interact is crucial to increasing supportive behaviors.

Accepting Physical Basis--Accepting Lesbianism

This category is fairly common for both identities and represents similar concepts. For illness, rather than blame based on the assumption that the identity is bad, there is acceptance of physically based limitation without an attempt to change or distort this reality. With lesbianism, acceptance is similar, assuming the existence and permanency of the identity. One difference is the idea that lesbianism is not bad, but good and desirable. There is not a parallel expectation that chronic illness should be seen as good and desirable.

Normalizing

For both identities, normalization appears to be an important and high level of support. Elements of normalizing include acknowledging the realities of life with each identity and working in collaboration with the participant to meet specific needs related to the identity.

With the chronic illness there were many more examples of collaboration. Perhaps the need for collaboration is greater because needs related to the illness are intrusive in a wider range of social interactions and less easily compartmentalized and shared only with sympathetic others. Perhaps there is greater expectations that others will be cooperative because there is less general awareness of non-support experienced by the chronically ill.

Association with Others Possessing the Same Identity

It was generally supportive to have contact with other lesbians and chronically ill people. The shared identity provided unconditional acceptance and great interest in discussing the details of the impact of the identity on daily life. The identity becomes the norm and normal rather than a stigmatizing difference.

At the same time, contact with like others can increase the awareness of one's own vulnerability both to disease processes as well as discrimination from the larger society. There is also the realization that there may be significant differences among those claiming the same identity, for example, how one manages one's illness, or one's perception of a politically correct lesbian. This realization may diminish the feelings of belonging to a group of like others, a feeling that is so unavailable in the able-bodied, heterosexual world.

Although expressed in different terms or taken for granted, there are many similarities in the construction of support for both the lesbian and chronically ill identities. Because there was so much more data available to confirm these categories in relation to chronic illness, it would be useful to do further research to test whether the chronic illness construction holds up for lesbians. The differences in construction of support in this study are grounded in the idea that lesbianism is a positive desirable identity while being chronically ill is not.

There is little research available that examines the specifics of support and non-support within the specific context of a potentially stigmatizing identity, so this aspect of the present study represents relatively unexplored territory. There is some research that is in agreement with specific aspects of this construction of support and non-support. While Miller's (1983) exploration of overcoming powerlessness continues to focus on the ill person, Wright (1980) urges the use of an interactional perspective of disability where both the disabled and the supporter share responsibility for facilitating communication. The current study documents the importance of specific types of behaviors of others in the experience of support.

Corbin's recent work (1984) with couples managing chronic illness elaborates on the importance of the collaboration process. It also provides support for complexity and variability being concepts important to the study of chronic illness. With the group she studied, active communication between couples was the process through which collaboration was able to take place.

Krieger (1983) found in her study of a lesbian community a problem of loss of self in communities that value likeness and do not have strategies for dealing with differences and conflict. This finding is supportive of the category of acceptance of the identity as only a part of one's whole being.

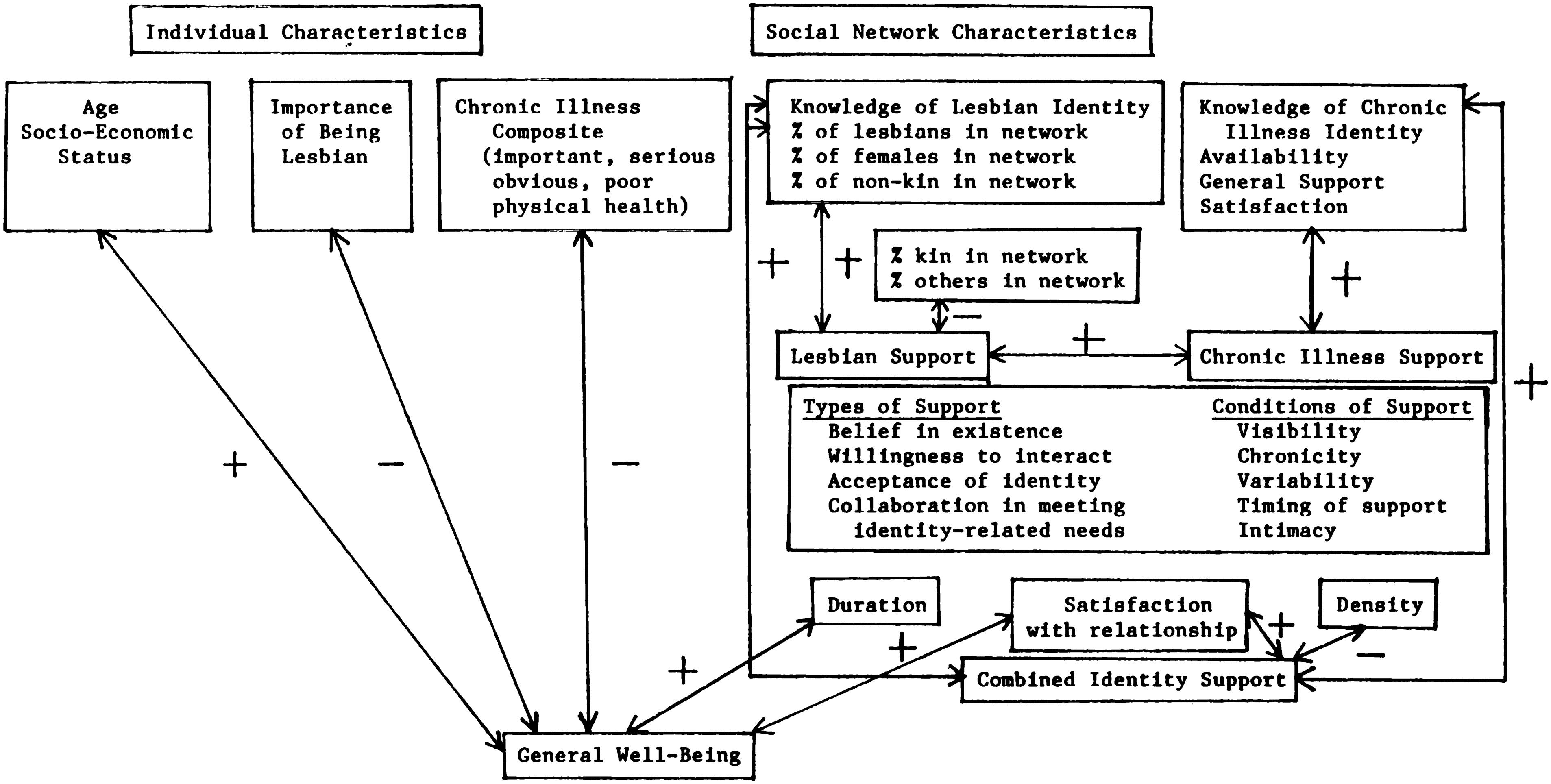
Conceptual Model for Identity Support and General Well-Being of Chronically Ill Lesbians

In bringing together all of the findings from this study (see Figure 2), one can begin to form a conceptual model for identity support and well-being for this group that may have implications for other minority groups or stigmatized populations, especially when the stigmatizing condition is not very obvious. Individual characteristics

Figure 2

CONCEPTUAL MODEL

Major Findings Related to Identity Support and General Well-Being of Chronically Ill Lesbians



can have a direct impact on well-being. Some of these are related to the specific identities while others are more general. Social network characteristics affect the amount of identity support available. With these particular identities, network support for one identity may be associated with different conditions than support for the other, limiting the ability to obtain support for both identities.

One theoretical relationship that was not examined in this study was that between individual characteristics of both supporter and potential supporter and the amount of support for the identities. Qualitative findings have provided a beginning direction for what individual characteristics may be most important.

Although this study did not reveal a relationship between identity support and well-being, one may exist. This relationship should be further tested using more specific measures of support developed from the typology of support in this study.

CHAPTER VI

SUMMARY, IMPLICATIONS, LIMITATIONS, AND SUGGESTIONS FOR FUTURE RESEARCH

This chapter includes a brief summary of this study and its major findings, implications of these findings for nursing practice, limitations, and suggestions for future theory development and research in nursing, social networks, social support, general well-being, and stigma.

Summary of Study

This study examined the social networks, social support, and general well-being of chronically ill lesbians. Lesbian and chronic illness identities were both conceptualized as potentially stigmatizing identities that can vary greatly among individuals who claim each of these labels.

Sixty-six chronically ill lesbians, mostly from the Bay Area, completed questionnaires about sociodemographics, lesbian and chronic illness identities, social networks, and general well-being. Twenty-two of these women were also interviewed about what they found supportive and non-supportive to their lesbian and chronic illness identities. Major findings in relation to each research question are follow.

Characteristics of Social Networks of Chronically Ill Lesbians

The average network had 16 members, most of whom were female and non-kin and about half of whom were lesbian. Participants found their relationship with network members to be generally important and supportive, although about one-third of the network was less than supportive to the lesbian or chronic illness identity.

The General Psychological Well-Being of Chronically Ill Lesbians

In general, these women had lower well-being than samples of healthy women whose sexual orientation was not questioned. They used mental health resources frequently and found them helpful in maintaining mental health.

Relationships Between Social Network Characteristics and General Well-Being of Chronically Ill Lesbians

No relationship was found between identity support and total well-being scores. One possible reason for this is the unrefined way in which support was measured. Measures of support developed from the typology of support discovered in this study might reveal a relationship between identity support and well-being. Duration of and satisfaction with relationships was associated with higher well-being.

What Chronically Ill Lesbians Find Supportive and Non-Supportive to These Identities.

A general construction of types of non-support and support emerged that was quite similar for both identities. Non-supportive behaviors included physical and verbal abuse, avoiding interaction about the identity, disbelief in the existence of the identity, minimizing or maximizing the impact of the identity, and lack of collaboration in meeting identity-related needs.

Supportive behaviors included belief in the existence of the identity, willingness to interact concerning the identity, acceptance of the identity, and collaboration in meeting identity-related needs. Conditions that affected whether a specific behavior was interpreted as supportive or non-supportive included visibility, chronicity and variability of the identity, the timing of support, and the intimacy of the relationship.

