

**Staying Well Together:
Social Support and Well-Being Among
Lesbian Couples in Manitoba**

By
Jan Mitchell

A Thesis
Submitted to the Faculty of Graduate Studies

In Partial Fulfilment of the Requirements of the Degree of
Master of Arts

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Jan Mitchell

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree
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Abstract

This research examines experiences of health and social support among a sample of nine lesbian couples and two individuals in Manitoba. The project used a feminist, qualitative approach. The research goal is to gain an understanding of the experiences of lesbian couples coping with an illness or disability, and the social support in their lives in relation to these experiences. Feminist standpoint theory sensitized this research. The sample was purposive and included the use of snowball techniques. Qualitative, in-depth interviews were conducted. The study focuses on lesbians' voices - as couples and as individuals - and the stories they share about their experiences trying to stay well together.

On the basis of the narrative accounts of the women in this study, it is evident that illness and disability are stressful experiences, and that being lesbian (whether or not one is closeted) may make accessing social support, and effective, appropriate health and social services difficult. Many of the women experience a feeling of invisibility within the formal health and social services sector. The women report receiving the most helpful social support from their partners, and generally less support from co-workers, family and friends. While a partner's support is considered by all of the women to be vital, several of the women reported that excessive and exclusive dependence on one's partner as the primary source of social support placed inordinate stress on the relationship. Nevertheless, the women tended to rely most on their partners, claiming "she's all I've got," when other sources of support were wanting.

The findings suggest that there is a need to create more lesbian-friendly services and policies, so that the health and well-being of lesbians in general,

and those with serious illnesses or disabilities are not further compromised. This research contributes to the literature on women's health, lesbian studies, and lesbian health.

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Prologue
from Cancer in Two Voices

"Streams of women move through our house, responding to Barbara's letter for help. I continue to work because I don't know what else to do. It is so much an integral part of who I am. Without it I feel diminished - less able to be the woman Barbara fell in love with. Less able to nourish and help her in this time.

I have to learn to allow others to help us, to do some of the care-giving. Yet I still feel torn and guilty at the relief I feel to be back in my own life for a few days. I call home every four hours to be sure each woman has shown up for her shift, that there are no unforeseen symptoms, and that Barbara is in good spirits.

She is losing her hair. Next month she will lose a breast. It makes the cancer less an intellectual reality and more concrete, more physical.

I worry about how I will negotiate the high wire of self and other. Autonomy and engagement. Commitment and absence. How will her cancer force me to engage with the choices of being both in my life and in hers as well - and still keep my balance?"

(Butler & Rosenblum, 1991: 17)

Cancer in Two Voices is a book written by Sandra Butler and her partner, Barbara Rosenblum, describing their experiences as a lesbian couple coping through Barbara's terminal struggle with breast cancer. The book was an important source of inspiration for this thesis research.

Chapter One: Introduction

In my graduate studies in Sociology, I was introduced in a Health Sociology class to the the story of Cancer in Two Voices. Set as a documentary and as a book, Cancer in Two Voices (1991) documents the lives of lesbian couple Sandra Butler and Barbara Rosenblum as they deal with Barbara's breast cancer and ultimate death. Before reading the book and seeing the film, I only knew that I had a general interest in doing research with the lesbian community. Seeing the film, Cancer in Two Voices, however, was a transformative experience. My reaction to seeing Sandra and Barbara as they described their stories was intensely emotional, and something told me immediately that I needed to follow in the direction that they began. I decided that the research I wanted to do should focus on the stories of lesbian couples, social support and health issues. Cancer In Two Voices became the inspiration for this entire research project.

This research examines the experiences of illness, social support and well-being among a sample of lesbian couples living in Manitoba. The main objective is to listen to the voices of lesbian couples who deal with illness/disability (e.g. with cancer, multiple sclerosis, drug/alcohol dependency, depression), and to understand how experiences of social support from partners, social networks and health care providers influence their well-being. Social support, which is known to be a positive influence on health and wellness (Dean & Lin, 1977), may be particularly beneficial for a stigmatized and marginalized group such as lesbians. The literature indicates that compared to heterosexuals, lesbians and gay men may not have access to the same degree of support from family, co-workers, and religious organizations, because of homophobic attitudes and stigma associated with

being lesbian (Ayala & Coleman, 2000; Wayment & Peplau, 1995; White & Levinson, 1993). In a heterosexist society, lesbians often feel the need to be secretive about their sexuality even once they have “come out” to themselves, therefore social support received from partners may contribute substantially to lesbians’ general well-being, and to their ability to cope with illness. The existence of social support for lesbians who are ill (e.g., someone to listen, to offer advice, to drive and accompany them to appointments) may, therefore, buffer the strain of these experiences.

While living within heterosexist society, lesbian communities are often hidden, and lesbians are rarely heard from regarding their experiences of illness and social support (White & Levinson, 1993). If, in fact, current formal practices and policies aimed at offering support to patients are not accessible to and inclusive of lesbians, as anecdotal evidence suggests, then it is important to consider what lesbian couples’ experiences are, and where lesbian couples find support.

In this research, I am interested in the experience of lesbians who are ill or disabled. I am learning about the social support that lesbian couples receive both from informal and formal helpers, and how support from a partner influences well-being. I document couples’ treatment by social response systems such as health care providers when they are attempting to access support. I also explore the impact of being closeted on lesbians’ experiences of coping through illness together, and the lessons participants have learned through the process of dealing with serious health issues.

The intent in this research is not to formulate one grand narrative into which all lesbians’ experiences of support must fit, but rather to explore how the varying experiences of illness and social support are affected by lesbians’

social positions. Time and context-based truths are constructed as lesbians' voices are heard, and it is hoped that some social and political action will be taken as a result of the research process and after (e.g., education, support and advocacy both within, and outside of the community for a focus on lesbian health).

Chapter Two offers a context to the research, including its theoretical framework, a synopsis of the social support literature, and a review of the existing literature on lesbian health. Chapter Three outlines the feminist qualitative methods and procedures which were used to undertake this research. Following in Chapter Four are brief descriptions of the women who participated in the research. Chapters Five, Six and Seven are devoted to the main themes that emerged from the data. Chapter Five, "Stress, Illness, and Social Support in Lesbian Relationships," describes the added strain that illness places on women whose lives are already quite stressful, and portrays the dynamics of these lesbians' relationships as they cope through illness together. Chapter Six, "Social Support and Social Networks Outside Couples' Primary Relationships," examines the other individuals who make up lesbian couples' social support networks. Chapter Seven, "Interactions with Health Care Providers," describes positive and negative experiences participants have had with health care providers, as well as the strategies they use in order to access better health care. Finally, Chapter Eight provides a discussion about the findings, as well as the effects and limitations of the study.

Feminist principles and theories are used to guide this research. In the objective of creating "usable knowledge," participants were encouraged to reflect upon their experiences, to learn and share knowledge, and to continue

the social action fostered by the research even after the project's completion (Ristock and Pennell, 1996: 11). Qualitative, in-depth interviews allow participants to communicate their diverse experiences of support in relation to an illness or disability. A feminist thematic analysis provides an important discussion of some of the factors that shape lesbians' lives and experiences.

Within this research, lesbians describe the supports they have both received, and from which they have been excluded. The project concludes with recommendations for further work, and with the hope that direct action will arise in the spirit of lesbians "taking their health into their own hands," to create of systems and supports which are inclusive of, and accessible to, lesbians and their families.

The findings of this research contribute to the broad literature on women's health, and to the area of lesbian studies. This research will help to achieve a more complete understanding of lesbian couples' health experiences together, and their experience of social supports.

Chapter Two: Context of the Research

Theoretical Framework

Feminist standpoint epistemology is used to sensitize this research on the experiences of lesbian couples dealing with health issues. Within sociological theory, feminist theory transcends the traditional micro-macro debate, and demonstrates the need for an analysis of both the private and public spheres of women's lives (Ritzer, 1992: 309). It is impossible to understand the larger structures which affect women's lives without first looking at those personal experiences. The main question, "And what about the women?" has urged on the development of feminist theory within sociology, serving as a reminder that much of history and experience has been defined by males whose lives are not usually mirrored by women's. Feminists see that women have historically played diverse roles, and they often experience social life differently than men, based on their social positions. "[T]he particularities of invisibility, inequality, and role are profoundly affected by a woman's social location, that is, by her class, race, age, affectional preference, religion, ethnicity, and global location" (Ritzer, 1992: 310). Thus, rejecting androcentric knowledge as a way of explaining women's experiences is a key feminist principle.

Feminist theory "begins with women, places women and women's experiences at the centre and names the oppression of women, [and] involves a holistic view of the world, an analysis which probes every facet of existence for women" (Rowland & Klein, 1996: 13, in Weedon, 1999: 37). As women's experiences are often excluded from contemporary research in many disciplines, feminist methods provide an approach to research that is

consistent with feminist aims of challenging inequality and empowering women. Feminist theory and research seeks to validate, give voice to, and understand the experiences of women who have been marginalized by traditional research. Dawn Currie explains that there are two important insights to be extracted from feminist theory when doing research: that the personal is the political, and that the distinction between objective and subjective experience is acknowledged as false (Currie, 1988: 232).

Studying the daily lives of women to learn more about, and thus create strategies to end women's oppression is necessarily a political act. Dorothy Smith's sociological approach "see[s] women actively constructing and interpreting the social processes and social relationships which contribute to their everyday realities" (Stanley, 1990: 24). Devault, commenting on Dorothy Smith, suggests that "the injunction to start inquiry from women's experience is a way of pointing the feminist researcher to material sites where people live their lives so that anyone's experience, however various, could become a beginning place [for] inquiry" (Devault, 1999: 40).

Feminist standpoint epistemology, as discussed by Harding (1986) argues for a feminist research "not only located in, but proceeding from the grounded analysis of women's lived realities" (Stanley, 1990: 25). It is a socially constructed way of making sense of the world, and it treats women's lives as an empirical point of reference (Jagger, 1983: 387). Standpoint feminist epistemology stems from social constructionist theory, and draws upon insights of Marx and Engels (Stanley, 1990), including Marxist ideas about class relations. Standpoint feminist theory claims that people's material conditions contribute to, structure and limit their own understandings of their lives (Harding, 1991). Members of powerful, dominant groups will have

opposing views of social reality compared to members of oppressed groups (Neilsen, 1990). Less powerful members of society experience a different reality, and indeed have the potential for a more complete view of social reality than others, precisely because of their disadvantaged positions (Harding, 1991; Neilsen, 1990). A group that is oppressed needs the knowledge, awareness and sensitivity of both the dominant group's perspective and their own in order to survive (Harding, 1991). In theory, the more oppressed a group is, the greater the potential for knowledge construction.

Neilsen (1990) suggests that women, as an oppressed class, have the ability not only to frame their own experiences of oppression, but to understand their oppressors' reality, too, and to do so more accurately, since the dominant group's view is "partial and perverse" in contrast to the subordinate group's view. Feminist standpoint theory comes as a response to the patriarchal notion that women's experiences are invalid bases for knowledge. In fact, feminist standpoint suggests that women's experiences are a more valid basis for knowledge than any other, because they offer a wider portrayal of the truth through insights into their oppressors (Neilsen, 1990; Stanley, 1990).

While women in patriarchal society are able to understand the different interpretations of reality of both males and females in society, gays and lesbians in heterosexist society "must learn heterosexual patterns of socialization and interactions, as well as their own, if they wish to avoid the severest consequences of homophobia, and to build personally satisfying and meaningful relationships" (Swignoski, 1993: 173). Lesbians, doubly oppressed by gender and sexual orientation, come to understand their own realities, and

the heterosexual social world in which they live, in order to survive. It is this “double vision” that makes the voices and experiences of marginalized groups extremely valuable (Swignoski, 1993).

A standpoint is “a social position from which certain features of reality come into prominence, and other aspects of reality are obscured” (Swignoski, 1993). A person’s standpoint comes from her social location, and emerges from factors such as gender, culture, class, ethnic background, and sexual orientation, and how they all interact to influence a person’s daily life (Swignoski, 1993). Stanley (1990) describes a standpoint as a position in society. It is a way of making sense that is affected by, and can in turn help shape, structures of power. From different standpoints, some things can be seen more clearly than from others. Knowledge is subjective, and is about *who* knows, and *how* they know, based on their standpoint. Stanley and Wise agree that “all knowledge necessarily results from the conditions of its production, is contextually located, and irrevocably bears the marks of its origins in the minds and intellectual practices of those...who give voice to it” (Stanley, 1990: 39).

In Harding’s early work on standpoint feminism, she outlines that to achieve a feminist standpoint, one must engage in the intellectual and political struggle necessary to see natural and social life from the point of view of that disdained activity which produced women’s social experiences, instead of from the partial and perverse perspective available from the ‘ruling gender’ experience of men. (Harding, 1987: 26)

Standpoints involve a level of consciousness about people’s locations in social structures, and relationships of those locations to people’s lived experiences (Harding, 1987). Standpoint epistemology does not imply that all women share a single perspective or position, but rather “insists on the

importance of following out the implications of women's (and others') various locations in socially organized activities" (Devault, 1999: 60). Not only is there no typical woman's life, nor any one particular "lesbian standpoint," but it is also important to note that "women's experiences of their lives are not necessarily the same as feminist knowledge of women's lives" (Harding, 1991: 10-11). Harding (1991) further develops her discussion of standpoint:

For a position to count as a feminist standpoint it must begin in the objective location of women's lives, and the authority for the feminist standpoint lies not in women's authentic renditions of their lives, but in the subsequently articulated observations and theory about the rest of nature and social relations - observations and theory that start out from that look at the world from the perspective of women's lives (Harding 1991: 124)

Social location is a powerful factor in shaping and constraining one's perceptions of reality. The following, from Himani Bannerji's Returning the Gaze (1993) explains how it is possible to see the relations of power in the lives of marginalized women, and further asserts the importance of using standpoint feminism to study women's daily lives. This quotation adds to the relevance of studying lesbians, and helps to locate the direction of this research, and the way in which the analysis will be carried out.

The point is to shift the centre itself from the mainstream to the so-called margin. By understanding "representation" to mean re-presentation of our realities, from a foundationally critical / revolutionary perspective, there can emerge the possibility of making our very marginality itself the epicentre for change. This has always been the principle of any fundamentally revolutionary or critical perspective. After all, all relations of ruling become more visible where they converge most fully: for example, in the structures of the daily lives of non-white women, particularly if they are working class, and I would add, lesbian (Bannerji, 1993: 31).

Feminist standpoint research attempts to understand how the social structure contributes to the problems found in people's day to day lives, and seeks to transform oppressive existing social structures (Devault, 1999; Harding, 1991; Stanley, 1990).

Feminist standpoint theory is very relevant to issues of voice (Stanley, 1990). Many women's voices have not been heard within mainstream theory, even by women, while the voices of dominant group members are most often heard. In the development of feminist standpoint epistemology, theory is constructed specifically from the voices and experiences of marginalized others (Harding, 1991). Two particularly silenced standpoints even in feminist literature have historically been women of color and lesbians (Stanley, 1990; Devault 1999). Standpoint feminist theory asserts that a purpose of research must be to empower the subjects of the research, and to advance their causes (Cook & Fonow, 1990). A beginning point of action is the telling of these women's stories (Stanley, 1990).