Implications of Findings for the Practice of Nursing

This study supports the potential stigma of being lesbian and chronically ill and the importance of acceptance of these attributes for support to occur. Because of the stigma, clients may not feel safe in disclosing the full implications of either identity to health care providers, and yet without this information nurses cannot give sensitive care.

Acknowledgment of the stigma and the stress of living with these identities is crucial for nurses. Careful exploration of one's own attitudes and behaviors, using the typology of non-support and support could help nurses begin to identity which of their behaviors may be non-supportive and begin to replace non-supportive behaviors with supportive ones. As behaviors become more supportive, chronically ill lesbians will feel safer to share more information about themselves and nurses will be able to plan more appropriate nursing care.

Nurses who are insiders to any stigmatized identity may be able to provide particularly sensitive care to others having the identity, but it should not be only their responsibility. Most nurses probably come in contact with chronically ill lesbians whether they are aware of them or not, and they have a responsibility to learn the meaning of these identities and their impact on one's health. The construction of support and non-support can sensitize nurses to critical issues related to identity support and begin to challenge their own attitudes and behaviors.

In order to counteract the impact of societal attitudes it may be particularly important for chronically ill lesbians to relate to each other. Nurses need to be aware of community resources, formal and informal, that facilitate women making these connections. Nurses may also be in a position to help make these connections themselves. For example, nurses could facilitate support groups for lesbians with chronic illness. This work might best be done by a pair of nurses, one of whom is an insider and one an outsider. This would provide sensitivity to issues as well as objectivity in dealing with them. It would also allow an outsider to become wiser abut what being an insider entails.

Limitations of This Study, Measurement of Variables

The lesbian and chronic illness identities were measured using specific aspects of the identities. It cannot be assumed without further testing whether these are the most appropriate aspects to measure or how they should be weighted. Concepts such as length of time possessing an identity need to be clarified for more reliable measurement.

The social network questionnaire was developed for this study, so reliability and validity have not yet been tested. It is possible that there are other important aspects of networks not measured or unnecessary one's that were measured.

Reliability and validity of the original General Well-Being Schedule have been established for general populations only. How applicable it is to stigmatized groups is questionable. The research edition has not been similarly tested for reliability and validity. There is some question about biases that may be built into this instrument, for example, the valuing of control of emotions, devaluing crying. It is also questionable how sensitive this instrument is in measuring the high variability associated with some chronic illnesses.

Analysis of the relationships between variables was correlational, so causation cannot be inferred. Because many correlations were done, it is possible that some of the relationships found occurred because of chance rather than as a reflection of a true relationships.

Differentiations were not made sufficiently between anticipated and actual support. It also was not clear how expectations of support might have affected the experience of support. Because the interviewer was an insider to this group, it is possible that some themes may have gone unexplored while others were interpreted as more important.

Suggestions for Future Theory Development and Research

Future development of theory and research in nursing, social networks and support, general well-being, and stigma could all benefit from the findings of this study. Nursing theorists need to acknowledge that most theories assume heterosexuality and may not be relevant to lesbians. Nursing theories that acknowledge sexual minorities and the stigmatization process that can occur between nurses and clients would be particularly helpful.

Nursing researchers need to sensitize themselves to issues of sexual minorities so that they can develop research tools and studies that encourage the disclosure and further exploration of the impact on health of stigmatizing identities. Researchers need to be clear about whom they are studying. If only heterosexuals are studied, this should be stated, so findings are not generalized beyond this group. When heterosexual assumptions are made it is unclear how many unidentified lesbians may be included, and the meaning of results becomes clouded.

The acknowledgment of how stigmatizing chronic illness can be is another area that needs further exploration by nurses, since they are continually working with chronically ill people. Nurses can be crucial in determining whether stigmatization or normalization occurs when they interact with clients. Research that examines more closely interactions between nurses and chronically ill clients might further clarify how normalization might take place.

Social Network and Social Support

Future research in this area should acknowledge that social networks are the vehicle of non-support as well as support. This study points out the need for more work related to the components of contextually specific support and non-support especially in relation to relatively invisible and and generally devalued identities. Studies that clarify the differences in expectations of support/non-support and actual versus anticipated support/non-support are needed.

Research on well-being and mental health needs to incorporate measures that are not biased toward male or heterosexual definitions of health. In measuring person-environment fit, the environment needs to be specified. Women may experience more well-being if they experience fitting into a minority subculture but not fitting into the society at large.

The concept of stigmatization deserves more research. We need to know more about the conditions that allow for decreased stigmatization and increased normalization of relationships with minority group members.

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NUMBER________

APPENDIX A-1

GENERAL INFORMATION

1. How old are you? ________years

2. What is your race/ethnicity?
   - ____1. Black
   - ____2. White
   - ____3. Latin/Hispanic
   - ____4. Asian
   - ____5. American Indian
   - ____6. Other, please specify______________

3. Residence: city______________ state______________

4. Please indicate your employment status. Check all that apply.
   - ____1. work full time
   - ____2. work part time
   - ____3. work more than one job
   - ____4. umemployed
   - ____5. currently attending school
   - ____6. volunteer work
   - ____7.Other, please specify ______________________

5. Please indicate your main occupation.__________________________

6. Do you currently work at your main occupation?
   - ____1. no
   - ____2. yes

7. Check all the source of income that apply to you.
   - ____1. income from work (salary, commissions,etc.)
   - ____2. welfare
   - ____3. unemployemployment compensation
   - ____4. disability
   - ____5. investments
   - ____6. independent wealth (from inheritance, trust funds,etc.)
   - ____7. family
   - ____8. alimony
   - ____9. child support
   - ____10. other__________________________

8. Please check your approximate total annual income from all sources.
   - ____1. less than $5,000
   - ____2. $5,000-10,000
   - ____3. $10,000-15,000
   - ____4.$15,000-20,000
   - ____5.$20,000-25,000
   - ____6.$25,000-30,000
   - ____7.$30,000-40,000
   - ____8. above $40,000

9. Please rate your degree of indebtedness. Check only one.
   - ____1. none, able to save
   - ____2. none, breaking even
   - ____3. low/manageable
   - ____4. moderate/manageable
   - ____5. high/manageable
   - ____6. beginning to have trouble managing debts
   - ____7.considering filing bankruptcy or getting expert help managing debts
   - ____8. other, please specify______________________________

10. Please check the highest level of school completed.

____1. less than 7th grade
____2. junior high school (9th grade)
____3. partial high school (10th or 11th grade)
____4. high school graduate (whether public, private preparatory, parochial or trade school)
____5. partial college (at least 1 year) or specialized training
____6. standard coolege or university graduate
____7. graduate professional training (graduate degree), please specify

____

11. Religion:

I was raised to be:	My religion/spiritual orientation now is:
____1. Catholic	____1. Catholic
____2. Protestant	____2. Protestant
____3. Jewish	____3. Jewish
____4. Feminist Religion/WICCA	____4. Feminst Religion/WICCA
____5. Other, specify________	____5. Other, specify________
____6. No religion	____6. No religion

12. I think of myself as:

_____ _____ _____ _____ _____

very religious/ spiritual — not at all spiritual/religious

13. Marital Status: (refers to legal marriage) My current status is:

____1. never married
____2. currently married
____3. separated
____4. widowed
____5. divorced

14. Current Relationships: check those that describe your situation.

____1. I am single
____2. I have a primary partner (female)
____3. I have a primary partner (male)
____4. Other, please specify________________________

15. Current Living Arrangement: Please check all those that apply.

____1. alone
____2. with my primary partner
____3. with friends
____4. with family members, please specify______________________
____5. other, please specify______________________________

16. My family's socio-economic status when I was growing up is best described as:

____1. upper class
____2. upper middle class
____3. lower middle class
____4. working class
____5. poor

17. Now I consider myself to be:
____1. upper class
____2. upper middle class
____3. lower middle class
____4. working class
____5. poor

18. Feminism: I consider myself to be:

_____ _____ _____ _____ _____
very feminist — not at all feminist

19. I am a ____________________feminist.

____not applicable

20. Children: Are you a biological mother of any children?
____1. no
____2. yes, how many__________ What are their ages?_______________

21. For each of the following which are available in your area (yes or no), how important each resource is to you, and how frequently you go to each.

Available yes	Available no		Importance very				not at all	Use often				never
___	___	1. women's bars	1.__	__	__	__	__	1.__	__	___	___	___
___	___	2. women's book stores	2.__	__	__	__	__	2.__	__	___	___	___
___	___	3. feminist cultural events	3.__	__	__	__	__	3.__	__	___	___	___
___	___	4. lesbian cultural events	4.__	__	__	__	__	4.__	__	___	___	___
___	___	5. feminist organizations	5.__	__	__	__	__	5.__	__	___	___	___
___	___	6. lesbian organizations	6.__	__	__	__	__	6.__	__	___	___	___
___	___	7. illness/disability organizations, groups	7.__	__	__	__	__	7.__	__	___	___	___
___	___	8. others, specify_______	8.__	__	__	__	__	8.__	__	___	___	___

22. Sexual Preference: Over the past year, my sexual <u>behavior</u> & <u>activities</u> have been:
____1. exclusively heterosexual
____2. primarily heterosexual
____3. primarily heterosexual but with substantial homosexual activity
____4. equally heterosexual and homosexual
____5. primarily homosexual but with substantial heterosexual activity
____6. primarily homosexual
____7. exclusively homosexual

23. Sexual Preference: Over the past year, my sexual <u>feelings</u> (fantasies, interest desires) have been:
____1. exclusively heterosexual
____2. primarily heterosexual
____3. primarily heterosexual but with substantial homosexual feelings
____4. equally heterosexual and homosexual
____5. primarily homosexual but with substantial heterosexual feelings
____6. primarly homosexual
____7. exclusively homosexual

24. I have identified myself as
____1. lesbian for__________years.
____2. bisexual
____3. heterosexual
____4. other, specify______________

25. My level of satisfaction with my sexual preference is:

very satisfied ____ ____ ____ ____ ____ not at all satisfied

26. I believe my sexual preference is:

very healthy ____ ____ ____ ____ ____ not at all healthy

27. How important is it to your life that you are a lesbian?

very ____ ____ ____ ____ ____ not at all

28. In general, how obvious is it to others that you are a lesbian?

very ____ ____ ____ ____ ____ not at all

Health Status:

29. Generally, my satisfaction with life is:

very satisfied ____ ____ ____ ____ ____ not at all satisfied

30. My overall health is:

excellent ____ ____ ____ ____ ____ very poor

31. My physical health is:

excellent ____ ____ ____ ____ ____ very poor

32. My emotional health is:

excellent ____ ____ ____ ____ ____ very poor

33. Chronic Illness/Hidden Disability: I have the following chronic illness(es), or hidden disabilities.

____

____

34. How important is it to your total life that you are chronically ill/disabled?

very ____ ____ ____ ____ ____ not at all

35. How serious is your chronic illness/disability?

____ ____ ____ ____ ____
very   not at all

36. In general, how obvious is it to others that you are chronically ill/disabled?

____ ____ ____ ____ ____
very   not at all

37. Have you ever been discriminated against because you are a lesbian?

____1. yes , specify________________________________
____2. no, and I am not worried about it happening
____3. not sure
____4. no, and I am worried that I might be

38. Have you ever been discriminated against because you are chronically ill/ disabled?

____1. yes, specify________________________________
____2. no, and I am not worried about it happening
____3. not sure
____4. no, and I am worried that I might be

39. Do you have a particular person with whom you confide, with whom you share your most intimate thoughts and concerns?

____1. no
____2. yes

APPENDIX A-2

No.________

INITIAL CONTACT QUESTIONS FOR ELIGIBILITY

Yes No Comments

1. Do you define yourself as a lesbian? ______ yes ______ no

2. How long have you been a lesbian? ________ years

3. How long do you expect to be a lesbian? ________ years
(do you expect this to change?)

4. Does being a lesbian have an impact on how you live your life?

______ yes ______ no

5, Do you have a chronic physical illness or physical condition(or more than one) that limit how your body works? What are they?

____

____

6. Is this condition visible or obvious to others? ______ yes ______ no

7. How long have you had this illness/condition? ________ years

8. How long do you expect to have this illness/condition?________ years

9. Does this illness/condition have an impact on how you live your life?

______ yes ______ no

APPENDIX A-3

NUMBER__________

DATE__________

PERSONAL NETWORK

NAME	RELATIONSHIP
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
6.	6.
7.	7.
8.	8.
9.	9.
10.	10.
11.	11.
12.	12.
13.	13.
14.	14.
15.	15.
16.	16.
17.	17.
18.	18.
19.	19.
20.	20.
21.	21.
22.	22.
23.	23.
24.	24.

SOCIAL NETWORK QUESTIONNAIRE

Please read all directions on this page before beginning this questionnaire.

Please list each person who is important in your life on the left. Consider all people who are important, whether you like them or not.

List names and then indicate their relationship to you. For example:

1. Sandy	lover
2. Terri	friend
3. J.L.	sister

When you have completed the questionnaire, please remove the list of names and keep it to refer to during our interview. There should be no names on the form that you return to me.

Use the following list to help you think of the people important to you, and list as many people as apply to you.

- partner
- friends
- family members/relatives
- housemates
- work/school associates
- neighbors
- health care providers
- counselor, therapist
- others

You do not have to use all 24 spaces. Use as many spaces as you have important people in your life.

When you have finished your list, please turn to pg.2.

2. What sex is this person? 0= male 1= female	3. How long have you known this person? 1= less than 6 months 2= 6-12 months 3= 1-2 years 4= 2-5 years 5= more than 5 years	4. How frequently do you have contact with this person? (visits, phone calls, letters) 5= daily 4= weekly 3= monthly 2= a few times a year 1= once a year or less.	5. How available is this person to you? 1= not at all 2= 3= 4= 5= a great deal
1. ______	1. ______	1. ______	1. ______
2. ______	2. ______	2. ______	2. ______
3. ______	3. ______	3. ______	3. ______
4. ______	4. ______	4. ______	4. ______
5. ______	5. ______	5. ______	5. ______
6. ______	6. ______	6. ______	6. ______
7. ______	7. ______	7. ______	7. ______
8. ______	8. ______	8. ______	8. ______
9. ______	9. ______	9. ______	9. ______
10. ______	10. ______	10. ______	10. ______
11. ______	11. ______	11. ______	11. ______
12. ______	12. ______	12. ______	12. ______
13. ______	13. ______	13. ______	13. ______
14. ______	14. ______	14. ______	14. ______
15. ______	15. ______	15. ______	15. ______
16. ______	16. ______	16. ______	16. ______
17. ______	17. ______	17. ______	17. ______
18. ______	18. ______	18. ______	18. ______
19. ______	19. ______	19. ______	19. ______
20. ______	20. ______	20. ______	20. ______
21. ______	21. ______	21. ______	21. ______
22. ______	22. ______	22. ______	22. ______
23. ______	23. ______	23. ______	23. ______
24. ______	24. ______	24. ______	24. ______

6. How supportive is this person to you? 1= not at all 2= 3= 4= 5= a great deal	7. How satisfied are you with this relationship? 1= not at all 2= 3= 4= 5= a great deal	8. Who else of those listed does this person have an on-going relationship with? (list number) For example, 1. 3,7,8,11 2. 8 3. none 4. 2,3,9
1. ______	1. ______	1. ______
2. ______	2. ______	2. ______
3. ______	3. ______	3. ______
4. ______	4. ______	4. ______
5. ______	5. ______	5. ______
6. ______	6. ______	6. ______
7. ______	7. ______	7. ______
8. ______	8. ______	8. ______
9. ______	9. ______	9. ______
10. ______	10. ______	10. ______
11. ______	11. ______	11. ______
12. ______	12. ______	12. ______
13. ______	13. ______	13. ______
14. ______	14. ______	14. ______
15. ______	15. ______	15. ______
16. ______	16. ______	16. ______
17. ______	17. ______	17. ______
18. ______	18. ______	18. ______
19. ______	19. ______	19. ______
20. ______	20. ______	20. ______
21. ______	21. ______	21. ______
22. ______	22. ______	22. ______
23. ______	23. ______	23. ______
24. ______	24. ______	24. ______

9. How balanced is your relationship with this person?

1= very imbalanced, I do much more for this person than she/he does for me.

2= I do a little more for her/him.

3= our relationship is balanced, we do about the same for each other.

4= this person does a little more for me than I do for her/him

5= very imbalanced, this person does much more for me than I do for her/him.

1. ____
2. ____
3. ____
4. ____
5. ____
6. ____
7. ____
8. ____
9. ____
10. ____
11. ____
12. ____
13. ____
14. ____
15. ____
16. ____
17. ____
18. ____
19. ____
20. ____
21. ____
22. ____
23. ____
24. ____

10. How important is this relationship to you?

1= not very important
2=
3=
4=
5= very important

1. ____
2. ____
3. ____
4. ____
5. ____
6. ____
7. ____
8. ____
9. ____
10. ____
11. ____
12. ____
13. ____
14. ____
15. ____
16. ____
17. ____
18. ____
19. ____
20. ____
21. ____
22. ____
23. ____
24. ____

11. Does this person know your sexual preference?

1= no
2= not sure, I think not
3= not sure, I think so
4= yes, I told
5= yes, found out another way

1. ____
2. ____
3. ____
4. ____
5. ____
6. ____
7. ____
8. ____
9. ____
10. ____
11. ____
12. ____
13. ____
14. ____
15. ____
16. ____
17. ____
18. ____
19. ____
20. ____
21. ____
22. ____
23. ____
24. ____

12. How does this person respond to your sexual preference?

1= positive/supportive
2= neutral
3= mixed, positive and negative
4= negative/not supportive
5= not applicable

1. ____
2. ____
3. ____
4. ____
5. ____
6. ____
7. ____
8. ____
9. ____
10. ____
11. ____
12. ____
13. ____
14. ____
15. ____
16. ____
17. ____
18. ____
19. ____
20. ____
21. ____
22. ____
23. ____
24. ____

13. What is the sexual preference of this person?

1= heterosexual
2= homosexual
3= bisexual
4= I don't know
5= other, specify____
____
6= not applicable

1. ____
2. ____
3. ____
4. ____
5. ____
6. ____
7. ____
8. ____
9. ____
10. ____
11. ____
12. ____
13. ____
14. ____
15. ____
16. ____
17. ____
18. ____
19. ____
20. ____
21. ____
22. ____
23. ____
24. ____

14. Does this person know you have a chronic illness/hidden disability?

1= no
2= not sure, I think not
3= not sure, I think so
4= yes, I told
5= yes, found out another way

1. ____
2. ____
3. ____
4. ____
5. ____
6. ____
7. ____
8. ____
9. ____
10. ____
11. ____
12. ____
13. ____
14. ____
15. ____
16. ____
17. ____
18. ____
19. ____
20. ____
21. ____
22. ____
23. ____
24. ____

15. How does this person respond to your chronic illness/hidden disability

1= positive/supportive
2= neutral
3= mixed, positive and negative
4= negative/not supportive
5= not applicable

1. ____
2. ____
3. ____
4. ____
5. ____
6. ____
7. ____
8. ____
9. ____
10. ____
11. ____
12. ____
13. ____
14. ____
15. ____
16. ____
17. ____
18. ____
19. ____
20. ____
21. ____
22. ____
23. ____
24. ____

16. This person has:

1= a chronic illness or hidden disability
2= a visible illness or disability
3= both 1 and 2.
4= no chronic illness or disability
5= I don't know
6= other, specify ____________

1. ____________
2. ____________
3. ____________
4. ____________
5. ____________
6. ____________
7. ____________
8. ____________
9. ____________
10. ____________
11. ____________
12. ____________
13. ____________
14. ____________
15. ____________
16. ____________
17. ____________
18. ____________
19. ____________
20. ____________
21. ____________
22. ____________
23. ____________
24. ____________

17. During the past year, have you lost any important relationships?

0= no
1= yes Number lost ____

18. Overall, how much support was provided by those relationships lost in the last year?

1= none at all
2=
3=
4=
5= a great deal

APPENDIX A-4

Social Network Data

Social Network Characteristic	Construct	Question Measure	Coding of Questions	Data Reduction
Size	Structure (N)	List each person who is important in your life.	Count of total number listed up to 24.	Composite scores for each participant
Relationship (type)	Structure (I)	For each person listed, indicate relationship (list of examples given are primary partner, lover, family/relatives, friends, housemates, work/school associates, neighbors, health care provider, counselor/therapist.	Primary partner friend family/relatives work/school associates neighbors professionals	Total for each category. Percent of total in network in each category
Sex	Individual Characteristics	What sex is the person?	0 = male 1 = female	Total for each category. Percent
Duration	Structure (I)	How long have you known this person?	1 = less than 6 mo. 2 = 6-12 mo. 3 = 1-2 years 4 = 2-5 years 5 = more than 5 yrs.	Frequency for each category. Percent of total for each category for network. *Mean* score for netowrk.