The primary focus of standpoint feminist epistemology is the situatedness of the subject or knower. Knowledge is "situated" in the context of one's own experiences (Harding, 1986). When listening to experiences of health crises and social support, it is important to frame these incidents in the larger context of participants' lives, and to look at where that speaker is located in the larger social structure. Lesbians' social positions, situated within a larger context of patriarchy, heterosexism and homophobia are linked closely to their lived experiences. People's social positions become their ways of making sense of the world, and these in turn greatly affect the ways in which they experience and think about health, illness, social support and relationships. Each woman's experience is produced differently, but common

larger oppressive systems may result in similar effects, including invisibility and inequality for lesbians.

Stanley (1990) says that standpoint feminist epistemology does not argue for women's separation, but rather to remove existing malestream, methodological separatism, which ignores, because it silences. In a sense, traditional theory cannot 'see' the social world from women's standpoint (Stanley, 1990: 39). With the creation of standpoint theory, women's perspectives are centralized in order to develop an accurate understanding of reality. Feminist standpoint epistemology argues that women and their views have a radically different vantage point than those of men. Using the position of marginalized women and their standpoint makes a dramatic difference in how knowledge is produced, and what knowledge emerges.

As the main theoretical influence, standpoint feminism is suitable to shape this research. Standpoint feminism starts from a consideration of the importance of women's values and looks toward the potential of feminist knowledge to change paradigms and create a truer picture of reality (Harding, 1986). It recognizes that all knowledge is 'situated' in the context of one's own experience and social location, and allows for multiple realities to emerge. It gives testimony about marginalized women's experiences, and makes a place for it in analysis that will be focussed differently than mainstream research (Devault, 1999: 38). It values the voices of the marginalized, and recognizes that it is often those on the margins, outside of power who initiate societal change (Stanley, 1990).

Placing this research within a feminist framework has implications for both the methods used and analysis that emerges. Feminist standpoint sensitizes me to consider lesbians' social positions, their lived experiences,

and their meanings of well-being and social support. Research grounded in feminism can more easily lead women to empowerment and social action, and allows me to keep the research and theoretical discussion grounded in the lived experiences of these women. A look now at the existing literature in the broad area of social support will be useful in understanding some of the underpinnings and assumptions of the concept of social support in this research.

A Review of the Social Support Literature

Limited literature exists which attempts to theorize lesbians' experiences of social support. However, there is a great deal of literature which describes the positive effects of social support on stress and health in the general population. This research project involves the application of a feminist sensibility to the study of social support, in view of the fact that the extant literature has mostly been silent on women's lived realities. If social support is considered a buffer to the stress of living in a marginalized and often hidden society (the way some lesbians may describe their lives), then it is fair to assume that without this buffer, the well-being of community members would no doubt suffer.

The concept of "social health" is important in the field of health sociology. Since the creation of the WHO's broad definition of health, there has been an increased emphasis on viewing patients as social beings. Researchers describe social health as "that dimension of an individual's well-being that concerns how [s]he gets along with other people, how other people react to [her], and how [s]he interacts with social institutions and societal mores" (Russell, 1973: 77). It is known that people who are well-integrated

into their communities tend to live longer, have a higher resistance to disease, and recover more quickly than those people who are socially isolated (Berkman & Syme, 1979; Cobb, 1976). Practical reasons for measuring a person's social health include the significance of both examining the existence of social support available, and investigating the social ties associated with a person's well-being. However, classic studies in the social support literature have not considered what it means to be ill and to seek support as an individual who is part of a marginalized community, like the lesbian community.

Troubling assumptions exist in past research, particularly with respect to the idea that it is always possible and desirable for people to be well-integrated into their communities. To emphasize the limits of the above definition of social health, let us consider as an example a lesbian who gets along well with others in her social group, however, heterosexist, homophobic society responds negatively to her based on her sexuality, and she is excluded from social institutions because of seeming chosen "deviance" from and rejection of society's established norms for women. Social health and well-being may involve some modification to Russell's definition, and may mean very different things for women of different social locations. Russell's definition would indicate necessarily that lesbians may not have control over all aspects of their own well-being, as many of society's attitudes and fears about homosexuality have negative effects on the well-being of lesbians.

The differing stressors faced by lesbians in society and the make-up of their support networks are not clearly acknowledged in traditional research on experiences of social support. A few studies in the 1990s have considered

lesbians' experiences of social support, and Thoits (1995: 56) acknowledges in general that members of disadvantaged social groups are especially vulnerable to external stressors, and thus especially in need of social support. Alternative sexual orientations have seldom been recognized as social statuses that may be potentially stressful in general, or when compounding other issues in a person's life, such as a health crisis. Much current research is still laden with heterosexist assumptions about people's experiences. To date, a great deal of anecdotal evidence from lesbians who have dealt closely with the health care system and social service agencies indicates that support from formal helpers is not easily accessible to lesbians, nor is it sensitive to the different life experiences and stresses faced by lesbians.

According to House (1990), social support consists of interpersonal interactions that include one or more of the following: emotional support (feelings of empathy, love, trust, caring, and support), instrumental help (aid in kind, exchanges, money, labour, and time), information (advice, strategies, and suggestions for coping), and appraisal support (affirmation, feedback, and social comparison).

The concept of social support has emerged in sociological theory as a stress-mediating or buffering system (Dean & Lin, 1977; Gottlieb & Wagner, 1991). Countless researchers have recognised the positive effects of support received from a person's social network in times of stress. Social support has been defined conceptually and operationally in three main ways, with emphases on the existence or quantity of social relationships in general, or in terms of the structure of a person's social relationships, or in terms of the functional content of the relationship. The latter method of operationally defining social support is the most widely used (House, Kahn, McLeod &

Williams, 1985). The existence or quantity of relationships necessarily determines the structure of those relationships and, in part, their functional content and qualities (House, et al 1985).

The buffering role of social support may be specified in terms of three principal hypotheses: social support moderates the impact of stressful life events; the social support hypothesis holds for variant illness histories; and social support is a dynamic variable which will be influenced by life-events (i.e., social support is not static) (Dean & Lin, 1977). The experience of social support can lead a person to believe that she is cared for, loved, and valued as a member of a network of communication and mutual obligation (Cobb, 1976). Studies confirm that social support not only buffers the impact of stressful life events, but is also crucial to recovering from illness, and maintaining well-being (Berkman & Syme, 1979; Cobb, 1976; Cohen & Syme, 1985; Croog, Lipson & Levine, 1972; Dean & Lin, 1977; Lin & Westcott, 1991; Pearlin, 1985). Conversely, "the effects of exposure to stress will be more pronounced in the absence of social supports" (Gore, 1985: 271).

Lesbian couples potentially face a variety of stressors within their relationships which require the existence of social support. An example of a stressful situation would be one partner having an illness such as breast cancer, and dealing with doctors, or trying to locate inclusive support groups for both the patient and the partner. Another example would be attempting to seek help as an abusive lesbian, or as an abused lesbian partner. With the lack of legalized unions, and the benefits associated with marriage, many lesbians feel the need to create living wills or health proxies which attempt to protect the rights of the other partner in case of an accident. These few scenarios are some examples of situations which would be considered stressful for any

person (heterosexual or homosexual, male or female), however, because lesbians also face sexism, homophobia, heterosexism, and perhaps racism, ableism, and ageism, their situations, and their experience of stress is often compounded. Sociologists acknowledge the importance of a supportive group of friends or family in times of stress.

Lesbians may experience a change in their social network (i.e., the group of people to whom they turn for support) once they have “come out” about their sexual orientation and about their same-sex relationships. In turn, this change may result in a corresponding shift in the degree of available social support. Negotiating an illness through the existing medical system as a lesbian (and as a woman with another minority status) may lead to great emotional and social stress, suggesting the importance of social support. The perception of the availability of social support is crucial to maintaining a feeling of well-being and to maintaining social health. In fact, Thoits (1995: 60) found that the perception of available support has an even stronger influence on well-being than the actual receipt of support.

A social network is described by McKinlay (1980: 82) as “that set of contacts with relatives, friends, neighbors, etc. through which individuals maintain a social identity and receive emotional support, material aid, services and information, and develop new social contacts.” In recent years, sociologists have looked more closely at the direct contribution of networks to various experiences of health and illness, and at how networks influence care-seeking and health behaviours. Hall and Wellman (1985: 24) studied social support and social networks, and found that “interpersonal ties provide supportive resources, help people stay healthy, and help people deal with the pressures, opportunities and contingencies emanating from large-scale social

systems.” Berkman & Syme’s (1979) longitudinal study of Alameda County recognized that residents who lacked social ties were more likely to die during the nine-year time span of the study. They theorize that those people who are socially isolated in their communities may deal with more serious health consequences as a result (Berkman & Syme, 1979: 200). Lin and Westcott say that the general positive relationship between being married and being healthy is very well-documented (1991). Lin and Westcott note that marriage allows partners the opportunity to confide in each other, and to pool their coping resources. Essentially, two people in a relationship cope together better than an individual copes alone. Social support is most effective when a person has access to a wide range of supports from a diverse social support network (Lin & Westcott, 1991).

One of the more interesting lines of inquiry in this literature is the concept “weak” ties in social networks (Liu & Duff, 1972). The strength of a tie is measured by a combination of the amount of time, emotional intensity, and reciprocal services provided (Granovetter, 1973). Both the structure and the content of a person’s network are important in considering the strength of the ties. Strong ties are characterized by a high degree of interdependence and/or consultation with a smaller number of people, and weak ties are described as having little interdependence and/or the range of consultation contacts is diverse (McKinlay, 1980). People who socialize with the same small group of friends, and who engage in little outside interaction will all tend to have the same social network, full of strong ties. By contrast, those people who have a variety of close friends *and* acquaintances will have strong *and* weak ties, and will have the opportunity to build bridges with other networks.

Granovetter (1973) argues that weak ties in social networks become very important resources during times of change or stress. The existence of weak ties makes it possible for members of one group to link up with members of other groups. Traditional studies of social support claim that there is often little change in the support received from family members before and after an illness experience, yet there is often a change or surprise regarding interaction with some of the weak ties. It may be the connection with a certain weak tie that becomes significant to a person during a very difficult period. For example, some studies, and a great deal of anecdotal evidence have revealed that lesbians, more so than heterosexuals, often remain close to their ex-partners. Although the frequency and intensity of these relationships may be low, it is often one of the partner's ex-lovers who can be counted on as a weak tie in times of stress. "Lesbian women and gay men tend to have more positive relationships with former lovers than heterosexuals do with former spouses. The "ex" in a lesbian or gay person's life may have the special status of best friend and may often be called on in times of stress. (Sanford & Forrister, 1983: 16).

In past studies of social networks, it has been noted that factors affecting variations in connectedness in ties include economic ties among members, type of neighbourhood, opportunities to make relationships outside existing networks, physical and social mobility, and personal characteristics (Mitchell, 1969). However, given that the outside stressors of lesbians might not have been considered in these heterosexist studies performed in the 1960s, 1970s, and 1980s, it is necessary to examine other factors affecting connectedness. Since many lesbians remain closeted, some of the factors noted earlier may be less relevant than others. Factors to consider may be sexual orientation, and

shared experience of illness, along with others, such as type of occupation, and whether or not a person/couple has children.

In considering the possible social networks and support of lesbians in relationships, it is interesting to note the work of Suzanne Slater, author of The Lesbian Family Life Cycle (1995). Slater discusses the various possible levels of interaction that a lesbian couple may have with the mainstream (heterosexual) community, with their families of origin, with the lesbian and gay community, and with other communities of affiliation. It is significant to conceptualize lesbians' interaction with others, when an aim of the research is to locate lesbians' social networks and sources of social support.

The *mainstream community* is used to refer to both the institutions and the social relationships that occur within the dominant, heterosexual culture. The majority of lesbians are employed at some point within the mainstream community. Most lesbians also create additional ties to heterosexual people. Living outside of the heterosexual norm, lesbians daily negotiate their identities, and decide to whom they will "come out." Some lesbians expend a great deal of energy and thought on selecting and managing external relationships, and many choose to associate closely with only a select few outside of the relationship. Depending on a couple's "outness," and the area in which they live (i.e., in an urban or rural area), a lesbian couple may have varying levels of interaction with the mainstream community. Dealing with a serious health issue means that lesbians might have increased interaction with services in the mainstream community for a time.

The family *of origin* includes members of a lesbian's immediate and extended family. Family of origin generally describes blood relations. Younger, non-parenting lesbians may identify their parents and siblings as

their family of origin, while older lesbian parents may identify their grown children as their family of origin. Regardless of the basis for inclusion of members, and regardless of sexual orientation, a person's family of origin often holds great emotional significance. When lesbians' interaction with their families of origin is viewed positively, lesbian couples may use the family of origin as a model for their own family. Families of origin offer a set of family values, customs, and a blueprint for family living (Slater, 1995: 32). When lesbian couples do not have connections with their families of origin (whether because of the lesbian's sexual orientation, because of her same-sex relationship, or for other reasons), these disengaged familial relationships can have profound effects on the perception and reality of available support, and on the quality of life of lesbian families (Slater, 1995: 32).

The *lesbian and gay community* serves as another social sphere in which lesbian couples may interact. Some couples may be "out" about their relationships and their sexual orientation only to other lesbians and gay men, thus the gay community may start off as a "practice ground for revealing their shared sexual identity in a quasi-public setting which is more likely to be supportive than that of other social groupings" (Slater, 1995: 33). Some couples reveal their relationship to others in the mainstream community and in the family of origin, only after positive interaction within the gay community. Others remain out as lesbians only to select friends (heterosexual or homosexual). The lesbian community may be particularly important in terms of offering inclusion and affirmation for lesbians who have experienced rejection by their families of origin or society at large. The lesbian community - most often an ambiguous entity - and its networks will vary in size, frequency of contact, and connectedness depending on its location.

According to Slater, lesbians who have an additional primary identity (assuming that being lesbian is, in fact, a primary identity) may maintain active membership in another social grouping, referred to as a *community of affiliation*. Many lesbians maintain ties to ethnic or religious groups, or to other groups of similarly identified people. In Canada, for example, First Nations lesbians may refer to themselves as “two-spirited” and may be involved socially with other two-spirited people. Lesbians with disabilities may be active in the disability community, and black lesbians may be active in the black community.

Researchers Wayment and Peplau (1995) acknowledged that the experiences of lesbians, social support and well-being were completely absent in the social support literature. They wondered if conclusions about heterosexual women, social support and well-being could be made about lesbians, so they systematically compared social support among lesbian and heterosexual women. In their research, lesbian and heterosexual women did not differ significantly in amount or types of support received, although coupled women (in both groups) reported receiving more social support in total than single women (Wayment & Peplau, 1995: 1193). Participants’ perceptions about the amount of support they received from their networks were found to be significantly associated with greater well-being (Wayment & Peplau, 1995: 1198).

While Wayment and Peplau’s study found similarities between lesbians and heterosexual women, other studies comparing lesbians and heterosexual women found some differences between the two groups. Kurdek (1988) noted variations having to do with lesbians and gender, since both lesbian partners are socialized as nurturers and non-initiators. Unlike

heterosexual couples, lesbian couples may receive limited support for their relationships from people in mainstream society (Deevey, 1995: 195). Because of the pervasive level of homophobia in our culture, lesbians are greatly in need of socially supportive networks.

Researchers who study gay and lesbian communities find that gays and lesbians will often turn to non-family members for support in times of crisis, in particular, members of the gay and lesbian community (Berger & Mallon, 1993; Levy, 1989). This finding makes sense considering that many gays and lesbians experience rejection or distance from their families of origin, and create "families of choice" after coming out (Berger & Mallon, 1993; Dorrell, 1991; Slater, 1995).

Researchers report that social support from family "contributes to the initiation, development, and maintenance of couple relationships" (Bott, 1971; Lee, 1979, Notarius & Pelligrini, 1984; Surra, 1988). When heterosexuals introduce their partner to family members and friends, they are often met with encouragement and support for the relationship, or sometimes with disapproval. Lesbians can not take for granted that their families will offer support for their relationship. Lesbians who do introduce partners to family and friends may not even receive acknowledgment of their relationship, let alone support or disapproval. Women who are not out to families about their relationships may not receive adequate social support from family members. Research about couples who are closeted found that "closeting greatly limits the amount of social support available to lesbians as they develop as individuals and as partners" (Caron & Ulin, 1997: 413). When a woman remains closeted to her network members, then the support they provide to her will not include direct support of her intimate relationship (Caron &

Ulin, 1997: 414).

Sinding's (1994) study "Supporting a Lesbian with Breast Cancer: Weaving Care Outside Family" documents the lesbian social network of a Halifax lesbian couple. This friendship network supported the couple by providing the full range of social support as one partner underwent treatment for breast cancer. Participants spoke of feeling a sense of duty when supporting a family member, but that supporting another lesbian friend was done out of genuine care, and/or a sense of sisterhood, and did not involve feelings of burden or obligation (Sinding, 1994: 9).

Bailey, Gurevich and Mathieson's (2000) study supports the tie between community and health for lesbian and bisexual women. They report that each participant who discussed her health, also mentioned the role of the lesbian community in her life. For many women, community was viewed as a buffer to stress, and a place to belong that is free of judgment. The researchers surmise that lesbians need and want support from their community because the heterosexual society does not legitimate their same-sex relationships (Bailey, Gurevich & Mathieson, 2000). Lesbians in their study felt a lack of support for their relationships from the mainstream heterosexual society (Bailey, Gurevich and Mathieson, 2000).

In a study of 17 lesbian, gay and bisexual youth in Seattle, Nesmith, Burton and Cosgrove (1999: 95) also found that non-family members were more supportive than family members for the youth. In response to perceived homophobia and discrimination, some youth report that they choose to remain closeted to family, which limits the availability or accessibility of social support for them (Nesmith, Burton & Cosgrove 1999: 96). For those youth in the study who had come out, 72% of the people in

their support networks were non-family members, and 23% were family members. The researchers assert that for gay, lesbian and bisexual youth as well as adults, finding and “developing a social support system are fundamental elements in protecting against risks imposed by homophobia” (Nesmith, Burton & Cosgrove, 1999: 97).

Certain events may increase or decrease social support, especially when groups are faced with external threats (Dean & Lin, 1977). There has been a great deal of research regarding the gay men’s community and the experience of HIV/ AIDS. Gottlieb and Wagner (1991) assert that support is more likely to miscarry when the supporter is exposed to the same adversity experienced by the recipient of support.

Green’s (1994) study of HIV-positive gay men and social support found that many factors make HIV-infected people vulnerable, partly because many groups who become infected are already on the margins of society. Such groups’ need for social support is increased, yet Green found that those with poorer prognoses may receive even less support than those who are still relatively healthy (Green, 1994: 83). When a group like gay men is faced with stigma and social isolation even in good health, it may be difficult to access support in times of crisis, or prolonged periods of ill health (Green 1994: 84). Green reports that many gay men do not have strong links with their families of origin (Green, 1994: 84; Wolcott, et al., 1986). Green (1994: 85) suggests that “gay men in North America in general report quite good support and adequately sized networks, although there is a tendency to have a degree of distance from their family, and fewer family members in their network” (Donlough et al, 1985; Wolcott et al, 1986; Namir et al, 1989). Gay men in many large cities have formed “buddy” programs, self-help groups, and HIV

organizations to provide many types of social support to HIV-affected community members (Green, 1994: 84). These are useful services, as it is known that the absence of social support renders a person vulnerable to the effects of adverse life events.

Jane Aronson's (1998) study examines the nature of lesbians' informal care as partners and as friends. She echoes the fact that studies of social support and informal caregiving focus only heterosexual family structures. Aronson affirms that lesbians' caring work is less likely than heterosexual women's caring work to be based on family ties, and that lesbians who are sick are most often cared for by networks of other lesbians. She compares and contrasts heterosexual and lesbians' caring work in relationships, and concludes that "lesbians' caregiving is similar to, but distinct from heterosexual relationships because of the absence of cultural legitimation for, and prescription of lesbian domestic partnership" (Aronson, 1998: 170). She also acknowledges the difficulty stemming from a lack of language to account for and legitimize lesbians' relationships and friendships (163). Her study is a call to

learn more about lesbians' relatively uncharted journeys through caring for and depending on other lesbians so that we can work to change the institutional and cultural processes that make those journeys more perilous, joyless and isolated, and foster those practices that ease and support them (Aronson, 1998: 164).

The social environment is recognized by most theorists as a complex structural, cultural, interpersonal and psychological system. It is affected by the larger structures in which people live, such as sexism, heterosexism, and homophobia. Lesbian couples' social support systems may induce and/or reduce stress depending on the external stressors and other factors in their

lives. No matter how many supports a person has in their network, or what types of support they provide, those who are satisfied with their social support networks have a greater ability to cope (Namir et al., 1987). Learning more about the social support of lesbians and their networks is crucial to learning about the experience of lesbian couples facing illness, and to promoting lesbian health and well-being.

The literature on social support focuses mainly on heterosexual family ties, and is generally blind to the unique experiences of lesbians and their relationships. Few studies have addressed the differing stressors faced by lesbians in contemporary society. The existing research on gay men and social support does not include a gender analysis about the lives of lesbians. Because of their social positions as women and lesbians, lesbians are at risk of experiencing sexism, homophobia and heterosexism, and do not always have adequate access to social support from outside their relationships.

A Review of the Existing Literature on Lesbian Health

In this research project, I speak with women in same-sex relationships who have dealt with an illness or disability together. It is helpful to be aware of the attention paid to lesbians within the traditional sphere of medicine, as well as by the women's health movement. Advocates in the lesbian health movement argue that lesbians' health needs, concerns, and behaviours have been largely ignored within the male-dominated institution of medicine (Rosser, 1994). "Avoidance and silence historically dominated both professional and societal attitudes towards lesbian health needs" (Solarz, 1999: 5). Often, the failure to recognize lesbians' health needs comes from the assumption that lesbians do not exist, that their health issues are the same as

those of heterosexual women, or - less frequently - that lesbians share the same health concerns as gay men (Rosser, 1994). Some literature in women's health suggests that none of these assumptions about lesbians' health is accurate, and that lesbians have some different health needs, concerns and behaviours than heterosexual women (Ramsay, 1994; Rosser, 1994). Many researchers have acknowledged the importance of further research in the area of lesbian health so as to improve health care services for lesbians (Solarz, 1999: 11).

Some lesbian writers, like Winnow (1992) describe the struggles of the lesbian health movement within a historical perspective. She says,

Our needs, if noticed at all, are placed on the back burners of the agenda makers. We are always 'the other' in the lesbian/gay and women's movements, although we were often the exciting and driving energy in both (Winnow, 1992: 69).

Several issues in lesbian health have been subject to biomedical research in the past two decades. Lesbians, like heterosexual women, develop many forms of cancer, yet research indicates that lesbians (who generally have had fewer sexual experiences with men) may be at a lower risk of developing cervical cancer than heterosexual women (Rosser, 1994). Very alarming, however, is the incorrect assumption held by many lesbians and health care practitioners alike that lesbian women do not need pap smears (Horsley & Tremellen, 1995; O'Hanlan 1995; Ramsay, 1994; Rosser, 1994). As pap smears are often conducted during a visit in which contraception is to be provided, this examination seems to be targeted only towards heterosexually active women (McClure & Vespry, 1994; Ramsay, 1994; Rosser, 1994). Misconceptions about health risks such as this can negatively affect lesbians' abilities to manage their health and seek health care. In a 1987 survey of

nearly 2000 lesbians, 55.6% reported having had an annual Pap smear (Johnson, Smith & Guenther, 1987). In a 1988 study of 1925 lesbians, researchers found that

50% had had a Pap smear in the last year while 5% had never had one. Forty-three percent reported occasionally doing breast self-exams (BSE) and 14% reported never having done BSE. Thirty percent of the sample smoked cigarettes daily, while 11% were occasional smokers. Fifty-four percent had never smoked. (Bradford & Ryan, 1988, in Roberts & Sorenson, 1999: 11)

Lesbians visit their gynecologists far less often than heterosexual women - an average of once every 21 months compared to heterosexual women's average of once every 8 months (Rosser, 1994). Thus, lesbians may be less likely to receive complete gynecological care, which includes being screened for breast, uterine, and cervical cancer. Lesbians may have a higher susceptibility to breast and uterine cancer than heterosexual women, due to the fact that they are less likely to bear children than heterosexual women (McClure & Vespry, 1994; Rosser, 1994). While they are led falsely to believe that they are at a low risk of sexually transmitted diseases and cancer, in fact, medical evidence suggests that there is a small risk of contracting HIV and other STDs through lesbian sexual activity (Rosser, 1994). It is possible for lesbians to transmit HIV and STDs to one another through oral sex. Women who have previously been in sexual relationships with men may transmit HIV and STDs to other women through a variety of sexual activities.

Some research suggests that there is a higher alcohol consumption among lesbians (Deevey, 1995: 199), although a recent survey comparing lesbians with heterosexual women found rates of alcohol and substance abuse lower among lesbians than heterosexual women (Hughes, Haas & Avery, 1997). Because of the possible lower emphasis on traditional beauty and body

image in the lesbian community, more lesbians than non-lesbians tend to be overweight (McClure & Vespry; 1994; Rosser, 1994; Trippet & Bain, 1992). Any combination of these behavioural risk factors tends to increase the risk of developing breast cancer (Burnett, et al, 1999: 38). However, infrequent visits by lesbians to a primary care physician or gynecologist may not allow for early detection of breast cancer, or any other health problems related to the previously mentioned health behaviours.

Ayala and Coleman's study of predictors of depression among lesbians found that lesbians in partner relationships have lower rates of depression and higher rates of self esteem than single lesbians (2000: 73). However, they theorize that lesbians in general may live with a greater risk of depression than heterosexual women (2000: 73). Rothblum (1990) indicates that being closeted as a lesbian, lack of involvement in, or termination of a relationship, lack of employment, and living in a rural community, are all factors that may place lesbians at risk for depression. Lesbians who abuse alcohol are also at a great risk of depression (Ayala & Coleman, 2000: 73).

Burnett et al. (1999) interviewed 139 lesbians who had a family history of breast cancer regarding screening behaviours for breast cancer. They report that only 29% of participants were "overall" adherers to age-specific guidelines for breast cancer screening (Burnett et al., 1999: 48). The researchers conclude that "lesbians are more similar than dissimilar to other groups of women with the same risk factors and demographic characteristics when looking at mammography screening adherence" (Burnett et al., 1999: 50). Being lesbian in and of itself does not place individuals at risk for breast cancer. Rather, any unhealthy behaviours, which might be driven by SES and socio-cultural variables rather than sexual orientation, are of greater concern

as they place women at risk of breast cancer (Burnett et al., 1999: 51).

It is essential to acknowledge diversity and inequality within the heterogeneous group “women.” Within the health care system and social services, women have experienced various forms of discrimination (e.g., sexism, racism, ageism, classism, ableism) and for some lesbians, these factors are compounded by heterosexist assumptions and homophobic attitudes. Aside from medical issues, lesbians may face adverse social attitudes, family rejection, internalized homophobia and the difficulties of coming out.

Because health care systems and social services are microcosms of the society in which we live, then it is reasonable to assume that lesbians seeking help may experience invisibility, exclusion, isolation, and mistreatment due to ignorance on the part of support people. Stevens (1994) interviewed 45 lesbians, and learned of 332 health care experiences. She found that the participants evaluated 77% of their health care experiences negatively based on homophobia and/or sexism. (Stevens, 1994: 644). Solarz (1999) says it is important for researchers and health care practitioners to identify the barriers that exist which prevent lesbians from achieving adequate health care. Structural barriers for lesbians include the lack of legal recognition of lesbian partners. There may be financial barriers for health care and medication that may affect lesbians’ use of services. Personal or cultural barriers include attitudes of health care providers who are unable or unwilling to make lesbian clients feel comfortable and validated (Solarz, 1999: 19). When lesbians are not comfortable with health care providers, they will likely have fewer check-ups than necessary, and will not engage in regular screening tests. Some lesbians only go to the doctor in cases of emergencies. In Stevens’ (1994: 653) study, “44% of the [lesbian participants] had virtually stopped seeking

health care as a result of negative health care encounters. Lapses of 7, 10 and 18 years between health care encounters were commonly reported.”

While lesbians are generally not found to be at a higher risk for any particular health problem solely because of sexual orientation, being a lesbian in contemporary society may pose various risks. Lesbians experience differential access to health care services, they may fear coming out, and they may be exposed to the damaging effects of homophobia if they do come out (Solarz, 1999: 15).

Schwanberg found that “attitudes towards lesbian women have been found to influence the type and quality of health care provided to clients in various situations” (Schwanberg, 1996: 71). Deevey considers that the most serious health issue for lesbians is that “we don’t feel comfortable or safe seeking care when we need it (until an emergency arises), because of the ignorance, anti-woman, and anti-lesbian attitudes we encounter in most of the medical system” (Deevey, 1995: 1990). Negative interactions with health care providers can very negatively influence lesbians’ well-being.

Winnow says that AIDS has had an enormous impact on the lesbian community and health. “Homophobia prevents funding for gays and lesbians and illness, but those who are not deterred by homophobia feel they give enough by funding AIDS related organizations” (Winnow, 1992: 71). Lesbians’ health needs are ignored and invisible. She warns that although health care practitioners have become aware of gay men due to AIDS, this does not mean that they are any less homophobic when dealing with lesbians (Winnow, 1992).