Social Network Data (Cont.)

Social Network Characteristic	Construct	Question Measure	Coding of Questions	Data Reduction
Frequency of contact	Structure (I)	How frequently do you have contact with this person? (visits, phone calls, letters).	5 = daily 4 = weekly 3 = monthly 2 = a few times a year 1 = once a year or less	Frequency for each category. Percent of total for each category for network. Mean score for network.
Availability	Structure (I)	How available is this person to you?	1 = not at all 2 = 3 = 4 = 5 = a great deal	Frequency and % for each category in network. Mean score for network.
Satisfaction	Evaluation	How satisfied are you with this relationship.	1 = not at all 2 = 3 = 4 = 5 = a great deal	Frequency and % for each category in network. Mean score for network.
Density	Structure (N)	Who else of those listed does this person have an ongoing relationship with?		
Reciprocity	Structure (I)	How balanced is your relationship with this person?	1 = very imbalanced (I do much more) 2 = 3 = balanced 4 = 5 = very imbalanced (This person does much more for me)	Frequency and % for each category in network. Mean score for network.

Social Network Data (Cont.)

Social Network Characteristic	Construct	Question Measure	Coding of Questions	Data Reduction
Importance		How important is this relationship to you?	1 = not very impor- 2 = 3 = 4 = 5 =	Frequency and % for each category in network. Mean score for network.
Support	Function	In general, how supportive is this person to you?	1 = not at all 2 = 3 = 4 = 5 = a great deal	Frequency and % for each category in network. Mean score for network.
Knowledge of sexual preference	Individual characteristics of members	Does this person know your sexual preference?	1 = no 2 = probably not 3 = probably so 4 = yes	Frequency and % for each category in network. Mean score for network.
Response to sexual preference	Individual characteristics of members	How does this person respond to your sexual preference?	1 = positive/ 2 = neutral 3 = mixed-positive and negative 4 = negative/not supportive. 5 = not applicable	Frequency and % for each category in network. Mean score for network.
Sexual preference of social network	Individual characteristics of members	What is the sexual preference of this person?	1 = heterosexual 2 = homosexual 3 = bisexual 4 = I don't know 5 = other (specify)	Frequency and % for each category in network. Mean score for network.

Social Network Data (Cont.)

Social Network Characteristic	Construct	Question Measure	Coding of Questions	Data Reduction	
Knowledge of chronic illness	Individual characteristics of illness	Does this person know you have a chronic illness?	0 = no 1 = yes 2 = not sure		
Response to chronic	Individual characteristics of members	How does this person respond to your needs associated with your chronic illness?	1 = positive/ supportive 2 = neutral 3 = mixed - positive and negative 4 = negative 5 = not applicable	Frequency and % for each category in network. Mean score for network.	Do I need to ask 2 questions regarding response to CI and response to special health needs How to get at both aspects without redundance.
Health status of social network	Individual characteristics of members	What is the health status of this person?	1 = has a serious chronic illness 2 = has a mild chronic illness 3 = has no chronic illness; in average health 4 = has no chronic illness; in very good health 5 = I don't know	Frequency and % for each category in network. Mean score for network.	Do I want to associate no CI with good health (simply relationship of CI and ill health)?
Network loss	Loss	During the past year, have you lost any important relationships due to moving, a job change, separation, death, or some other reason?	0 = no 1 = yes	Frequency and % for each category in network. Mean score for network.	Do I need to know relationship of losses (if not, omit).
Support from losses	Loss	Overall, how much support was provided by these people who are no longer available to you?	1 = none at all 2 = a little 3 = a moderate amount 4 = quite a bit 5 - a great deal		

Relationships of Dimensions, Constructs, and Components and Items of the Social Network Questionnaire

Dimension	Construct	Components	Questions
Structure	Structure of Network	Density	
		Size	
	Structure of Individual Relationships	Duration of Relationship	
		Frequency of Contact	
		Availability	
		Type of Relationship	
		Uni-mulitdimensional	
		Reciprocity	
Individual Characteristics of Network Members		Sex	
		Sexual Orientation Status	
		Chronic Illness Status	
		Knowledge of Ego's Lesbian Identity	
		Knowledge of Ego's Chronic Illness Identity	
Function	Support/ Nonsupport	Tangible/Material Aid or Lack	
		Informational Aid or Lack	
		Emotional Aid or Lack	
		Specific Supportiveness of Lesbian Identity	
		Specific Supportiveness of Chronic Illness Identity	
Evaluation	Importance		
	Satisfaction		
Loss	Loss of Supportiveness		

APPENDIX A-5

June, 1978

THE GENERAL WELL-BEING SCHEDULE
(RESEARCH EDITION)

READ: This section of the examination contains questions about how you feel and how things have been going with you. For each question check [✓] the answer which best applies to you.

1. How have you been feeling in general? (DURING THE PAST MONTH)
   1. ☐ In excellent spirits
   2. ☐ In very good spirits
   3. ☐ In good spirits mostly
   4. ☐ I have been up and down in spirits a lot
   5. ☐ In low spirits mostly
   6. ☐ In very low spirits

2. How often were you bothered by any illness, bodily disorder, aches or pains? (DURING THE PAST MONTH)
   1. ☐ Every day
   2. ☐ Almost every day
   3. ☐ About half of the time
   4. ☐ Now and then, but less than half the time
   5. ☐ Rarely
   6. ☐ None of the time

3. Did you feel depressed? (DURING THE PAST MONTH)
   1. ☐ Yes-- to the point that I felt like taking my life
   2. ☐ Yes-- to the point that I did not care about anything
   3. ☐ Yes-- very depressed almost every day
   4. ☐ Yes-- quite depressed several times
   5. ☐ Yes-- a little depressed now and then
   6. ☐ No-- never felt depressed at all

4. Have you been in firm control of your behavior, thoughts, emotions or feelings? (DURING THE PAST MONTH)
   1. ☐ Yes, definitely so
   2. ☐ Yes, for the most part
   3. ☐ Generally so
   4. ☐ Not too well
   5. ☐ No, and I am somewhat disturbed
   6. ☐ No, and I am very disturbed

5. Did you make any changes in yourself and/or your life situation? (DURING THE PAST MONTH)
   1. ☐ I felt no need to make changes in myself or my life situation
   2. ☐ I tried to make some changes, but they did not work
   3. ☐ I only made a few minor changes
   4. ☐ I made several minor changes only
   5. ☐ I made a few major changes
   6. ☐ I made several major changes

6. How much energy, pep or vitality did you have or feel? (DURING THE PAST MONTH)
   1. ☐ Very full of energy - lots of pep
   2. ☐ Fairly energetic most of the time
   3. ☐ My energy level varied quite a bit
   4. ☐ Generally low in energy, pep
   5. ☐ Very low in energy or pep most of the time
   6. ☐ No energy or pep at all -I felt drained, sapped

Have you been bothered by nervousness or your "nerves"? (DURING THE PAST MONTH)

1. [ ] Extremely so - to the point where I could not work or take care of things
2. [ ] Very much so
3. [ ] Quite a bit
4. [ ] Some - enough to bother me
5. [ ] A little
6. [ ] Not at all

How well were you able to satisfy or meet most of your needs? (DURING THE PAST MONTH)

1. [ ] All my needs were completely satisfied
2. [ ] Most of my needs were generally satisfied
3. [ ] About half of my needs were reasonably satisfied
4. [ ] Only a few of my needs were reasonably satisfied
5. [ ] I was only able to barely satisfy my major needs
6. [ ] I could not satisfy my most important needs

How happy, satisfied, or pleased have you been with your personal life? (DURING THE PAST MONTH)

1. [ ] Extremely happy - could not have been more satisfied or pleased
2. [ ] Very happy most of the time
3. [ ] Generally satisfied - pleased
4. [ ] Sometimes fairly happy, sometimes fairly unhappy
5. [ ] Generally dissatisfied, unhappy
6. [ ] Very dissatisfied or unhappy most or all the time

10\. Did you feel healthy enough to carry out the things you like to do or had to do? (DURING THE PAST MONTH)

1. [ ] Yes - definitely so
2. [ ] For the most part
3. [ ] Health problems limited me in some important ways
4. [ ] I was only healthy enough to take care of myself
5. [ ] I needed some help in taking care of myself
6. [ ] I needed someone to help me with most or all of the things I had to do

11\. Have you felt so sad, discouraged, hopeless, or had so many problems that you wondered if anything was worthwhile? (DURING THE PAST MONTH)

1. [ ] Extremely so - to the point that I have just about given up
2. [ ] Very much so
3. [ ] Quite a bit
4. [ ] Some - enough to bother me
5. [ ] A little bit
6. [ ] Not at all

12\. How self confident did you feel? (DURING THE PAST MONTH)

1. [ ] Completely self confident
2. [ ] Very high in self confidence
3. [ ] Fairly high in self confidence
4. [ ] A little low in self confidence
5. [ ] Very low in self confidence
6. [ ] Not at all self confident

13. Have you felt you needed a vacation, more recreation, or a change in your current living, or working routine? (DURING THE PAST MONTH)