Lesbian women seriously weigh the costs and benefits of coming out about their sexual orientation to health care providers. Some lesbians in this

study, as in other studies, do not reveal information about their sexual orientation to health care professionals for fear of rejection, ridicule, disrespect and inappropriate treatment (Stevens, 1992; Stevens, 1994; Trippet & Bain, 1992). Disclosing one's sexual orientation in a heterosexual medical system to homophobic health care professionals can have a detrimental effect on lesbians' self-esteem, future help-seeking behaviour, and physical safety (Rankow, 1996, Stevens, 1992, Stevens, 1995, Tiemann, Kennedy, & Haga, 1998; Trippet & Bain 1993). Similarly, not coming out and presenting an inaccurate self to others also has costs. When lesbians come out, some experience homophobic attitudes, while others endured awkward, uncomfortable medical visits. Many lesbians report that once they do come out, their doctors are not sensitive to or knowledgeable about the stressors, health risks, or counselling needs of lesbians (White & Dull, 1998: 97). Some feel very reluctant to return for medical care after a negative health care encounter. Nonetheless, Ayala & Coleman cite that women who are open about their sexual orientation have higher levels of self esteem, and lower levels of anxiety than those lesbians who are less open (Ayala & Coleman, 2000; Jordan, 1995).

Kate O'Hanlan, a physician and lesbian herself, carried out a large study on lesbians and health needs (1995). She found that 72% of the lesbians in her study felt ostracised by their doctors, and 84% said that they would not necessarily go back to their doctors for treatment of new illnesses" (O'Hanlan, 1995). Some women said that at times, they were tempted to never again seek health care.

Stevens found that many lesbians in her 1994 study also had stories to tell about health care encounters in which they were victims of sexism.

Negative stories were about dominating clients, subordinating women while positioning themselves higher. There were multiple stories about the various ways providers, particularly male physicians, "kept women in their place." They dismissed women's complaints, failed to provide adequate information, prognosticated with little sensitivity about how the women were incorporating bad news about their health, passed judgment on the appearance of women's bodies, diagnosed women's social functioning, and perpetrated sexual harassment. (Stevens, 1994: 652-3).

Lesbians face stigmatization both within and outside of health care. After living in mainstream society in non-normative relationships, lesbians become acutely aware and sensitive to language and signals that indicate safety with regards to disclosing their sexual orientation (Deevey, 1995: 190). One of the biggest problems lesbians face is dealing with ignorance, and heterosexism, or the assumption that all people are, or should be heterosexual. "Although less overtly violent than homophobia, heterosexism exerts an insidious, powerful force on the lives of gays and lesbians who feel undervalued or invisible within the dominant culture" (Ridson, 1998: 1567). Robertson (1993) says that "the traditional health care system has based its care and treatment of women on assumptions of heterosexuality" (65). When heterosexuality is assumed, and lesbians are nervous about disclosing their orientation, they endure embarrassing and awkward questions and procedures. In Stevens' review of lesbian health literature from 1970-1990, she found that "the studies were nearly unanimous in showing that health care providers' heterosexual assumptions were a major hindrance to effective therapeutic communication" (Stevens, 1993: 19). Stevens continues that lesbians rarely have a comfortable opportunity to come out to care providers (1993: 20). Heterosexism is a barrier to lesbians' achieving appropriate health care and social support from formal systems.

Winnow (1992: 75) calls for lesbians and all women to act up to fight for safe, supportive, appropriate lesbian health care.

I firmly believe that we are on the brink of disaster, and that we must be very careful if we are to stop the destruction before there is no 'us.' We have to stop being nice girls and start fighting as though our lives depended on it. Because they do.

Summary

Health care practitioners and social service providers are beginning to realize that women's social locations within society tend to have an impact on their life chances and well being. It is important that lesbians' experiences from the margins of health care are heard. "Lesbians are outsiders to power, economic security, and social acceptance, yet they bring a wealth of experience from the margins to challenge the oppressions of current health care delivery" (Stevens, 1993: 40). Many lesbians feel isolated from mainstream society, and lack access to culturally sensitive services. Homophobia and heterosexism from health care providers present lesbians with great health risks.

It is assumed that lesbians in relationships tend to rely mostly on their partner for many types of social support during health crises, but lesbian couples' intimate lives have rarely been studied.

Chapter Three: Methods and Procedures

This chapter outlines the concept of “research as empowerment,” which guides the research. The chapter also addresses the goals and design of the research, the research questions, and the research process.

Research as Empowerment

The goal of empowerment is central to the feminist movement, and this process often begins with the reclaiming of voices and the telling of stories of women, or other oppressed groups. Ristock and Pennell (1996) provide a discussion of the concept of research as empowerment, and the ways in which researchers and community members can collaborate to bring about this goal. Working toward the overall goal of research as empowerment, as described by Ristock and Pennell (1996), in the case of this research, means that the researcher examines power relations as they affect lesbians in society, considers the different cultural contexts in which the participants live, and cultivates social action based on the research (1996: 2). Essentially, research as empowerment committed to identifying, facilitating, or creating contexts in which silenced or marginalized people gain understanding, voice, and influence in their lives.

As discussed earlier, standpoint feminist epistemology offers theoretical insights and sensitizes this research. Research as empowerment involves the goals of building new theories, and changing the conditions of people’s lives, both individually and collectively (Ristock & Pennell, 1996: 2). In this research, two goals were to create new knowledge about lesbian couples’ experiences of social support and health, and to initiate social action in the lesbian community. This is consistent with the goal of research as

empowerment, in that marginalized women are given voice to speak out about the conditions of their lives, and to create strategies to understand and change these conditions.

Ristock and Pennell characterise empowerment research in three main ways. Firstly, research as empowerment does not follow a strictly defined route (1996: 17). Researchers and others (e.g., participants, advisory committees, community members) may be involved in different ways and at various points throughout the research process. In this project, plans were often changed and revised based on collaboration with people involved in the study. I met regularly with the staff of the Rainbow Resource Centre (RRC) (formerly known as the Winnipeg Gay/Lesbian Resource Centre, or WGLRC), as well as with members of my thesis committee at the University of Manitoba. Because I shared the office space with staff at the RRC, our interaction about the project consisted of both informal and formal meetings, and sharing of information about the work.

Secondly, the researcher is not alone in determining the research questions and design. At the beginning of the research process, advisors, staff at the RRC and acquaintances offered suggestions, advice and revisions on how best to carry out the study. Advice was given about how best to locate participants, how to narrow the focus of research questions, and how to handle analysis of the data. Throughout the research process, I consulted my university based advisors often regarding questions and complexities about doing the research. I found it was important that no matter how involved I felt in the research, I remained reflexive, and so I often checked in with advisors and community members about the significance and progress of the work.

Thirdly, “empowerment promotes the building of confidence, skills, and support networks,” strengthening all who participate in the process of research as empowerment (Ristock & Pennell, 1996: 17). Sarah said, at the end of her interview,

I’m just really excited that you’re doing this. I mean, I was thinking after we met last time that it’s striking that no one has ever asked us these questions before, you know, so I think it’s really great that you’re doing this work. It’s really empowering.

I know that community groups, individuals and newspapers, have taken interest in the research. Some people at the RRC have talked about follow-ups to this study (i.e., workshop, support groups, and pamphlets). Swerve, Winnipeg’s gay, lesbian, bisexual and transgendered (GLBT) newsmagazine would like to do an article upon the completion of the work. Many participants also informed me that they felt good about participating in the study. Many women had never spoken about their experiences before, and they were happy for an opportunity to share their stories. I learned more than I ever could have imagined from the women who participated in this study, as well as from my advisors - both in the academy and in the community. The process of undertaking this research was empowering on many levels for me, and for many of the women who participated, as relayed to me several times during the debriefing that followed the interviews.

One of the major principles behind research as empowerment requires that the researcher be aware of her own power and use it responsibly throughout the research. So, although I shared the status of “lesbian” with the women who participated, other conditions of my life were sometimes very different. The major difference was most often age, with me often being 10 - 25 years younger than the women I interviewed. Other differences were

related to social class and educational background. When there was an extreme difference in education between me and a participant, I was careful not to use academic jargon, and to speak in plain language, as I would with friends. However, when the participants had more education than I did, I found myself at times feeling intimidated, wondering if they would be critiquing the project while at the same time participating in it. The most obvious difference in power was that I was the researcher, asking the questions, and the women were the participants, responding to questions.

I was prepared to deal with power and status differences between me and the participants, but what I had not expected was the difference between participants themselves. I had some assumptions about the sample which were not correct. For example, I assumed that most lesbians would have supportive, high quality relationships, and that all couples would struggle through a difficult health issue with intense love and commitment. However, when I first came across a partner who was not all that emotionally supportive, my shocked reaction surprised me. I was not as prepared for that possibility as I could have been. I needed to check in with myself regarding my own biases and assumptions about lesbian relationships.

Feminist research as empowerment is a process of building knowledge and achieving goals through its critical analysis of power and examination of narratives. There are many possible methods which may be used to achieve empowerment through community research. Since the data collection was completed, I have maintained contact with many of the women who participated in interviews. Some call to update me on their health conditions, and others talk to me at community events. Many exciting developments have been taking place alongside the project, as well. A few of the project

participants have expressed an interest in helping to start up a partners' support group. Two young women who studied Feminist Community Organizing in Women's Studies at the University of Manitoba approached me to ask about my research and knowledge of lesbian health issues. Their goal was to create a pamphlet about lesbian health for use and display at the RRC. Since this research has begun, I was asked to be a part of a national teleconference on lesbian health with seven other Canadian researchers. I have also given several lectures and workshops about lesbian health, homophobia, and heterosexism in the disciplines of nursing, medicine, and health sociology.

I have constantly "checked in" with myself while doing this research. My own self analysis throughout the process was key in allowing the flow of mutual self-disclosure to continue with the participants. Such an approach also keeps me open and reflexive while thinking about the analysis. Finally, because I am able to relate to the women on some of their experiences, and because I am deeply concerned about the related foci on community and on formal systems of support from which lesbian couples may be excluded, I have personal interest invested in this research.

Goals and Design of the Research

The goal of this study is to understand how the experiences of social support from lesbian partners and others in the support network contribute to the well-being of lesbian partners who are coping with illness or disability. The research is based on interviews with lesbian couples in Manitoba who have dealt with, or currently deal with, a serious health issue.

Knowing how important social support is in terms of maintaining

well-being, and knowing that lesbians often experience isolation as a result of being open about their sexual orientation, I sought out women's experiences that may have rarely been discussed outside the couple. Many of the couples told me that I was the first person who had ever asked them these types of questions about their lives. Many researchers have acknowledged that lesbians live in a climate which is homophobic, however, it is not clear what it is like to be involved in a same-sex relationship, *and* to struggle with health issues. I was interested in listening to what that experience was like - how are lesbians in relationships affected by illness or disability? In what ways do partners support each other? What kinds of informal and formal supports are available to lesbian couples? From whom? How is this support negotiated? How do lesbians in couples think about well-being? What are their concerns for the future? Through the interviews, I learned about the many factors which affect the lives of lesbian couples coping with serious health issues.

I want this research to illuminate some of the barriers that lesbians face in trying to support each other and maintain well-being while coping with difficult health issues. As well, I want to determine if any barriers have been broken down for lesbians who are trying to seek care. I asked very concrete questions about support from partners, gaps in formal supports, and experiences of homophobia and heterosexism in service provision. I hoped to gain some knowledge in order to make policy recommendations regarding ~~health and social services for lesbians and their families.~~

I used a flexible, feminist, qualitative approach in doing the research. I wanted to embark on the beginning of social action through empowerment research. Answering questions from a loosely-structured interview guide, participants used their own language to construct, describe and explain the

diversity of their experiences in a way that made sense to them. My own experience as a lesbian and as someone who has dealt with loved ones' illnesses and disabilities informed my approach to the work, and is no doubt reflected in the research process. The study, then, focuses on lesbians' voices and the stories they share about their experiences of trying to stay well together.

Research Questions

The interview guide includes questions about relationships, health issues and coping, social support, social networks, well-being and healthy lesbian relationships (see Appendix A, Interview Guide - Couples). Questions were formulated based on articles I had read, and on conversations with advisors, family and friends about the work. Some new questions developed after the first few interviews.

I first asked about background demographic information, including how long the couple had been together, what kind of commitment they had, their ages, education levels, occupations, and if they had any children. I also asked if they are "out" about their sexual orientation and their relationships, for how long they had been out, and to whom.

I then asked about the health issue that the couple was coping with in the relationship, and we talked about how it had affected their relationship. Some questions focussed on power, dependence, and negotiating balance in the relationship, and most people responded in detail about these dynamics. I asked both partners about how they provided support for one another, and how this was negotiated. After thoroughly discussing support within the relationship, I asked the women to tell me about the other individuals in

their support network. In my efforts to find out if lesbians have “weak ties,” I would explain to participants Granovetter’s (1993) theory “the strength of weak ties,” and ask them if they thought they had experienced support from a weak tie, such as a person who lives far away, or with whom one generally has limited contact, but whose help becomes crucial during a difficult period. Sometimes participants had already told me about weak ties in their responses to questions about social networks, and other times, their answers were in response to my explaining the concept. While explaining the theory may have affected the responses I received from participants, I decided it was a useful method in terms of jogging participants’ memories to elicit as much information as possible. Most participants could think of at least one weak tie.

To finish the joint interview, I asked the couples how they thought relationships stay “healthy” under the stress of an illness, and often with little outside support. I asked the couples to think about their situations by asking them, “If you could give any advice to another couple who will be going through the same health issue, what would it be?” Putting the women in the expert role was effective in eliciting important insights, as they shared the lessons they have learned.

The Research Process

Winnipeg is a city with a population of approximately 650,000 people. There is a small but visible gay community, and the city is the first in Canada to have an openly gay mayor. The RRC is well known and offers many services, and there is a monthly newsmagazine published by and for the queer community. However, there have been recent examples of intolerance, for instance when a school board wanted to include anti-homophobia

education within the school's curriculum around diversity. Many gays and lesbians do not feel comfortable being open about their relationships in public. There are few places in the city that are known to be gay-positive and many of those places revolve around alcohol consumption. Bars, bookstores, and restaurants were targeted as places to advertise the study, along with University women's and Lesbian/Gay/Bisexual centres, health care centres, and counselling agencies.

There are several methodological difficulties that researchers are faced with in trying to locate a sample of lesbians. Because of existing social repercussions, many lesbians remain "in the closet," or are out only to their partner and a few close friends. Many women who are in, or who have been in, same-sex relationships may not even use the word "lesbian" in reference to themselves. In seeking a sample, there is the tendency for lesbians who are involved in political or social groups, or who are known to other lesbians, to respond. Kehoe reports, on research in the US, "Our studies of homosexuals are largely studies of active gays, those for whom sexual orientation constitutes a lifestyle" (1986: 46).

Since direct questioning and self-reporting are really the only ways to determine a person's sexual orientation, and since the above characteristics describe generally the type of lesbians who will volunteer to participate in a study, I acknowledged at the outset of the study that it may be difficult to achieve great diversity in my sample. I was nonetheless determined to use as many methods as I could to locate a heterogeneous sample of lesbian couples in Manitoba who have dealt with health conditions.

To begin, I placed an advertisement in the June 1998 "Gay Pride" issue of *Swerve*, Winnipeg's gay/lesbian newspaper, which was distributed to over

6000 people throughout the province. I then did a round of phone calls to people I know both in the lesbian and the feminist communities in Winnipeg, and asked for ideas about where to start in terms of recruiting participants. I received advice from many individuals who had an interest in the research. I put up posters at various locations throughout the city which I knew were frequented by lesbians and gays. The posters included project information, a local phone number with a private voice mail, as well as the toll-free number of the RRC where messages could be left. Further along into my sampling efforts, one of my community advisors suggested that I acquire a letter of endorsement from the project's funder, the Prairie Women's Health Centre of Excellence (PWHCE), in order to add some legitimacy to the information I was sending out about the research project. The PWHCE responded quickly to the request, and I included their letter in my package, along with a letter I had written about the study, and a poster detailing the project. This package was sent to individual community members, and to counsellors, doctors, clinics, and social service agencies. I delivered posters and project information to more than 50 organizations, public venues, businesses, and health or social service centres (see Appendix C, Sampling Site List and Appendix D, Posters for Study).

I attempted to locate at least five rural lesbian couples, but I did not locate as many rural women as I had hoped. Despite my best efforts, few rural lesbian couples came forward on their own to participate in the study. One woman took advantage of the toll-free number listed on the advertisements for the study, and called the RRC to let me know she was interested in participating in the study (her partner was not interested, and thus this woman participated on her own). In July 1998, I made contact with a woman

in rural Manitoba who knew many lesbians and gay men who lived in the area. She was helpful in identifying a few couples she thought might fit the study criteria, and she distributed study information on my behalf at community events. However, the outcome was that only one couple was interested in participating.

In August 1998, after no contact with other rural couples, some members of my advisory committee helped me by penetrating their own, and other known friendship networks, making phone calls, sharing information about the project, and inviting acquaintances to participate. I adapted the Letter of Introduction that I had been sending out, and in it, stressed the importance of having a balance of urban and rural couples. While I located two couples by this method, I was still disappointed at the small numbers. Lack of rural response could be due to a variety of reasons: couples may have decided to live in rural areas so as not to be recognizable as an out lesbian couple; they may not want to be associated with the lesbian community of the city; they may not be on any mailing lists or have networks that I could access, or perhaps the timing of the interviews (summer) was less than ideal, as some people are unavailable due to holidays.

By the beginning of July 1998, people started to call the private phone number at the RRC, where I had left a detailed message with more information about the study. Being aware of confidentiality, my message asked the women to leave a time when they might call me back, so that I could be present to answer their call. On the phone, I would explain the research, tell the caller about my method of interviewing couples together, and ask about the health issue being dealt with by the couple. I ensured that both women in the couple agreed to being interviewed, and sometimes I

spoke with both partners on the phone.

When I met with couples for the first time - usually in their homes, although sometimes at the RRC - I told them more about the project, and asked if they had any questions about it. The participants often wanted to hear about how I received funding. Typically, they were excited by the fact that lesbian health research was receiving support. I told participants that I am a lesbian (if they did not know), and I shared with them my experiences in terms of supporting many family members who have dealt with acute illnesses, chronic conditions, and disabilities. Once the participants' questions about the study were answered, I gave them a letter of introduction to read (or re-read, if they had seen one already). I followed by reviewing the consent forms with the women, and reminded them of my assurance of confidentiality (see Appendix E, Letter of Introduction / Consent Form).

Interviews were used to ensure the confidentiality of the participants. The original plan was to use focus groups with 6-8 couples in each group, however, due to issues of participants' confidentiality, and the sensitive nature of some of the topics, I decided that interviews were a more appropriate method of data gathering. Some women are closeted, or simply are not comfortable discussing their experiences in a group setting, and as I went on with the research, I realized that making the decision to use interviews only, was the best one. The topics discussed in the interviews were sensitive in nature, and often involved tears and strong emotions. During interviews, couples reminded each other of events, dates, and feelings, and checked in with each other as to the validity of their accounts. In couples where both women suffered with a health issue, the narratives were even more complex.

Interviews ranged from 60 to 150 minutes. All of the participants allowed me to audio-tape their interviews, although some asked me to turn off the recorder at times to share more personal information that they did not want included in the transcript of the interview. The interview guide was effective in eliciting a narrative-like response from the women. The method of *active interviewing*, as described by Gubrium & Holstein, recognises the competence of interview respondents “not only as ‘askers’ and ‘tellers’ of experience, but also as organisers of the meanings they convey” (Gubrium & Holstein, 1995: 4). The women with whom I spoke are experts on their own lives, and so I listened intently as they described their experiences in an order that made sense to them.

Gubrium and Holstein describe the use of *creative interviewing*, in which a researcher uses “many strategies and tactics of interaction, [which are] largely based on an understanding of friendly feelings and intimacy, to optimise cooperative mutual disclosure, and a creative search for mutual understanding” (Gubrium & Holstein, 1995: 77). I often related to issues that the women were talking about, and in most cases, I was comfortable disclosing some of my own experiences and feelings regarding relationships and social support. The fact that I shared some details about my experiences dealing with relationships and family health crises was helpful in creating a comfortable environment for women to construct and describe their own stories.

People sometimes asked me of their experience, “Does this fit?”, or “Is this what you’re looking for?” I tried to convey to the participants that it was not crucial to have everyone’s experiences mirror the rest. Rather, in this research, I was interested in looking for the diversity of experiences of lesbian

couples' experiences of social support and meanings of well-being. It is equally interesting to find similar themes throughout interviews as it is to find disparate experiences.

After each interview, the tape recorder was turned off, and the women and I had time to de-brief the interview, and to discuss any concerns or questions they had about the research process. Often, I would stay and visit, talking about other issues, such as sports, kids, cooking, university, or lesbian community activities. Gubrium and Holstein state that "[d]rawing on mutually familiar events, experiences, or outlooks not only secures rapport or 'communion,' but fixes the conversation on particular horizons of meaning or narrative connections, encouraging the respondent to elaborate" (Gubrium & Holstein, 1995: 7). I strongly feel that by interacting with the women on a friendly level both before and after the couple interviews, I worked on establishing a sense of trust that enabled them to speak more openly and comfortably.

One issue that struck me while going through this process is that I was often the only person with whom participants had shared their stories in detail. Some people had either been closeted, or not out to many people, or didn't think that their experiences counted, or simply, as "Sarah" (pseudonym) said, "no one's ever asked us these questions before!" I sensed that many of the women who participated felt empowered by the research process, and during the debriefing, many participants assured me that being involved in the research gave them a voice, and affirmed their experiences. I hope that the research we have created will add some new knowledge to ways of thinking about lesbian partners and support, and levels of lesbian community support, and to confront some barriers on the part of service

providers.

Once I left the interviews, I taped a short de-briefing of my own, or I prepared notes regarding how the interview went. I took notice of whether or not it was comfortable, or if there were questions I had regarding some of the things participants said. I made a note of whether I felt there was tension between the couple due to some of the questions. I also thought about how I observed the couple interact together, and with me. I made rough notes of themes that I found arising from interviews. Carrying my journal with me always kept me in touch with the goals of the research, and reminded me of the salience of the topic. Interviews were transcribed shortly after the interviews were completed. Some of the interviews were transcribed by me, and some by a professional transcriptionist.

Analyzing the Data

The data analysis has been taking place on an ongoing basis. In attempts to begin formally analyzing the data, I gathered up the notes I had made on the interviews, and put them in the folder with their respective transcript. I read transcripts once through, and then listened to the tapes and read through the transcripts again. I made notes in margins, and I used several different coloured highlighters to make note of key phrases or themes that I had noted in other interviews. I began to get a sense of what to look for in the transcripts, but also was open to finding different, conflicting or contradictory themes. As I continued to listen to the tapes, make notes, and tease out themes, I compared each interview with the previous. I compared and contrasted similar themes by making lists of many examples noting the transcript ID, page number and line number of each theme. Some themes

could be more clearly combined with others later in the process, and after several rounds of coding and grouping data, I began to see which themes were most dominant. The themes I identify provide detailed descriptions of the women's experiences.

My goal was to hear about lesbian couples' experiences of support while coping with serious health issues. As I suspected, the ways in which people relay their stories is often quite revealing of the social contexts in which they live. It is possible to examine feelings regarding the relationship and a partner's support, feelings about support received from those in formal and informal networks, and thoughts on well-being.

Language is central to a thematic analysis. Interviews have been transcribed verbatim, and the women's original speech and grammatical patterns remain untouched. The original accounts, as told by the women who participated, are useful in learning more about the meanings of their stories. I began by teasing out themes of the narratives in broad, loose categories of illness, social support, well-being, and relationships.

The women with whom I spoke do not live in a vacuum, and their lives - and certainly their experiences of social support and well-being - do not go unaffected by the sexist, racist, classist, heteropatriarchal norms of society. Standpoint feminism has a bearing on what types of themes emerge from the data in this research, and how they were examined. Keeping in mind Dawn Currie's (1988) description of the benefits of using a structural analysis as a context to women's subjective accounts, I attempt to contextualize the women's experiences in the analysis of the data. It is not simply enough to listen to women's stories. It is essential to examine the structural conditions and the ways in which they manifest themselves in women's daily lives.

Lesbians' experiences are constantly being framed in terms of the realities of heterosexism and sexism. A discussion of the social support and well-being of lesbian couples is well supported within a feminist analysis of the larger structures of complex social relations which in/directly affect the women's lives and experiences. Feminist theory also helps me to analyze issues around gender or sexual orientation, and how they affect the ways women provide or receive support.

The analysis of the transcriptions is essentially based on my theoretical position that there are many voices to be heard. Stories about illness and social support can be told in very different ways. I am interested in similarities between couples, as well as differences that emerge. The goal is not time and context-free generalizability, but rather the development of work that describes *these* lesbian couples, their experiences with health and illness, and their feelings about the support in their lives. The research that emerges is reflexive and contextual, allowing for multiple realities, but also identifies some common themes and experiences about lesbians, health, and conceptions of social support.

The profiles in the following chapter provide relevant background information describing the couples' lives, and provide a context for the presentation of the data that follows.

Chapter Four: The Sample

The sample in this project is purposive, and was, in some cases, obtained through snowball techniques. The sample is comprised of women who are fairly comfortable being “out,” at least in some circumstances. That is, they called me to respond to an ad that asked for women in same-sex relationships to participate in the study. Some women were more worried than others about confidentiality, but many women would have chosen to use their real names if possible (it was my decision to use pseudonyms for all participants). I knew some of the women ahead of time - both as friends and as acquaintances - and many I met for the first time through the project. Interviewing acquaintances was a challenge only when I attempted to acquire background information during interviews, as participants might say, “You already know the answer to that!” Interviews with acquaintances were comfortable on some occasions, and slightly uncomfortable when private information emerged that was previously not known to me (e.g., intimacy issues between a couple).

The results of this study pertain only to women in the study. Clearly, self-selection into the study and the particular characteristics of the women who did participate suggest that the findings are not generalizable to the larger lesbian population. I would expect that the results would be different had I interviewed women who were very closeted.

Between June 1998 and October 1998, I conducted interviews with 9 lesbian couples, and two individual lesbians whose partners did not participate. I interviewed two women without their partners, because their partners decided during the process, not to participate. These interviews with

individuals examined the same broad, general questions as in the couple interviews (See Appendix B, Interview Guide - Individuals). In both cases, couples had planned to participate together, but one partner decided to withdraw from the study. The interviews with these two individual women still describe the experiences of lesbian couples, and the data were extremely valuable, so I decided to include them in the discussion.

The occupations of the women ranged: I met with women who work in male-dominated trades, women who are stay-at-home mothers, teachers, self-employed individuals, students, as well as social service providers. Some women had been out to their families for only a couple of years, while others had been out for many years. For some, this was a first lesbian relationship. Relationships ranged in length from 2 years to 12 years.

Participants ranged in age from those in their early twenties to those in their late forties. Six of the women had children. Two women had less than a Grade 12 education, three women had their Grade 12 diploma, four women had college degrees, eight had University Bachelors degrees, and three had Masters degrees. Seventeen women were White, two were of mixed heritage, and one was Aboriginal.

There is quite a variety in terms of health issues dealt with by the participants. Health issues included alcoholism, depression, chronic pain, fibromyalgia, kidney disease, arthritis, and cancer. The sample was broad enough to learn about many of the conditions which affect the lives of lesbian couples coping with illnesses and disabilities. Most of the health conditions that the women described to me in the interviews were chronic in nature and included mental health as well as physical health conditions (e.g., depression, multiple sclerosis), and some of those were also characterised by serious acute

periods as well (e.g., women with chronic illness such as MS or arthritis often experienced quite serious flare-ups during which they were hospitalized). One woman faced, and ultimately died as a result of terminal cancer. Four women with chronic illnesses had also dealt with, or were dealing with acute health conditions (e.g., serious injuries). Eight women were dealing with chronic health problems, four of which were mental health issues.

In what follows, I provide a brief profile of the women who participated in the research process. This information provides a context to understand the data that are presented and discussed in later chapters. Each couple is unique, and many factors, such as the health conditions vary significantly. Pseudonyms (chosen by the participants) are used for all of the women.

Rene and Jamie

I interviewed Rene and Jamie in June of 1998. Rene and Jamie had been in a relationship for four years, and they defined their commitment as monogamous. Rene was diagnosed with a serious form of cancer, which was in remission at the time of the interview. Rene called me a few months after the interviews to let me know that the cancer had returned. I learned in September, 1999 that Rene had died.

Rene and Jamie are both White women. At the time of the interview, Rene was 37 years old. She had her high school diploma, as well as a college degree. Both Rene and Jamie worked in male-dominated professions. Rene had come out within the past few years to family, and select acquaintances at work and in the straight community. She had been out to herself and had dated women for nearly a decade. Since the onset of Rene's illness, she found

she was more “out,” and cared less about who knew and who didn’t know about her relationship with Jamie. The couple shared a large network of lesbian friends. Rene was very active in sports before her illness, and had hoped to return to them once again one day. Rene was a very warm, outgoing person, and was very animated throughout the process of telling me her stories.

At the time of the interview, Jamie was 33 years old. Jamie finished high school, and trained in the military for several years. Jamie was not “out” about her sexuality or her relationship with Rene, either to her family, or to people with whom she works. She feels the stigma of being lesbian in society, and fears the quality of her relationships with her co-workers would change if she came out. She tried to come out once to her family, when she was involved in a previous lesbian relationship, but they responded by distancing themselves from her. She has regained contact with them (and has never again said a word about her sexuality or her relationship) and is not willing to risk the loss of that contact with them again. She thinks that her family, as well as some people at work suspected the true nature of her relationship with “roommate” Rene, but she has not confirmed it for them. Jamie is somewhat more quiet and introverted than Rene, and describes herself as a worrier.