1. ☐ No, I felt no such need
2. ☐ Yes, and I took a vacation or did something else that was refreshing
3. ☐ Yes, and I did do something that helped some
4. ☐ Yes, and I did something but it did not help
5. ☐ Yes, but I was not able to do anything about it
6. ☐ Yes, but I felt I would be worse off if I did any of these things

14. Did you have any trouble getting to sleep or staying asleep? (DURING THE PAST MONTH)

1. ☐ Could not sleep at all without some kind of pills or medicine
2. ☐ Was not able to sleep at all well
3. ☐ Had a good bit of trouble
4. ☐ Some - enough to bother me
5. ☐ A little bit
6. ☐ No trouble at all

15. Have you been under or felt you were under any strain, stress, or pressure? (DURING THE PAST MONTH)

1. ☐ Yes - almost more than I could bear or stand
2. ☐ Yes - quite a bit of pressure
3. ☐ Yes - some - more than usual
4. ☐ Yes - some - but about usual
5. ☐ Yes - a little
6. ☐ Not at all

16. Did you take care of or do most things as well as you should have? (DURING THE PAST MONTH)

1. ☐ No, because I was too emotionally disturbed
2. ☐ No, because I was physically sick, ill, or impaired
3. ☐ No, because I did not want to or felt too bored
4. ☐ No, because too many demands were made on me
5. ☐ No, because I was trying to do too many things
6. ☐ Yes, I took care of most of the things I should have

17. How did you feel when you were around people? (DURING THE PAST MONTH)

1. ☐ Full of life - very interested in them
2. ☐ Enjoyed being with them
3. ☐ Generally interested with a fair amount of enjoyment
4. ☐ I did not enjoy being around people
5. ☐ I felt apart, isolated, alone, even among friends
6. ☐ I avoided people as much as possible

18. Did you feel that others would be better off if you were dead? (DURING THE PAST MONTH)

1. ☐ Never felt this way at all
2. ☐ I may have felt this way a time or two, but not sure
3. ☐ I definitely felt this way a time or two
4. ☐ I definitely felt this way several times
5. ☐ I definitely felt this way many times
6. ☐ I definitely felt this way just about all the time

19. Have you been concerned, worried, or had any fears about your health? (DURING THE PAST MONTH)

1. ☐ Extremely so
2. ☐ Very much so
3. ☐ Quite a bit
4. ☐ Some, but not a lot
5. ☐ Practically never
6. ☐ Not at all

20. Have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel or of your memory? (DURING THE PAST MONTH)

1. ☐ Not at all
2. ☐ Only a little
3. ☐ Some - but not enough to be concerned or worried about
4. ☐ Some and I have been a little concerned
5. ☐ Some and I am quite concerned
6. ☐ Yes, very much so and I am very concerned

21. How well were you able to meet the physical, mental or social demands expected of you? (DURING THE PAST MONTH)

1. ☐ I met all of them to my complete satisfaction
2. ☐ I met most of them to my satisfaction
3. ☐ I met some but not others to my satisfaction
4. ☐ I was only able to barely meet a few demands
5. ☐ I was not able to meet any such demands

☐ No such demands were expected of me

22. Did you feel active, vigorous, <u>or</u> dull, sluggish? (DURING THE PAST MONTH)

1. ☐ Very active, vigorous every day
2. ☐ Mostly active, vigorous - never really dull, sluggish
3. ☐ Fairly active, vigorous - seldom dull, sluggish
4. ☐ Fairly dull, sluggish - seldom active, vigorous
5. ☐ Mostly dull, sluggish - never really active, vigorous
6. ☐ Very dull, sluggish every day

23. Have you been anxious, worried or upset? (DURING THE PAST MONTH)

1. ☐ Extremely so - to the point of being sick or almost sick
2. ☐ Very much so
3. ☐ Quite a bit
4. ☐ Some - enough to bother me
5. ☐ A little bit
6. ☐ Not at all

24. <u>Compared to the past 12 months</u>, what has your general state of well-being or distress been like DURING THE PAST MONTH?

1. ☐ A much higher state of well-being than usual
2. ☐ A somewhat higher state of well-being than usual
3. ☐ About the same state of well-being as usual
4. ☐ About the same state of distress as usual
5. ☐ A somewhat greater state of distress than usual
6. ☐ A much greater state of distress than usual

25. How would you describe your physical shape or condition? (DURING THE PAST MONTH)
   1. ☐ In excellent physical shape or condition- good firm muscle tone
   2. ☐ In good physical shape or condition
   3. ☐ In fair physical shape or condition
   4. ☐ Poor physical shape - but not weak or shaky
   5. ☐ Poor shape and somewhat weak or shaky
   6. ☐ Poor shape and very weak or shaky

26. Did you say or do anything that may have caused someone to doubt your sanity, or wonder if you were emotionally or mentally disturbed? (DURING THE PAST MONTH)
   1. ☐ Yes - definitely so
   2. ☐ Yes - I probably did
   3. ☐ I think I did, but I am not too sure
   4. ☐ I do not think so, but I may have
   5. ☐ No - but I came close to doing so
   6. ☐ No - definitely not

27. Did you feel that things were turning out for you the way you wanted? (DURING THE PAST MONTH)
   1. ☐ Yes, everything seemed to turn out fine for me this month
   2. ☐ Yes, most everything turned out the way I wanted them to
   3. ☐ I did not notice any change for better or worse
   4. ☐ Some things changed for better, some things for worse
   5. ☐ No, I had some distressing setbacks
   6. ☐ No, nothing seemed to turn out the way I wanted this month

28. Have you felt that you could not get going? (DURING THE PAST MONTH)
   1. ☐ Never
   2. ☐ A few times
   3. ☐ A number of times
   4. ☐ I often had to drag or force myself to get going
   5. ☐ Everything has been an effort the whole month
   6. ☐ Yes, to the point that I could not even force myself to do anything for several days

29. Did you feel relaxed, at ease or high strung, tight, or keyed-up? (DURING THE PAST MONTH)
   1. ☐ Felt relaxed and at ease the whole month
   2. ☐ Felt relaxed and at ease most of the time
   3. ☐ Generally felt relaxed but at times felt fairly high strung
   4. ☐ Generally felt high strung but at times felt fairly relaxed
   5. ☐ Felt high strung, tight or keyed-up most of the time
   6. ☐ Felt high strung, tight or keyed-up the whole month

30. How did you feel about yourself as a person? (DURING THE PAST MONTH)
   1. ☐ I felt completely satisfied with myself
   2. ☐ I felt all right or was contented about the kind of person I am
   3. ☐ I had mixed feelings about myself
   4. ☐ I felt very disappointed in myself several times
   5. ☐ I disliked myself to the point that I wished I were different
   6. ☐ I felt disgusted with or hated myself; felt worthless or unworthy

31. How has you appetite been? (DURING THE PAST MONTH)

[   ] Much too good - I eat too much for my health
2. [   ] Very good - I fully enjoyed all my meals
3. [   ] Generally good
4. [   ] Only fair - there have been times when I did not care about eating
5. [   ] Generally poor - no real taste or desire for food
6. [   ] I have gone for days without eating because I had no desire for food

---

32. Have you cried, had crying spells, or felt like crying? (DURING THE PAST MONTH)

1. [   ] Not at all
2. [   ] I cried, but because I was happy
3. [   ] I felt like crying but kept myself from doing so
4. [   ] I cried, and felt better after doing so
5. [   ] I cried, but did not feel any better
6. [   ] I wanted to cry, but could not cry even when I tried

---

33. Were you generally tense or did you feel any tension? (DURING THE PAST MONTH)

1. [   ] Yes - extremely tense, most or all of the time
2. [   ] Yes - very tense most of the time
3. [   ] Not generally tense, but did feel fairly tense several times
4. [   ] I felt a little tense a few times
5. [   ] My general tension level was quite low
6. [   ] I never felt tense or any tension at all

---

34. Did you have any doubts about your ability to succeed in life? (DURING THE PAST MONTH)

1. [   ] I never had any such doubts at all
2. [   ] I have had a few small doubts
3. [   ] I had such doubts now and then but not very strong
4. [   ] I often had such doubts, but not too strong
5. [   ] I had such strong doubts that I felt insecure or useless
6. [   ] I felt I was a complete failure with no future

---

35. Did you enjoy life? (DURING THE PAST MONTH)

1. [   ] None of the time
2. [   ] A little of the time
3. [   ] Some of the time
4. [   ] A good bit of the time
5. [   ] Most of the time
6. [   ] All of the time

---

36. Did you drive and push yourself very hard - almost too hard DURING THE PAST MONTH?

1. [   ] None of the time
2. [   ] A little of the time
3. [   ] Some of the time
4. [   ] A good bit of the time
5. [   ] Most of the time
6. [   ] All of the time

37. My daily life was full of things that were interesting to me DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

38. I felt downhearted and blue DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

39. I felt calm and peaceful DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

40. My love/sex life was full and complete DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

41. I felt tired, worn out, used up, or exhausted DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

42. I felt jittery, irritable, or on edge DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

43. I felt cheerful, lighthearted DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

44. My life situation was all I could wish for DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

45. I felt lonely DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

46. I worked or did things at a fast tempo or pace DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

47. I was emotionally stable and sure of myself DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

48. I felt eager to tackle my daily tasks or make new decisions DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

49. I was moody or brooded about things DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

50. I felt angry, frustrated, or bitter DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

51. I lived the kind of life I wanted to DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

52. I woke up feeling fresh and rested DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

53. Other people acted or talked as if something was wrong or strange about me DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

54. I felt proud or good about some things I did DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

55. I felt restless, fidgety, impatient DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

56. I felt well adjusted to my life situation DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

57. I felt loved and wanted DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

58. I felt I could easily handle or cope with any serious problem or major change in my life if I had to DURING THE PAST MONTH.

1. [ ] None of the time
2. [ ] A little of the time
3. [ ] Some of the time
4. [ ] A good bit of the time
5. [ ] Most of the time
6. [ ] All of the time

59. Have you had severe enough personal, emotional, behavior, or mental problems that you felt you needed help DURING THE PAST YEAR?