Both women began to take their health much more seriously after Rene’s diagnosis of cancer, and had very positive outlooks on life. Rene and Jamie shared a very holistic view of what health is. Jamie and Rene were the first couple I interviewed, and we all made an effort to stay in touch. We would occasionally get together, or talk at community events before Rene died. I now try to stay in contact with Jamie.

Sarah and Kate

At the time of the interviews, Sarah and Kate had been in an “intentional, committed relationship” for three years. I interviewed the women on a warm summer morning, sitting outside on their porch. They had lived together as a family for two of those years. They had a private, personal ring exchange as a sign of commitment, part way into the first year of their relationship. When the pair first started dating, neither was out to many people. While Sarah had been out to herself for several years, she had not come out to her family, nor had she dated. Kate was previously married, and met Sarah at the end of her marriage. She had not previously identified as a lesbian. This was the first lesbian relationship for both of them. After becoming more “out” in the gay-positive neighbourhood in which they live, both say that the issue of having a commitment ceremony with friends and family has re-emerged as a possibility. Both women deal with chronic health issues.

Sarah and Kate are both White women. At the time of the interview, Sarah was 35 years old. Sarah is not out at work, but is out to family, and friends. Sarah is a very quiet, introverted person. She was diagnosed a few years ago with a chronic condition that is characterized by great fatigue.

Kate was 37 years old at the time of the interviews. Kate has three children. Kate - the more outgoing of the couple - is out as a lesbian to her kids, to her family, to her kids’ schools, at work, and in the community. After a few months of being very ill in 1997, Kate was diagnosed with a serious chronic, degenerative illness. She has had both the experiences of being in crisis with her illness, and dealing with chronic effects of the disease.

Sarah and Kate spoke at length about the different effects of dealing

with acute versus chronic conditions. They spoke at length about how different factors, such as having children, being women, and being chronically ill affect their lives together to varying degrees.

Theresa

Theresa used the toll free phone number that I advertised on my poster when I was looking for participants. She was in a relationship, but she and her partner decided that only Theresa would participate in the interviews. At the time of the interview, Theresa dealt with a serious chronic illness.

At the time of the interview, Theresa, a White woman, was 36 years old, living in a rural area. She had a college degree. She disclosed personal details about her relationship, and the possibility of it ending due, in her mind, to her illness. Theresa is lonely, frightened, and in pain on many levels. She describes herself as an introvert, and lives with her partner and her dog in a home that is isolated from a small rural community. She does not have a network of friends and family. She does not use a label to describe her sexual orientation, and has previously dated men. This is her first relationship with a woman. She is open about this relationship to friends and family.

I followed up with a few phone calls to Theresa. She wanted to talk, and said that the initial interview made her quite sad. She feels like everyone is frustrated with her because she is constantly sick and feeling depressed. Each time I spoke with her she exuded a profound sense of hopelessness. I let Theresa know that she could call me collect at anytime at the research office if she wanted to talk. We also spoke about the importance of her seeing her therapist, as she did regularly. Theresa said she felt comfortable using the

crisis lines and her therapist as her main supports whenever she needed them.

Jane and Jill

I met Jane and Jill in their home in July, 1998. They had been together for several years in a monogamous relationship. Jane was diagnosed with a serious chronic illness over four years ago. The couple talked very sincerely about how the illness has affected their lives and their relationship.

Jane and Jill are both White women. At the time of the interview, Jane was 37 years old. Jane is out as a lesbian to most people, including her colleagues and most of her family. Her family lives out of province, so they don't have a great deal of contact, but when they do, they include Jill as part of the family. The unpredictability of Jane's symptoms is a tough issue to deal with, and she finds she must limit her activities, as fatigue is an ever-present factor.

At the time of the interview, Jill was 37 years old. Jill came out as a lesbian to her family many years ago, and disclosed her relationship with Jane four or five years ago. She relates that while her family wasn't overwhelmingly supportive, they weren't outwardly negative either. Jill describes herself as an extremely active, physical person, and considers "healthy" to mean the presence of a healthy, fully-functioning body. She finds that Jane's illness has a serious effect on the well-being of their relationship, as they can no longer share the physical activities they once did. Jill openly shared her stress, disappointment, and frustrations about living with Jane's illness.

Dannie and Sam

Dannie and Sam have been together for over four years. They live together, and consider their relationship “committed, monogamous, and life-long.” Dannie and Sam deal with a health issue that is unique in this study: they are trying to have a baby. They have no children yet, but both women have undergone donor insemination, and they have looked at the possibility of adoption and foster-parenting. They felt that their situation was related to the project in that it is an ongoing health struggle, and puts them in contact, as a lesbian couple, with a whole variety of health and social service providers in Manitoba. Their situation may not require the same amounts of support from outside ties as some of the other health conditions, but it is characterized by many of the same features, such as medical visits, disappointments, frustration with the body, and stress on the relationship.

Dannie and Sam are both White women. At the time of the interview, Dannie was 35 years old. Dannie is very out about her lesbian identity, and has had relationships with different women before Sam. Dannie had seven attempts at conception through donor insemination. Since Dannie’s attempts were not successful, Sam decided to “take over” the insemination process for a few months.

Sam was 38 years at the time of the study. Sam has tried four attempts at conception, and although the fourth was successful, the fetus spontaneously aborted within the first week. At the time of the study, Sam was taking a break from the insemination, but would start again after giving her body a couple of months to rest. Sam is also very out as a lesbian, and has had relationships with women.

Sam and Dannie are positive that they will have a child, and their

commitment to this goal is unfaltering. Their commitments to each other, and to a child they hope they will know one day, are obvious. Dannie and Sam shared a great deal about how well they have gotten to know their bodies, and how important communication is when a couple is going through any type of health issue.

Leigh and Dawn

Leigh and Dawn are among the youngest women to participate in the study. At the time of the interview, Leigh and Dawn had been a couple for three years, and were living together. We gathered in Leigh and Dawn's house, and they shared with me what it was like to be in a relationship in which both partners struggle with chronic health issues.

Leigh and Dawn are both White women. At the time of the interview, Leigh was 25 years old. She is out as a lesbian to most people, including her family, and she has had relationships in the past with women. Her family does not acknowledge her relationship with Dawn, nor do they acknowledge her mental health issues. Leigh has dealt with her own health issues for over four years. She says she has lost some friends because of her health struggles, but has also made some closer friends once they come to understand her life. Leigh tends to socialize a bit more with people in the couple's network. She is an intense person, speaking with a sharp, sarcastic sense of humour.

During the interviews, Dawn was 28 years old. She is out as a lesbian to most people, and while she doesn't "go down the street and announce it to people," her family and friends know about and accept her relationship. She had one long-term lesbian relationship before Leigh. Leigh and Dawn frequently travel on holidays with Dawn's parents. Dawn has lived with her

own health issues for well over a decade. Both she and Leigh are on medication to deal with their health issues. Dawn doesn't really feel as if she has a large network of friends, and she says that her health struggles can be really wearing on others' emotions. Dawn is the quieter of the pair, and she spends more time alone, away from friends. I appreciated Leigh and Dawn's candor throughout the interview process. Both partners shared quite intimate details about their lives, and their thoughts about their future together.

Adrienne

I interviewed Adrienne and Dar in their home in the summer of 1998. They have been together for three years. Dar and Adrienne have a monogamous relationship and have ordered rings to symbolise their commitment. They have a strong, formal commitment to each other. They expressed interest in being interviewed about their experiences, with depression and a sexually transmitted disease, and their struggles to maintain well-being in the face of many layers of oppression. Since Dar left 10 minutes into the interview, the data include only Adrienne's thoughts.

Adrienne was 43 at the time of the interview. She is White. She has three children. Adrienne came out as a lesbian five years ago, but is not out at work, as she finds her profession to be quite homophobic. However, Adrienne enjoys being within the gay and lesbian community. Her family, friends and neighbours know about her relationship with Dar. Adrienne's ex-husband is not supportive of her or her relationship, and she and Dar had had many problems with his abusive behaviour towards them in the year prior to the interview.

This joint interview was very emotional, and Dar became overcome

with grief. She left the room about ten minutes into the interview, and did not return. Adrienne speaks very passionately about the many stigmas that she and Dar experience. She also describes the effects that health issues have on an individual, a couple, and a family. Certain issues were extremely hard to talk about, and the entire interview lasted almost three hours. It was an emotionally draining process for us all.

Adrienne says that their relationship has been strengthened through dealing with their own and each other's health crises. They have learned levels of tolerance, understanding, and compassion that they hadn't known before. They realize, however, that they still have many struggles ahead of them in their efforts to maintain well-being as individuals, and as a couple.

Sirshu and Hazel

I met Sirshu and Hazel for an interview at their summer home outside of Winnipeg in early September, 1998. Sirshu and Hazel have been together for 14 years. Sirshu and Hazel have lived both together and separately during their almost two decades together. The couple was recounting their experience several years ago, when Hazel dealt with an acute injury, and how this injury has led to a chronic health problem. Sirshu also deals with chronic pain, however the interviews were mostly focussed on Hazel's health issues, and how they affected the relationship.

At the time of the interview, Hazel was 39 years old. She is White, and most of her family lives in another province. Hazel's religious upbringing, with a strong emphasis on community, is evident in her extroverted character, and her enjoyment of cooking for, and socializing with others. Within the past ten years, she has been out as a lesbian to most people,

including her family and her employers. This is not her first relationship with a woman. She is a great story teller, and shared many details about how her chronic health injury has impacted her life.

Sirshu is 40 years old, and White. She describes herself as an introvert, someone who needs very few other people around to be content. She loves to read, and is interested in New Age rituals and healing techniques. She has come out to some of her family, only in the past few years, but has never been out to employers. Hazel teases Sirshu about her New Age interests, but also holds a deep respect for Sirshu's need for solitude and space. Hazel and Sirshu are opposites in many ways, but have quite a loving and supportive relationship.

Ann and Diane

I met with Ann and Diane at their place of work. Ann and Diane have been together for over six years. They have a monogamous, committed relationship. Their lives were affected greatly when Ann became critically ill in late 1997, and was hospitalized for three months.

Ann was 32 years old at the time of the interviews. Raised in Winnipeg, she is of multi-ethnic heritage. Ann identifies as a dyke, and has been out to herself and people in her life for many years. Being sick and off work for three months has led to major financial strain for the couple. When Ann became ill, people from gay and lesbian communities were very concerned and offered support in various ways.

At the time of the interview, Diane was 43 years old, and describes her ethnic background as "Heinz 57," or mixed. Diane has one grown daughter. She has dated women for many years, and now identifies as queer. She is very

out about her relationship with Ann.

Ann will undergo aggressive treatment for her illness for a minimum of four more years, and faces many more tests and drugs both during and after that time. The financial cost of being in the hospital and being chronically ill has caused the couple to have to cash in RRSPs, and maximize their use of credit cards. There were some very scary times throughout Ann's time in the hospital, when she was close to death. The couple is very close emotionally. They communicate a great deal, and both have an excellent sense of humour. Ann and Diane consider that the illness has made their bond to each other even stronger than it was before the health crisis.

Penni and Rosie

Penni and Rosie live in rural Manitoba. The couple talked to me about the effects of Rosie's health issue on the relationship, and on their families.

At the time of the interview, Penni was in her late thirties. She is a White woman who grew up in a small Manitoba town, and, as an adult, continues to be well-known in the same town. She enjoys travelling to larger cities, where she often participates in whatever gay/lesbian events and activities are taking place. She openly described her own struggles to maintain well-being, and the effects of Rosie's chronic health issue on her well-being. Penni lives in a house with her two children. She and Rosie had lived together in the past, but at the time of the interview, were living separately. Penni has been out as a lesbian for several years, and has dated a variety of women through those years.

At the time of the interview, Rosie, an Aboriginal woman, was in her late twenties. Rosie has worked in construction in the past. At the time of the

interview, she was not working, but she had plans to return to her construction job in the future. Rosie has two young children of her own, who Penni cared for when Rosie's health problems were escalating. Rosie now lives with her two children, within walking distance of Penni, in a basic, small house with no phone. She has dated women and men, and is open about her relationship with Penni.

Both partners were talking very seriously about how much of an effect the health issues had on their commitment, and whether or not they could, or would stay together.

Thelma and Louise

Thelma and Louise live in Winnipeg with Thelma's teenage daughter. The family has been together for over five years.

At the time of the interview, Thelma, a White woman, was in her late forties. She identified openly as bisexual for many years, and was previously married. She now identifies as a lesbian, and is out everywhere.

Louise is also White, and in her thirties. She is out to some people, but is less open about her lesbian identity than her partner. Louise is currently not working due to the extreme chronic pain with which she suffers. Although quite shy, Louise shared some intimate details of her struggles of living in extreme pain from day to day, and her fears for the future.

Though all of these lives are different, most of the women say that they participated in the study to have their stories told, and also because they hoped their experiences might help other couples who are struggling with similar issues. I now turn to the main themes of the research, divided into three chapters.

Chapter Five: Stress, Illness and Social Support in Lesbian Relationships

Lesbian couples may already face daily stress whether or not they are “out” about their sexual orientation. Often, this is due to experiences of, or fear of, perceived homophobia in mainstream, heterosexual society. Some lesbians also face other social stigmas in their day-to-day lives, based on gender, and the type of health issue they experience. People’s energy may be depleted, finances may be stretched, and worries may be great, as couples deal with illness and make the adjustments necessary to re-balance their lives. Participants experiences revolve around three major issues: being a lesbian, dealing with an illness/disability, and being in a relationship.

To Come Out or Not to Come Out

Some women do not come out to people outside of their immediate network because of their profession, which they believe to be unwelcoming of gay and lesbian people. Sarah is a minister, Adrienne is a nurse, Sirshu is a teacher, and Jamie is a security officer. Although each is out to some people, none of these women is out in her professional life. Adrienne feels as if she is living two separate lives, but is afraid of losing her job if her sexual orientation is discovered. Sarah expresses it this way: “There’s a huge cost to not being out at work, and to dealing with stressful health issues at home.” Sarah says that while she and her partner Kate face serious health concerns at home, it is a very lonely and isolating experience not being able to explain the situation to co-workers. People in a social network can offer support in many ways, but if they are unaware of the situation, they have no way of understanding the need for support.

Like Sarah, Jamie is not out at work. Both women have very real fears of losing their partners to illness, yet neither is able to disclose these fears in a safe way to other people in their day-to-day environments. Jamie has not even told her family about the nature of her relationship with Rene, let alone Rene's cancer, because when she tried to disclose her sexual orientation to them a few years ago, they ceased communication with her, and excluded her from family events.

Women who are not out say they constantly worry about what they say and to whom, for fear that the truth would be found out, and that they will somehow become even more isolated. Jamie worried about losing her job, losing the respect of co-workers and other students, and having decreased quality care for her partner. When Jamie's partner Rene eventually passed away, Jamie still did not feel safe disclosing the details of her role in her "roommate's" life, illness, and death. No one in her family, nor any of her co-workers know about her experience, watching a partner slowly die of cancer.