1. ☐ Yes, and I did seek professional help
2. ☐ Yes, but I did not seek professional help
3. ☐ I have had (or have now) severe personal problems, but have not felt I needed professional help
4. ☐ I have had very few personal problems of any serious concern
5. ☐ I have not been bothered at all by personal problems during the past year

60. Has anyone said or suggested that you should seek professional help for some personal, emotional, behavior, or mental problem DURING THE PAST YEAR?

1. ☐ YES - and I did go (or am going now) but it did not help
2. ☐ YES - and I did go (or am going now) and it did help
3. ☐ YES - and I seriously considered going, but did not go.
4. ☐ YES - but I felt it would not help me with my problem(s)
5. ☐ YES - but I did not feel that I needed such help
6. ☐ NO - but I did go (or am going now) but it did not help
7. ☐ NO - but I did go (or am going now) and it did help
8. ☐ NO - but I would go if I felt I needed such help
9. ☐ NO - and I would not go under any condition

61. Has anyone (such as in your family, a close friend, someone at work, or in your neighborhood, etc.) been a source or cause of disturbance or distress to you DURING THE PAST YEAR?

1. ☐ Yes, very much so and I am still disturbed
2. ☐ Yes, very much so for a while, but I am over it now
3. ☐ Yes, to some extent and I am still disturbed
4. ☐ Yes, to some extent but I am over it now
5. ☐ Only a few minor things that did not last very long
6. ☐ No, not at all

62. Have you ever felt that you were going to have or were close to having a nervous breakdown?

1. ☐ YES - during the past year and I still feel near one
2. ☐ YES - during the past year but I do not feel near one now
3. ☐ YES - more than a year ago, and I am not completely over it yet
4. ☐ YES - more than a year ago but I am completely over it now
5. ☐ NO - Never

63. Have you ever had a nervous breakdown?

1. ☐ YES - during the past year and I have not completely recovered yet
2. ☐ YES - during the past year but I am over it now
3. ☐ YES - more than a year ago and I am not completely over it yet
4. ☐ YES - more than a year ago but I am completely over it now
5. ☐ NO - Never

64. Have you ever been a patient or out-patient at a mental hospital, a mental health ward of a hospital, or a mental health clinic, for any personal, emotional, behavior, or mental problem?

1. ☐ YES - and I am still going
2. ☐ YES - during the past year but not now
3. ☐ YES - more than a year ago
4. ☐ NO - Never

65. Have you ever seen a psychiatrist, psychologist, or psychoanalyst about any personal, emotional, behavior, or mental problem concerning yourself?

1. ☐ YES - and I am still going
2. ☐ YES - during the past year but not now
3. ☐ YES - more than a year ago
4. ☐ NO - Never

66. Have you talked with or had any connection with any of the following about some personal, emotional, behavior, mental problem, worries, or "nerves" CONCERNING YOURSELF DURING THE PAST YEAR?

		1	2
a.	Regular medical doctor (except for definite physical conditions or routine check-ups)	☐ Yes	☐ No
b.	Brain or nerve specialist..........................	☐ Yes	☐ No
c.	Nurse (except for routine medical conditions)......	☐ Yes	☐ No
d.	Lawyer (except for routine legal services).........	☐ Yes	☐ No
e.	Police (except for simple traffic violations)......	☐ Yes	☐ No
f.	Clergyman, minister, priest, rabbi, etc............	☐ Yes	☐ No
g.	Marriage or family counselor.......................	☐ Yes	☐ No
h.	Social or Welfare Worker...........................	☐ Yes	☐ No
i.	Group therapy......................................	☐ Yes	☐ No
j.	Occupational or educational counselor..............	☐ Yes	☐ No
k.	Drug abuse clinic or center(s).....................	☐ Yes	☐ No
l.	Alcohol abuse clinic or center(s)..................	☐ Yes	☐ No
m.	Suicide prevention center..........................	☐ Yes	☐ No
n.	A "hot line" service for emotional problems........	☐ Yes	☐ No
o.	Any other formal "mental health" assistance........	☐ Yes	☐ No

67. Do you discuss your problems with any members of your family or friends?

1. ☐ Yes - and it helps a lot
2. ☐ Yes - and it helps some
3. ☐ Yes - but it does not help at all
4. ☐ No - I do not have anyone I can talk with about my problems
5. ☐ No - no one cares to hear about my problems
6. ☐ No - I do not care to talk about my problems with anyone
7. ☐ No - I do not have any problems

OVERALL EVALUATION OF YOUR LIFE SITUATION

68. Considering your life as a whole, rate yourself on:

A. How things were this time a year ago: *Check one box only under Last Year.*

B. How things are (going) at present: *Check one box only under Now.*

C. How you think your life situation will most likely be this time a year from now: *Check one box only under Next Year.*

LAST YEAR	NOW	NEXT YEAR	
[ ] 10	[ ] 10	[ ] 10	.....Absolutely tops - could not be better
[ ] 09	[ ] 09	[ ] 09	.....Very well, could hardly be better
[ ] 08	[ ] 08	[ ] 08	.....Actually quite good
[ ] 07	[ ] 07	[ ] 07	.....Pretty good really
[ ] 06	[ ] 06	[ ] 06	.....Somewhat positive
[ ] 05	[ ] 05	[ ] 05	.....Positive and negative aspects about even
[ ] 04	[ ] 04	[ ] 04	.....Somewhat negative
[ ] 03	[ ] 03	[ ] 03	.....Pretty bad really
[ ] 02	[ ] 02	[ ] 02	.....Actually quite bad
[ ] 01	[ ] 01	[ ] 01	.....Very bad, could hardly be worse
[ ] 00	[ ] 00	[ ] 00	.....Absolute bottom - could not be worse

NURSING RESEARCH PROJECT
for
LESBIANS
with
CHRONIC ILLNESS
or
HIDDEN DISABILITY

Hello. My name is Susan E. Browne. I am a nurse working on my doctorate in nursing at the University of California-San Francisco. For my dissertation, I am studying the health of lesbians with chronic physical illnesses or hidden disabilities. I will be looking specifically at how we get support and deal with non-support, our general health and well-being, and our relationships with health care providers.

If you are a lesbian and have what you define as a chronic physical illness or hidden disability, I am interested in talking with you. Participation in my study would involve an interview with me and completion of questionnaires.

STRICTEST CONFIDENTIALITY WILL BE MAINTAINED.

If you are interested in more information, please contact me at (415) 431-2344 or write me at 14A Belvedere Street, San Francisco, Ca. 94117.

If you know of someone else who might be interested in participating, please share this information with them.

THANK YOU VERY MUCH FOR YOUR HELP WITH THIS WORK.

Susan

INFORMATION SHEET

My name is Susan E.Browne. I am a nurse working on my doctorate in nursing at the University of California-San Francisco. For my dissertation, I am interested in learning more about lesbians who have chronic physical illnesses or hidden disabilities.

Consent - Consent of the participant is a vital part of the research process. This means one gives voluntary informed consent. To protect your rights, you should read this carefully before deciding if you want to participate in this study.

1. I will ask you to complete three questionnaires at your convenience. It will take 1-2 hours.

2. I will have an interview with you for about 2 hours. You can decide a convenient time and place. If it is better for you, we can break up the interview into shorter segments. You will be free to stop participating at any time for any reason without negative repercussions to you.

3. The topics of the questionnaires and the interview will be general information about being a lesbian, being chronically ill, your relationships with others who are important to you, relationships with health care providers, and your general sense of well-being. Some of the information may seem very personal to you. You are free to not answer any questions you choose.

4. If you agree, I will tape our interview and take some notes. None of these materials (or the questionnaires) will have your name on them, but rather a code number. After I finish interviewing you and the questionnaires are complete, your name will be destroyed. Tapes will be destroyed as soon as the information (without any names) is transcribed from them. You may use fictitious names in the interview if you like. Your confidentiality will be protected as much as possible within the law. Any publication or presentation of the findings will not allow for identification of individuals.

5. There will be no direct benefit for you in participating in this study. I hope to learn more about the social relationships and general well-being of chronically ill lesbians.

6. If you have any questions about this study I have not answered, you may contact me at 415-431-2344 or write me at 14 A Belvedere Street, San Francisco, Ca. 94117.

7. If you have comments about participation in this study, you should first talk with me. If for some reason you do not want to do this, you may contact the Committee on Human Research which is concerned with the protection of volunteers in research projects. You may reach the committee office by calling 415-666-1814, or writing the Committee on Human Research, 116 Clinics Building, University of California, San Francisco, Ca. 94143

PLEASE KEEP THIS SHEET FOR YOUR INFORMATION.

APPENDIX A-8

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO: HUMAN AND ENVIRONMENTAL
PROTECTION COMMITTEES
CLINICS 116

TO: Afaf Meleis, PhD/Susan E. Browne
N 505 Y/14 A Belvedere Street, SF, CA 94117

RE: Social Networks, Social Support and Psychological Well-being of Chronically Ill Lesbians

The UCSF Committee on Human Research (an IRB holding DHHS assurance G0155) approved the above request to involve humans as research subjects.

APPROVAL NUMBER: 932321-02* **This number is a UCSF CHR number which should be used on all consent forms, correspondence and patient charts.**

APPROVAL DATE: June 28, 1984

Full review ________
Expedited review XX

EXPIRATION DATE: June 28, 1985 **If the project is to continue it must be renewed by the expiration date. If the number has an asterisk, the short-form renewal process may be used.**

SUBMISSION ADDENDA: No XX **or Yes** _____**. A yes indicates that there was correspondence between the Committee and the investigator during review of this submission; it does not stand unaltered.**

CONDITIONS:

ADVERSE REACTIONS/COMPLICATIONS: All problems having to do with subject safety must be reported to the CHR within five working days.

MODIFICATIONS: All protocol changes involving subjects must have prior CHR approval.

LEGAL NOTICE: The University will defend and indemnify a principal investigator in legal actions arising from research activities involving humans if the activities had current CHR approval.