Penni and Rosie are the only out lesbian couple living in their small rural town, and thus deal with many issues of visibility. Both women are out as lesbians, and both routinely deal with homophobia in their town. When one of them began to go through several health issues, the stress in their lives was increased. They explain they felt like the whole town was watching them to see how they dealt with issues, and with no role models of other lesbian couples, the pressure was extremely difficult. To cope, Rosie began to abuse alcohol, saying that she "always worried about what other people thought. Once I had a few drinks under my belt, well...." she became more comfortable. Rosie's addiction led to even greater stress in her relationship with Penni, and more feelings of scrutiny and judgment from neighbours and friends.

Homophobia from mainstream society, as well as internalized homophobia keeps some lesbians in the closet. Participants fear negative repercussions such as job loss, rumours, distance and awkwardness if they were to be open about their sexual orientation. Being closeted, having to hide a significant relationship, and fearing the effects of homophobia all add stress to a situation which is stressful enough (i.e., facing a serious illness or disability).

What's Gender Got to Do With It?

Gender impacts on participants' experiences as lesbian couples coping through health issues in a variety of ways. Participants indicate that gender becomes intertwined with sexual orientation and makes the experiences of stress, support and health even more complex. Knowing that women are often expected to be the caregivers in heterosexual families, I wondered how women in lesbian relationships felt about care-giving, and how couples experienced illness and support.

Many women facing illnesses together describe how gender can impact strongly on experiences with health care practitioners. Many participants felt they were not treated with respect by service providers because of their gender. In fact, most women at some point in their interviews echoed this theme that male doctors and medical specialists can be condescending, rude, and abrupt with female patients. Kate comments on one trip to the emergency room.

All of the emergency room doctors and the cardiologists that I spoke with were very patronizing, and what I'm clear on is I don't think they even bothered thinking about whether I was a lesbian or not, and they just treated me like I was a complete idiot, and just wasting their time. So it's like if a woman is sick, it's psychosomatic. It's appalling!

Sarah relates micro incidents of sexism and disrespect to the larger structure of the medical system. She describes her understanding of an imbalance in funding and research accorded to women's health issues, compared to health issues that affect men:

The gender stuff is so strong... It's really, really terrible that when you look at the funding for breast cancer and compare it to funding for any other..... and the percentage of women who die from breast cancer, compared to the number of men who die from AIDS is astronomical, and yet the funding is like 1% of the funding that AIDS gets. And on the one hand, you don't want to pit these things against each other, and on the other hand, women are dying..... and people don't care.

It is important to consider being female and being lesbian within the larger systems of sexism and heterosexism. Sarah describes a sense of invisibility that some lesbians face, and she theorises about gender as it relates to lesbian existence.

I think there are some issues that would be different, because I think there are a lot of assumed supports in the world that don't exist if you are invisible. So, even in terms of being able to just talk about your experience everywhere you go without thinking about it twice. That's a cost I think we pay because we're lesbians and not normative in society, you know? And there's significant pieces to that like, for me especially where I work and not being able to say, "You know, I have to leave at 11:00 because I have to take my partner to the doctor," having to say, "I have to leave because.....I have to leave." And also really trivial things about going to Safeway and I think in the straight world, you just kind of have more permission to say, "Oh, my husband is really sick," and people kind of give you a lot of support, even if it's just the cashier. But we just don't have that, I think, as lesbians, at least. I don't claim it, for sure. And I think there's a pure gender piece, too. I just think as women we don't always demand, or we don't always get the same respect or being taken seriously or whatever that men do. And then as lesbians, I think that's just heightened, I mean, we said a couple of times, especially when we were in the emergency room, like you know, if Kate's husband was there, it felt like it would have been really different. People would have treated her with a lot more respect and a lot more attentiveness you know, if her husband had been there, saying, "Like, excuse me, could you take care of my wife?!" So, I think

there's a difference, too. One other thing is, sometimes I wonder if we were a straight couple and the woman of the couple was sick, I think the husband would get a huge amount of concrete support from the family and from neighbours and from friends in terms of, "Let me take the kids for an hour. Let me bring over supper," which just doesn't happen for us because we're both women, so everyone assumes, I think, that those things are no big deal because women are really good at making supper and doing the laundry and taking care of kids. So, I suspect that, never having been in this situation as a straight person I don't know that for sure, but it feels to me like there would be a different level of practical support. I think it would be different maybe if it was the husband who was the chronically ill one, but I think if the wife was chronically ill, there would be that sort of, "Oh, poor guy, we should have him over. Oh, he has to take care of those kids. Oh, poor guy," which I just don't think lesbians experience at all.

Many women in the study believe that women seem to be better caregivers, and that it is easier for women to juggle other tasks along with caring for a partner or family member. The fact remains that although some lesbians challenge traditional gender role stereotypes, lesbians are still raised in mainstream society, and may hold on to expected norms. In general, gender expectations of men do not include nurturing, becoming family managers, and caring for others in the same way they do for women. Lesbians in relationships who feel it is their responsibility to be a main supporter may not feel comfortable asking for help, even when they desperately need it.

Lesbian Life when Women Live with Other Stigmas

The women in this study are somewhat diverse, including those who are mothers, students, Aboriginal, unemployed, poor, sick, disabled, and, obviously, lesbian. Most women found at least one factor other than sexual orientation and illness that also compounded the stress in their lives. Participants say that dealing with stigma and feeling different is draining, especially in the case where a couple needs support to cope through a health

crisis. Adrienne explains her own experience as a woman who faces many stigmas.

It's interesting, like sometimes I think about the layers of oppression that we have to deal with. The fact that I'm large - to put it bluntly, I'm fat, and I'm seen by a large percentage of society as asexual. Do I care? No. That's just the way it is... and then there's the fact that I'm Jewish, and that's a stigma. And I'm a lesbian. That's another stigma. And, I'm working class, divorced... and you know, all these different things. Sometimes, it's hard to cope with.

Like Adrienne, several other women in the study deal with issues of class, ability, and size.

A stigma that was discussed frequently during the interviews was living with a mental health issue. Participants like Adrienne recognize the “double-whammy” of being a lesbian and struggling with mental health issues. Some participants feel that in fact there is more stigma attached to being clinically depressed than there is to being gay or lesbian. In a similar way that many lesbians handle coming out about their sexual orientation, participants are cautious about those to whom they reveal intimate details of their health. Leigh found that it was far easier to come out to her parents about her sexual orientation than it would ever be to “come out” about her medical diagnosis of depression. Her partner Dawn agrees. She claims that “being gay is easy compared to dealing with a mental illness. People would be more freaked out if I told them I was in the hospital and had shock therapy, than I'm gay.”

Adrienne, Leigh, Dawn and Penni all have a sense that some people perceive the use of medication for depression as a crutch. Penni says, “If you had a heart condition, no one would question why you'd take medication, but people are really freaked out by mental illness and taking pills for it.” Lesbians

like Adrienne who deal with mental illness, find that depression is not widely understood, there is fear around it, and those who deal with it often feel silenced:

They [society] don't understand how it can affect your whole life: your job performance, your family life, your sexual life, your social life, everything! It's a devastating condition. It really is, and it's not simply a matter of 'smile' or 'lighten up.' No, it affects your whole thought process and outlook on life. There is still a stigma out there towards depression, and frankly, I don't understand why society doesn't understand it.

One woman in the study also deals with a health issue that carries great stigma, and often causes guilt or shame in its sufferers. This woman deals with genital herpes, a sexually transmitted virus that she will now deal with for the rest of her life. It is with extreme difficulty that she speaks of this health issue. She and her partner recognize the stigma attached to herpes, and can rationalise the unfairness of these judgments, but remain very emotionally affected by the presence of herpes in their lives. This participant comments,

The thing that I find hard about it... is that there's such a stigma, but I don't understand where that comes from. No, I take that back. I partly understand it, I mean, there's such a stigma about sex anyway in society that this is one more aspect of it.

Lesbians are already an invisible minority in society, and carry stigma in a society which does not fully accept homosexuality. Dealing with other stigmas such as gender, and illnesses which are not widely understood or recognised as valid can be extremely challenging. Some women like Adrienne are not certain that those with power in mainstream society will ever understand the different layers of oppression, and how they affect lesbians' lives.

They have no idea about some of us – the complexities of our lives. It's kind of hard to explain, but again, there's a lack of understanding. There's a lack of realization that different people live their lives differently. To them, everything means straight, white, middle-class, and that's it. Anything that deviates from that is suspect.

Frustrations in the Journey Through Illness

Many women experience physical and emotional changes with regards to their bodies after dealing with a health condition. Dealing with new body issues can be extremely frustrating and overwhelming for anyone. Barbara describes the changes in her body as she deals with chemotherapy in Cancer in Two Voices:

What is it like to live in a body that keeps on changing? It's frightening, terrifying, and confusing. It generates a feeling of helplessness. It produces a slavish attention to the body. It creates an unnatural hyper vigilance toward any and all sensations that occur within the landscape of the body. One becomes a prisoner to any perceptible change in the body, any cough, any difference in sensation. One loses one's sense of stability and predictability, as well as one's sense of control over the body. It forces you to give up the idea that you can will the body to behave in ways that you'd like. Predictability ends. One grieves over its loss, and that further complicates the process of adjustment to an unstable body. Time becomes shortened and is marked by the space between symptoms. (Butler & Rosenblum, 1991: 136)

Supporting a partner through a difficult health issue may involve being sensitive to new or unique body issues. Many women found that they began to see their bodies in a different way, to have a new relationship with their bodies after dealing with their health issues. Adjusting to a body that does not work, look, or feel the way it did before the illness/disability is a difficult shift to make. Many women spoke of weight gain, scars, loss of feeling in different body parts, loss of hair, and unwelcome effects of new medications on their bodies.

People often discuss illness to mark time and to divide periods of their lives (Charmaz, 1991: 198). A few participants compared their bodies before and after illnesses had occurred. For example, before Kate was diagnosed with polycystic kidney disease, she frequently jogged and did aerobics. Her condition no longer allows her to do strenuous physical activity, and the cysts have led to some weight gain. Kate describes her feelings about the changes that took place in her body after being quite ill.

I gained ten pounds and it's not leaving me, and I'm looking in the mirror and I'm seeing my mother's body and it's going in a bad direction...and I'm just feeling like...frumpy, and having been really sick....At first, I thought it was just the cysts, and that I was going to get my body back one day.... I mean, it's a question mark, but even if the ten pounds is just a temporary thing, it's a symbol to me that the time that I had before - before I was going to have to deal with these kinds of body issues - is gone. And now, it's just borrowed time. And that sounds kind of extreme, but that's kind of how I feel.

Like Kate, Rene was very active in sports before she was diagnosed with cancer. She and her partner, Jamie, shared their love for sports, and it was a loss and a change for both of them that Rene had to cease her participation. At the time of the interview, Rene said that, although she loved sports, she was hesitant about returning to strenuous work-outs and games. She described how she was different in her relationship with her body after having had cancer.

That's one thing that I have never really felt before. I never had fear before. You know, um, if I smacked my knee, I smacked my knee. But my body is scared now - it doesn't want to hurt anymore.... Um, I don't know... I guess I'm not as - I don't have as much confidence in my body anymore, and my capabilities, and...the strength in my body is just not there. And I know Jamie is frustrated with me - I know it. And I was a little frustrated with me, too, but I just - I'm listening to my body, I guess.

For almost a year, Sam and Dannie have been dealing with the overwhelming and costly experience of trying to conceive a child. Both women have undergone fertility treatments, and at the time of the interview, Sam was the more likely candidate. A month prior to our interview, she had conceived but the fetus spontaneously aborted within the first week. Dealing with this loss, and seven unsuccessful attempts at fertilisation between the two partners leads to an array of feelings, not the least of which are disappointment in, and frustration with, one's body. Sam shares

I am...certainly frustrated, especially since I've always used my body and taken it for granted....and the fact that I haven't missed a period since I was 12. I'm like clockwork. My temperature chart is just like the one that's in the textbook. All of these things around my menstrual cycle and my physical build indicates that I'm built for babies..... all those things tell me that....

Issues and changes around intimacy often present during or after experience with a serious health condition. Intimacy, affection, and sex often take on new meanings in the lives of many women after they or their partners have dealt with a serious health issue. Diane and Jamie both shared the experience of being worried and afraid of hurting their partners. Jamie relates to a change in sex and intimacy in her relationship:

Um, I found that when she was sick, even before the cancer was diagnosed, because of the pain she was in, and she couldn't move and stuff.... like sex just.....sort of hardly ever happened. But it wasn't like an issue, because the intimacy - like, I mean, we always held each other and whatever.... I just treat her so gingerly, and.... I just don't want to hurt her.

Charmaz writes that intrusive chronic illnesses do take the spontaneity out of sex, and create changes in intimacy for many people (Charmaz, 1991: 63). Sometimes it is hard for couples to shift back into the levels or

expressions of intimacy that they shared prior to the illness. Kate talked about how sexual intimacy had only recently become an issue, and described how it was affecting the couple's dynamic.

Up until recently, it's just like never been a problem, never even been in conversation. It's just been active and fine and really great till now, and... we're still trying to figure out what it is, and it's been a real struggle for us to try and be intimate with each other and it's interesting because it took a long time before we could even talk about that.... because we couldn't believe it was happening.... So, it has something to do with uh what she's processing and feeling, and what's going on and of course it's going to impact - eventually it's going to impact your sexual relationship. We'll both have to figure it out, and that's hard. I don't know... I'm not afraid that like we won't work it out, but it doesn't make me happy that we're having to work it out. The one thing that we could hang on to that was always great is..... different.

Sometimes the ill/disabled woman herself becomes less interested in intimacy for her own reasons. Jane finds that MS has led to major shifts in how her body feels, and she has a very limited amount of energy. She has, therefore, had to make changes to her days so that she can still work full time. This is her main focus, and takes a great deal of energy, so sexual intimacy has been made a lower priority. Changes in her body also contribute to this shift:

Yes... our sex life has been affected a great deal. I mean, most of all, I lost sensation in my hands due to the MS. Basically, my hands feel like you do after you've had a shot of novocain... Touch was a very pleasant sensation for me prior to the MS, and now..... any type of caress is.... unpleasant for me.

Changes to the body, and patterns and expressions of intimacy have varying effects on participants. It may take a long period of time before new body issues are integrated and comfortable expressions of intimacy can be found.

The Uncertain Nature of Chronic Illness

A main difficulty in Sarah and Kate's situation is that each woman deals with chronic illnesses, both of which are also characterised by flare-ups that may be incapacitating for a period of time. Sarah says that the shifts associated with acute periods of illness are easier to cope with than the long-term imbalances and unknowns of chronic illness. The nature of chronic illnesses is such that, at times, one's health may be manageable, and at other times, daily living may be next to impossible. Charmaz writes, "Living with a serious chronic illness takes effort and devours time. It means overcoming stigmatizing judgments, intrusive questions, and feelings of diminished worth" (1991: 2).