QUESTIONS: Please contact the Human and Environmental Protection Committees office (Erica Heath or Louise Tipton) at (415) 666-1814, room Clinics 116 **.**

Sincerely,

Carol Vile RN M.S. for

Walter L. Way, M.D.
Chairman
Committee on Human Research

CC: Contract and Grants
Drug Info and Analysis Service
___ VAMC Research Office

Enc: extra copies of protocol

APPENDIX B-1

Correlations Among Individual Lesbian Identity Variables

	Lesbian Behavior	Lesbian Feelings	Satisfaction	Healthy	Importance	Obviousness
Lesbian Feelings	.31 p=.008 (66)					
Satisfaction with being lesbian	.29 p=.014 (66)	-.05 p=.679 (66)				
Healthiness of being lesbian	.17 p=.0152 (65)	.14 p=.241 (65)	.15 p=.203 (65)			
Importance of being lesbian	.28 p=.017 (65)	.09 p=.445 (65)	-.02 p=.885 (65)	.14 p=.238 (64)		
Obviousness of being lesbian	.20 p=.070 (65)	.07 p=.532 (65)	.18 p=.106 (65)	.01 p=.958 (64)	.31 p=.006 (64)	
Length Time as lesbian	.17 p=.094 (63)	.20 p=.048 (63)	-.04 p=.672 (63)	-.06 p=.575 (62)	-.12 p=.256 (62)	-.09 p=.371 (62)

Kendall's Tau Table

Correlations Among Composite Lesbian Identity Variable and Individual Variables

	Lesbian Behavior	Lesbian Feelings	Satisfaction	Healthy	Importance	Obviousness	Length Time Lesbian
Composite Lesbian Identity	.62 (66) p=.000	.50 (66) p=.000	.37 (65) p=.000	.34 (65) p=.000	.60 (63) p=.000	.67 (65) p=.000	-.13 (63) p=.305

Pearson's Correlation.

APPENDIX B-2

Correlations Among Individual Chronic Illness Identity Variables

	Length Time Chronic Ill	Importance	Seriousness	Obviousness
Importance	-.04 p=.699 (57)			
Seriousness	-.03 p=.751 (56)	.47 p=.000 (63)		
Obviousness	-.06 p=.586 (55)	.23 p=.034 (62)	.32 p=.004 (60)	
Physical Health	.23 p=.025 (58)	.25 p=.024 (65)	.40 p=.000 (64)	-.11 p=.324 (62)

Kendall's Tau

Correlations Among Composite Chronic Illness Variable and Individual Variables

	Importance	Seriousness	Obviousness	Physical Health	Length Time Chronically Ill
Composite Chronic Illness Identity	.67 p=.000 (65)	.81 p=.000 (64)	.66 p=.000 (62)	missing	.10 p=.463 (58)

Pearson's Correlation

APPENDIX B-3

Sample Characteristics

Frequency Distribution of Age of Participants in Entire Sample (n = 66)

Age	Number	Percent
19-29	20	30.3
30-39	36	54.4
40-49	4	6.0
50-59	5	7.5
60 and above	1	1.5
Total	66	99.7

Range	Median	Mean	Standard Deviation
19-73	32	34	9.05

Frequency Distribution of Employment Status (n = 66)

	n	%
Working Full-time	19	29
Working Part-time	26	39
More than One Job	6	9
Unemployed	9	14
Student	19	29
Volunteer	10	15
Other	16	24

Numbers and percents not cumulative because respondents could check more than one option

Frequency Distribution of Occupational Categories Using Occupational Scale of Hollingshead Four Factor Index of Social status

Score	Description	Frequency
9	Higher Executives, Large Business Owners, Major Professionals	3
8	Administrators, Lesser Professionals, Medium-Sized Business Owners	17
	Teachers	(8)
	Nurses	(6)
	Others	(3)
7	Smaller Business Owners, Farm Owners, Managers, Minor Professionals, Entertainers, Artists	5
6	Technicians, Semiprofessionals, Samll Business Owners ($50,000-75-000)	17
	Therapists	(6)
5	Clerical and Sales Workers, Small Farm and Business Owners ($25,000-50,000)	7
4	Skilled Manual Workers, Craftsmen, Tenant Farmers, Samll Business Owners (less than ($25,000)	4
3	Machine Operators, Semiskilled Workers	3
2	Unskilled Workers	0
1	Farm Laborers, Menial Service Workers	0
None		2
Unclassified		5
	Total	66

Frequency Distribution of Sources of Income (n = 66)

	n	%
Work	41	62
Welfare	2	3
Unemployment	6	9
Disability	14	21
Investments	13	20
Independent Wealth	8	12
Family	14	21
Alimony	1	2
Child Support	2	3
Other	17	26

Numbers and percents not cumulative because respondents could check more than one option

Frequency Distribution of Perceived Socio-Economic Status (n=65)

	n	%
less than 5,000	10	15
5,000 - 9,999	20	30
10,000 - 14,999	16	24
15,000 - 19,999	7	11
20,000 - 24,999	7	11
25,000, 29,000	3	5
30,000 - 39,999	1	2
40,000 and above	2	3
Total	66	101

Frequency Distribution of Perceived Socio-Economic Status (n = 65)

	When Growning Up		Now	
	n	%	n	%
Upper	2	3	1	2
Middle	30	46	33	51
Working	26	39	19	29
Poor	8	12	12	18
Total	66	100	65	100

Frequency Distribution of Religiousness/Spiritualness (n = 66)

	Value	n	%
Very Religious/Spiritual	1	9	14
	2	23	35
	3	22	33
	4	6	9
Not at All Religious/Spiritual	5	6	9
Total		66	100

Mean 2.65 Standard Deviation 1.12

Frequency Distribution of Religion

	Raised to Be		Now	
	n	%	n	%
Catholic	15	23	2	3
Protestant	32	49	5	8
Jewish	14	21	11	17
Feminist/Wicca	-	-	10	23
Other	3	5	15	33
No Religion	2	3	21	16
Total	66	101	64	100

Frequency Distribution of Those Listing a Second Current Religion (n = 12)

	n	%
Feminist/Wicca	7	58
Other	5	42
Total	12	100

Frequency Distribution of Current Legal Marital Status Status (n = 66)

	n	%
Current Legal Marital Status		
Never Married	51	77
Currently Married	1	2
Separated	--	--
Widowed	--	--
Divorced	14	21
Total	66	100

Frequency Distribution of Current Relationship Status (n = 65)

	n	%
Single	30	46
Primary Partner - Female	32	49
Primary Partner - Male	1	2
Other	2	3
Total	65	100

Frequency Distributions of Lesbian Variables (n = 66)

	Sexual Behavior in Last Year		Sexual Feelings in Last Year	
	n	%	n	%
Exclusively Lesbian	56	85	33	50
Primarily Lesbian	6	9	23	35
Primarily Lesbian with Substantial Heterosexual	2	3	9	14
Equally Lesbian and Heterosexual	1	2	1	2
Primarily Heterosexual with Substantial Lesbian	1	2	-	-
Primarily Heterosexual	-	-	-	-
Exclusively Heterosexual	-	-	-	-
Total	66	101	66	101

Satisfaction with Sexual Preference

	Value	n	%
Very Satisfied	1	53	80
	2	10	15
	3	1	2
	4	2	3
Not at All Satisfied	5	-	-
Total		66	100

Mean 1.30 Standard Deviation .40

How Healthy is Your Sexual Preference

	Value	n	%
Very Healthy	1	60	92
	2	3	5
	3	2	3
	4	-	-
Not at All Healthy	5	-	-
Total		65	100

Mean 1.11 Standard Deviation .40

How Important That You Are Lesbian

	Value	n	%
Very Important	1	50	76
	2	10	15
	3	3	5
	4	1	2
Not At All Important	5	1	2
Varies	9	1	2
Total		66	102

Mean 1.35 Standard Deviation .78

How Obvious to Others You Are Lesbian

	Value	n	%
Very Obvious	1	8	12
	2	26	40
	3	16	24
	4	13	20
Not At All Obvious	5	2	3
Total		65	99

Mean 2.62 Standard Deviation 1.04

Frequency Distributions of Chronic Illness Variables

My Physical Health Is:

	Value	n	%
Very Poor	1	5	5
	2	15	26
	3	26	39
	4	17	23
Excellent	5	1	2
Total		64	95

Mean 2.97 Standard Deviation .99

How Important That You Are Chronically Ill?

	Value	n	%
Very Important	1	37	57
	2	20	31
	3	4	6
	4	3	5
Not At All Important	5	1	2
Total		65	101

Mean 1.63 Standard Deviation .911

How Serious Is Your Chronic Illness?

	Value	n	%
Very Serious	1	13	20
	2	25	38
	3	17	26
	4	9	14
Not At All Serious	5	-	-
Total		64	98

Mean 2.34 Standard Deviation .96

How Obvious That You Are Chronically Illness?

	Value	n	%
Very Obvious	1	4	6
	2	9	14
	3	11	17
	4	17	26
Not At All Obvious	5	21	32
Not Sure	8	1	2
Varies	9	3	5
Total		66	102

Mean 3.68 Standard Deviation 1.26

APPENDIX B-4

General Social Network Characteristics

Frequency Distribution of Relationships of Network Members to Participants in the Total Network (n = 63)

	Mean Percent	Standard Deviation
Non-Kin	60.5	13.8
Partner/Lover	4.4	2.8
Friend	47.0	15.3
Housemate	3.0	5.7
Ex-Lover	3.8	5.8
Ex-Friend	1.0	4.2
Child	.7	2.3
Other Intimate	.6	2.0
Kin	20.2	12.1
Mother	4.3	3.3
Father	3.6	4.7
Sister	3.7	5.0
Brother	3.3	1.8
Step-Parent	.6	2.2
Grandparent	.9	2.4
Child	.6	
Partner's Relative	.2	1.6
Other Relative	3.0	5.8
Health Care Providers	9.6	8.0
Therapist	4.3	4.6
Other Health Care Provider	4.3	5.5
Sponsor (AA, AlAnon)	.6	1.9
Ex-Health Care Provider	.4	1.6
Other	9.7	8.7
Co-Worker	2.9	5.3
Client	.4	2.3
Boss, Supervisor	1.9	3.6
Teacher	1.5	3.2
Other Professional	1.3	4.0
Landlord	.3	1.5
Neighbor	1.4	4.1

Frequency Distribution of Duration of Relationships (n = 63)

	Value	Mean%	s.d.
Less than 6 Months	1	8.1	10.1
6-12 Months	2	10.8	11.7
1-2 Years	3	14.5	11.7
2-5 Years	4	20.6	12.7
More than 5 Years	5	46.0	19.7

Mean 3.9 Standard Deviation .51

Frequency Distribution of Frequency of Contact with Network Members (n = 63)

	Value	Mean%	s.d.
Daily	5	15.9	12.4
Weekly	4	33.3	18.3
Monthly	3	25.6	15.0
A Few Times a Year	2	19.0	13.2
Once a Year or Less	1	5.6	8.7

Mean 3.3 Standard Deviation .45

Frequency Distribution of Importance of Network Relationships (n = 63)

	Value	Mean%	s.d.
Not Very Important	1	6.3	14.4
	2	6.0	8.8
	3	17.6	12.9
	4	21.6	15.2
Very Important	5	46.3	24.5

Mean 3.0 Standard Deviation .67

Frequency Distribution of Availability of Network Members (n = 63)

	Value	Mean%	s.d.
Not At All Available	1	6.7	11.1
	2	16.7	15.3
	3	26.0	14.6
	4	20.8	14.4
Very Available	5	28.0	19.9

Mean 2.5 Standard Deviation .56

Frequency Distribution of General Support of Network Members (n = 63)

	Value	Mean%	s.d.
Not At All Supportive	1	7.6	9.6
	2	9.9	11.4
	3	18.8	12.8
	4	21.8	15.1
Very Available	5	41.6	24.8

Mean 2.8 Standard Deviation .61

Frequency Distribution of Satisfaction with Network Relationships (n = 63)

	Value	Mean%	s.d.
Not At All Satsified	1	7.6	10.2
	2	12.1	11.7
	3	22.0	15.4
	4	26.0	16.4
Very Available	5	31.9	22.3

Mean 2.6 Standard Deviation .53

Frequency Distribution of Balance with Relationships (n = 63)

	Value	Mean%	s.d.
Very Imbalanced. I Do Much More	1	6.5	8.9
I Do a Little More	2	13.9	12.0
Balanced	3	58.5	23.1
Other Person Does Little More	4	10.1	10.9
Very Imbalanced Other Person Does Much More	5	6.4	8.6
Varies		.3	1.4

Mean 2.5 Standard Deviation .32

APPENDIX B-5

Lesbian Social Network Characteristics

Frequency Distribution of Knowledge of Participant's Sexual Preference (n = 63)

Does This Person Know Your Sexual Preference	Mean%	s.d.
No	5.1	11.3
Not Sure, Think Not	2.9	5.4
Not Sure, Think So	5.3	11.1
Yes, I Told	71.9	31.0
Yes, Found Out Another Way	12.5	21.4

Frequency Distribution of Response of Network Member to Participants' Sexual Preference (N = 63)

	Mean %	s.d.
Positive/Supportive	64.5	20.3
Neutral	10.1	11.2
Mixed, Positive and Negative	7.9	8.7
Negative	4.8	6.3
Not Applicable	10.7	13.9

Frequency Distribution of Sexual Preference of Network Members (n = 63)

	Mean %	s.d.
Heterosexual	40.2	16.3
Homosexual (male or female)	46.4	19.3
Lesbian	43.4	20.5
Bisexual	5.3	7.1
I Don't Know	3.7	6.6
Other	.9	2.7
Not Applicable	1.9	4.7

APPENDIX B-6

Chronic Illness Social Network Characteristics

Frequency Distribution of Knowledge of Participants' Chronic Illness/Disability (n = 63)

Does This Person Know You Have a Chronic Illness/Disability	Mean %	s.d.
No	4.5	10.9
Not Sure, Think Not	1.5	3.3
Not Sure, Think So	6.7	13.0
Yes, I Told	76.9	30.0
Yes, Found Out Another Way	6.8	15.8

Frequency Distribution of Network Members' Responses to Participants' Chronic Illness/Disability (n = 63)

	Mean %	s.d.
Positive/Supportive	59.0	26.1
Neutral	12.1	13.6
Mixed, Positive and Negative	11.3	12.5
Negative	4.7	6.9
Not Applicable	9.5	14.3

Frequency Distribution of Chronic Illness/Disability Status of Network Members (n = 63)

	%
Has Chronic Illness or Hidden Disability	20.9
Has a Visible Illness or Disability	3.8
Has Both Visible and Invisible Illness/Disability	3.6
Has No Chronic Illness Disability	52.1
I Don't Know	12.5
Other	2.0

APPENDIX B-7

Frequency Distribution of Responses to Mental Health Status Questions from the General Well-Being Schedule

59. Have you had severe enough personal, emotional, behavior, or mental problems that you felt you needed help DURING THE PAST YEAR?

% (n = 64)

1. [76.6] Yes, and I did seek professional help
2. [4.7] Yes, but I did not seek professional help
3. [1.6] I have had (or have now) severe personal problems, but have not felt I needed professional help
4. [15.6] I have had very few personal problems of any serious concern
5. [1.6] I have not been bothered at all by personal problems during the past year

60. Has anyone said or suggested that you should seek professional help for some personal, emotional, behavior, or mental problem DURING THE PAST YEAR?

% (n = 63)

1. [6.3] YES - and I did go (or am going now) but it did not help
2. [39.7] YES - and I did go (or am going now) and it did help
3. [4.8] YES - and I seriously considered going, but did not go
4. [ ] YES - but I felt it would not help me with my problem(s)
5. [1.6] YES - but I did not feel that I needed such help
6. [4.8] NO - but I did go (or am going now) but it did not help
7. [22.2] NO - but I did go (or am going now) and it did help
8. [19.0] NO - but I would go if I felt I needed such help
9. [1.6] NO - and I would not go under any condition

61. Has anyone (such as in your family, a close friend, someone at work, or in your neighborhood, etc.) been a source or cause of disturbance or distress to you DURING THE PAST YEAR?

% (n = 65)

1. [43.1] Yes, very much so and I am still disturbed
2. [9.2] Yes, very much so for a while, but I am over it now
3. [21.5] Yes, to some extent and I am still disturbed
4. [10.8] Yes, to some extent but I am over it now
5. [12.3] Only a few minor things that did not last very long
6. [1.5] No, not at all

62. Have you ever felt that you were going to have or were close to having a nervous breakdown?

% (n = 63)

1. [9.5] YES _ during the past year and I still feel near one
2. [23.8] YES - during the past year but I do not feel near one now
3. [9.5] YES - more than a year ago, and I am not completely over it yet
4. [34.9] YES - more than a year ago but I am completely over it now
5. [22.2] NO = Never

63. Have you ever had a nervous breakdown?

% (n = 62)

1. [ ] YES - during the past year and I have not completely recovered yet
2. [3.2] YES - during the past year but I am over it now
3. [8.1] YES - more than a year ago and I am not completely over it yet
4. [16.1] YES - more than a year ago but I am completely over it now
5. [72.6] NO - Never

64. Have you ever been a patient or out-patient at a mental hospital, a mental health ward of a hospital, or a mental health clinic, for any personal, emotional, behavior, or mental problem?

% (n = 65)
1. [7.7] YES - and I am still going
2. [4.6] YES - during the past year but not now
3. [20.0] YES - YES - more than a year ago
4. [67.7] NO - never

65. Have you ever seen a psychiatrist, psychologist, or psychoanalyst about any personal, emotional, behavior, or mental problem concerning yourself?

% (n = 63
1. [36.5] YES - and I am still going
2. [22.2] YES - during the past year but not now
3. [28.6] YES - more than a year ago
4. [12.7] NO - Never

66. Have you talked with or had any connection with any of the following about some personal, emotional, behavior, mental problem, worries, or "nerves" CONCERNING YOURSELF DURING THE PAST YEAR?

		% (n = 65)
a.	Regular medical doctor (except for definite physical conditions or routine check-ups)	27.3
b.	Brain or nerve specialist	13.6
c.	Nurse (except for routine medical conditions)	15.2
d.	Lawyer (except for routine legal services	4.2
e.	Police (except for simple traffic violations)	4.6
f.	Clergyman, minister, priest, rabbi, etc.	4.6
g.	Marriage or family counselor	21.5
h.	Social or welfare worker	10.8
i.	Group therapy	23.1
j.	Occupational or educational counselor	20.0
k.	Drug abuse clinic or center(s)	6.5
l.	Alcohol abuse clinic or center(s)	6.2
m.	Suicide prevention center	4.6
n.	A "hot line" service for emotional problems	4.6
o.	Any other formal "mental health" assistance	4.5

67. Do you discuss your problems with any members of your family or friends?

% (n = 65)
1. [59.0] YES - and it helps a lot
2. [37.0] YES - and it helps some
3. [1.5] YES - but it does not help at all
4. [1.5] NO - I do not have anyone I can talk with about my problems
5. [ ] NO - No one cares to hear about my problems
6. [1.5] NO - I do not care to talk about my problems with anyone
7. [ ] NO - I do not have any problems

APPENDIX B-8

Overall Evaluation of Life Situation from the General Well-Being Schedule (n = 65)

A. How things were this time a year ago:

B. How things are (going) at present:

C. How you think your life situation will most likely be this time a year from now:

	LAST YEAR	NOW	NEXT YEAR	
(10)		1.5	9.7	Absolutely tops - could not be better
(09)	6.2	7.7	25.8	Very well, could hardly be better
(08)	15.4	26.2	22.6	Actually quite good
(07)	7.7	21.5	16.1	Pretty good really
(06)	10.8	10.8	19.4	Somewhat positive
(05)	16.9	18.5	6.5	Positive and negative aspects about even
(04)	9.2	7.7		Somewhat negative
(03)	12.3	1.5		Pretty bad really
(02)	15.4	4.6		Actually quite bad
(01)	3.1			Very bad, could hardly be worse
(00)	3.1			Absolute bottom - could not be worse
MEAN SCORE	4.89	6.46	7.7	