Intense acute episodes of chronic health conditions make balance unpredictable in relationships, and this can be frustrating. "Chronic illness can set people apart from others and take over their lives. [It] can catapult people into a separate reality with its own rules, rhythm and tempo" (Charmaz, 1991: 4). At one point, after Kate had gotten over a particularly acute period in her illness, Sarah describes feeling relieved that the intense period was over. Sarah's sense of relief, and "being able to breathe again" led to a conflict and Sarah released some built-up stress. She relates feeling somewhat selfish about this, but thinking,

What about me? Like, when do I get what I need and when do I get what I want? When is it going to be my turn? I feel like I've been trying to hold everything together for a long time, and I don't want to do that anymore, but it feels like I don't have a choice, and that feels unfair to me.

Most couples, like Kate and Sarah find that setting up power dynamics in their relationships helps in order to accommodate the shifting of balance.

I think we've kept trying to do it, to name the moments when we're in a particular moment in our relationship where the power is imbalanced, but in our overall vision, it won't always be like this. Like, our overall vision is one of equality in power, so I feel like we've tried to be conscious of those issues... But they're also hard issues.

Being flexible with planning, taking on more than one's share, and being generally understanding are all features that participants say help to ease the shift into different dynamics of power and dependency.

Women in the study who experience chronic illness such as depression or MS find it the most difficult to maintain well-being over time, as the definition of "healthy" is continually changing. As Charmaz describes in Good Days, Bad Days, "A good day permits an even schedule and is savoured. A bad day forces attending to immediate needs and may be dreaded" (1991: 5). Some days, says Leigh, to be healthy is to be able to go to classes and study for school; other days, to be healthy may be "to be able to get up and out of bed without wanting to die." People begin to understand their lives based on how they feel, as chronic illness often becomes the lens through which days are experienced and judged.

Leigh and Dawn deal with two chronic illnesses in their relationship. While they admit that sometimes one does get frustrated when the other is sick, both women agree that it is comforting and a relief to be able to relate to what the other person is feeling. Explains Dawn,

When she's down? Sure, I mean there's this thought, "For one second, why can't you just feel okay?" So there's that initial reaction, but there's no underlying anger. There's no underlying confusions or questions about what's causing it, because I know..... I know what it's like. If you have the knowledge of what it's like to feel depressed, you can be sympathetic.

On the other side, Leigh recognises that it can also be difficult when both

partners deal with a similar chronic illness such as depression:

The negative is that sometimes, even though you can understand, it's really hard to deal with because you might be dealing with the same thing or you're just tired of dealing with it, or you've had a long day and you're just making that extra push to be empathetic and calming yourself down and all you want to do is just go to sleep or pound a wall. You might just be having one of those days...

The couple agrees, though, that it would be much more challenging and draining to be in a relationship with someone who had no experience with depression. Understanding the illness means not having to explain many experiences that people with depression endure. Dawn and Leigh say that in their lives, there is no judgment, no blaming, and little misunderstanding and confusion.

Penni and Rosie, by contrast, both face different health issues in their lives, but did not find that they could share their experiences and relate well together when each was in crisis. Due to an inability to communicate (Penni says she often became outraged and "manic;" Rosie was often intoxicated), and Penni's perception of not being supported by Rosie, the experience drove a wedge between them, and led to a separation. Chronic illnesses impact on many areas of life, including relationships, social networks and well-being. The uncertainty associated with a chronic illness leads to frustration and an inability to make future plans.

Concerns about the Present, Fears for the Future

Worries and fears often seemed to be difficult topics for the women to discuss. Where there is a serious health condition present, the women in the study worry about quality of life, finances, intimacy, children's well-being, getting sick again, and the effects that one's ill health will have on a partner's

well-being. Yet while most concerns are fairly generalizable to any couple's worries about health and well-being, differences such as facing homophobia from mainstream society, and facing potential rejection and lack of support from family because of sexual orientation are specific to lesbian couples. Lesbians who struggle with chronic conditions experience unique fears and worries.

Financial strain was felt by most of the women I interviewed, and almost all worried about their financial security for the future. As Ann will need chemotherapy for a minimum of four more years, she and Diane are concerned about the financial costs involved. During the time she was in the hospital last year, Ann lost three months of her salary, as her position at work did not allow for any sick leave. She cashed in all her RRSPs. Ann and Diane do not have a medical plan, and many of the drugs that Ann depends on are not covered. Diane has maximised the limits on each of her credit cards helping Ann pay for the medication she needs to stay well. Without same-sex spousal benefits, the couple worries about their future.

Hazel and Sirshu recounted to me their experience 12 years ago when Hazel fell and broke both her ankle and her leg. At the time of the break, Hazel had just graduated, and was about to start working and paying off her student loans. She was rendered immobile for ten weeks and could not work. The following year saw Hazel off work, and walking with crutches or a cane. This injury has since become a chronic problem, and she has trouble with her ankle, leg and hip. Hazel was on social assistance right after the accident, and began to work during the following school year. Because both Sirshu and Hazel work mainly only year-long contracts, and because the two women have slightly different financial goals, Sirshu worries a great deal about the

couple's financial future.

Women who have children worry about how their children cope when someone in the family deals with serious health issues. Penni and Rosie have shared the job of caring for Rosie's two young children since they became a couple six years ago. As Rosie is struggling to deal with her alcohol addiction, she also wants to become a better parent. Both women feel that Rosie's alcoholism has affected Rosie's and Penni's daughters in a variety of negative ways. Penni's teenage daughter will not speak to Rosie, as she sees how hurt her mom was by Rosie's actions when she was drinking. Rosie's youngest child became very close to Penni who took over the main caregiving role in relation to him. Now that Rosie is healthier and trying to play a more active parenting role, the young child seems confused over who is "mom." Penni and Rosie agree that Rosie has depended a great deal on Penni in terms of caring for the children while Rosie was using alcohol, and that this balance of caring must be re-evaluated based on what is best for the children.

~~Sarah and Kate think that it is sometimes difficult~~ for Kate's three children to understand what it means to live with two moms and two chronic illnesses. One child was very worried when Kate was hospitalized during a serious acute stage, and his stress led to hypochondriasis. The oldest child seems unaffected except that she feels her friends' families "do more stuff." Kate and Sarah do what their energy levels allow in terms of keeping up the activities of a "normal" family. They find that keeping different methods of communication open with each of the kids is important in allowing them to express their worries. The reality for Kate's condition, though, is that it is relatively uncommon, and she may live with it another

five years, or another twenty-five years. Having the unknown looming around them is stressful and worrisome for the entire family.

Almost all of the women who deal with a health issue (chronic and acute) and their partners fear that the health condition will worsen, return, or that they will die. Making long-term goals may be challenging or frightening, because at the back of their minds is the prospect that one partner might get sick again, and the plan will have to be changed.

Louise, who deals with severe chronic pain worries that she is

~~..... going to be worse rather than better in a couple of years. That really worries me. Working really worries me, being able to hold an income, you know.... I mean, there always disability or welfare, but... one can't live on that - and I don't want to live on that. It's just not something I want. And, I guess, if things do get much worse with my back, maybe I.... won't be able to handle the extra pressure, or..... maybe Thelma won't be able to. I don't know... I have lot of unknowns, lots of questions.~~

Adrienne worries about her own, as well as Dar's, health, and prays that Dar will not try to commit suicide again. Fears, worries and concerns may be different for every individual, depending on a variety of factors. Rene and Jamie had serious worries about the possibility of Rene's cancer returning. At the time of the interviews, they were thrilled at Rene's remission status. However, Jamie shared her fears for their future together:

I didn't know many people with cancer..... and then, you know, all of a sudden, you know, my partner is diagnosed with it! And I - I saw the outcome, and not knowing much about cancer I - you know, I thought that she was going to die. And I didn't tell her that... but... yeah I really thought that. I didn't say it...no, it was my own thing...I didn't spell it out or whatever, but I mean, it's there..... So, of course, fear of her getting sick again. But you can't live like that, I guess. That's a big fear, though....from what I hear or read, if you do go back into the cancer after the first time, your chances for survival.....come down.....(sigh) I don't know...what we would do if that ever happened...I don't even care about the financial aspects of the house, or whatever..... I don't

care about that, I just want her to be around...

As Sarah faces the prospect of living for the rest of her life with fibromyalgia, and with Kate's chronic degenerative disease, she fears the future. It is

the sense of just enduring...like just that kind of feeling like we're just only barely making it all the time, instead of being able to feel like there's joy... and excitement and passion.... and all that kind of good stuff.

Charmaz (1991: 42) describes illness as "intrusive" when people acknowledge that the effects of illness are not temporary, but will continue on with uncertainty. Living with intrusive illnesses may lead to a loss of control on a variety of levels. When I asked Jane, who deals with a serious chronic illness, whether she had any fears about the future, she described the reality of living with two potential possibilities for the future:

I have one where I ~~basically go on fairly able-bodied, probably would be able to work full-time and doing stuff I enjoy.~~ The other possibility is I could wake up tomorrow and begin a process where I would be blind, or I would lose speech. ~~I wouldn't be able to swallow, or I wouldn't be able to dress myself, or I have to wear diapers, those kinds of things....~~ It does feel out of my control.

"The relative visibility, embarrassment or stigma produced by illness or the subsequent loss of control can significantly define a day" (Charmaz, 1991: 49). Jane obviously sees one of the possible futures as more positive than the other. The future in which she has more control, and is not as affected by her illness is the one for which she hopes. When people are trying to recover from, or accept an illness in their lives, often, Charmaz says, they put their lives and their identities on hold (1991: 14). As they evaluate each passing day as good or bad, essentially, they are evaluating their own selves. "Ill people

measure the quality of the day against the self they recognize, acknowledge and wish to be. Thus they judge whether the day is consistent with the self they wish to affirm and present to others” (Charmaz, 1991: 50).

Theresa described feeling trapped in her life. She struggles with a serious chronic illness, is totally uncertain of her future, and her relationship is not emotionally supportive. She shared that she feels people are giving up on her, and that everyone, including her partner is frustrated with her for being ill. At times, she has wanted to leave the relationship, and to live alone, but she fears leaving.

I keep getting worse, and how much worse am I going to be in a month? I just don't know...and if I'm alone, am I going to be able to walk myself to get groceries? What then...?

Living with chronic illness involves many questions, frustrations, fears and uncertainties for participants.

Healthy Lesbian Relationships

Many women described the benefits of being in a healthy relationship while coping through a health issues. When discussing the notion of “healthy lesbian relationships,” many women spoke of the importance of being healthy individuals, and looking after their own well-being even while enmeshed in the complex situation where one partner’s health may be the focus of attention. In relationships in which two individuals are dealing with health issues, it becomes even more important that each woman maintain her own individual sense of well-being even while caring for a very ill partner.

In Cancer in Two Voices, Sandy describes the need to be individuals, and the fear and tension partners often feel when taking space:

Barbara has expressed a desire to have quiet time to herself this fall. I understand that the first stage of the two of us huddled together in the face of this disease is winding down. We both want and need to move to a different level of separation. I want Barbara to feel safe and protected by me, while at the same time, I need to feel engaged with my own life in a daily way. I'm preparing to rent office space to use for a few hours each day, buy a computer, begin work on a short piece for an anthology. All steps that generate guilt, uncertainty, and confusion in me, but some welcome distance as well. It's time for us to find a different way forward (Butler & Rosenblum, 1991: 35).

For Adrienne, being a healthy individual is important, and supersedes being in a healthy relationship of any kind. Women speak of taking many different steps on their own to maintain well-being. In addition to maintaining individual physical health, participants speak of "self-care," and how important it is for both partners to attend to this in a relationship where an illness or disability is present. Despite the strain in caring for a partner and oneself, however, almost every woman could think of at least one thing that she took part in to feel good, lift her spirits, or keep herself from feeling unwell. Adrienne describes how and why she maintains wellness as an individual.

I sustain myself by doing things that give me pleasure. Even if it's something as simple as going for a walk down to the creek to meditate or pray. I have to do that—even if it's only ten minutes a day. I've tried talking to Dar about that, saying that's so important because it's like the analogy of a well. If the well runs dry, there's no water for anybody, and we have a lot of demands on both of us... a lot of stress. And if we don't have that to fall back on, like, if you don't have yourself - what have you got?

Other activities in which women engage to maintain well-being include meditation, daily exercise, walking, swimming, learning new skills, going out with a friend for coffee, dancing, cooking, and eating well. Participants said these sorts of things contribute to a sense of well-being

physically, and promote positive self-esteem, which they say plays a role in being a healthy individual. Women say that while it may be difficult, giving each other space and taking time for oneself are two integral elements to preserving a sense of well-being as an individual, as well as to maintaining balance in the relationship. Healthy individuals, participants report, create stronger, more satisfying relationships.

In the process of re-examining aspects of their lives during illness, couples may begin to think more about what a healthy relationship means to them. "Healthy" means different things to different couples when they think in terms of intimate relationships. All of the women explained in varying ways that maintaining intimate relationships requires respect, care and attention. Dawn says, "a healthy relationship is finding the right person and working on it, I mean, no relationship is perfect. Everyone has their down days, and their little differences." Jamie had always wanted a relationship like hers and Rene's, and she found maintaining it to be quite simple:

It's easy, you know? We have a great amount of respect for each other and a sincere desire to ~~make each other~~ happy. And it's giving... we're always more concerned with giving to each other than receiving.

Dannie and Sam describe a healthy relationship as "being really in tune with what each other needs, and caring for the other when she is in a rough emotional spot."

An important feature necessary to maintain well-being in a relationship, Hazel says simply, is "Communicating - talking or screaming or whatever. Whatever it is, just make sure that - joy or pain, or whatever - you're sharing it!"

Leigh and Dawn find the qualities of a good relationship to combine many different types of support, including being emotionally supportive,

doing activities together, preparing food for one another, talking, and offering strategies and new perspectives. All participants expressed the view that when one partner is sick, a healthy relationship must include patience and acceptance that things sometimes take a long time to work out. Some couples give advice like: “do not argue when one of you is sick,” “be aware of and sensitive to partner’s limitations,” and “be open; don’t have secrets.”

Most women in the study found that they were working at becoming healthy individuals as well as continually cultivating healthy lesbian relationships. Kate summarizes the words of many of the women:

Communicate with each other. Define your control issues. Find healthy stress responses. Support each other in concrete and emotional ways. Don’t try to control each other’s lives. Listen to her. Step back and figure out what the relationship means to you. Respect each other as individuals. Be sustainable as an individual. Do your own work, stay healthy, stay grounded, share values, and grow together as individuals in the relationship.

Among the various descriptions of relationships, and pieces of advice, two main issues that women use to describe healthy lesbian relationships are communication and support from partners. It is clear that healthy relationships are influential in maintaining well-being. Partners in such relationships are able to communicate effectively and to provide support for each other.

“She’s All I’ve Got”: Social Support as the Main Feature of Healthy Relationships

When the tape was turned off in one interview, a woman shared a private story with me regarding the significance of her partner in her life. Her final words were, “she’s all I’ve got.” She explained that she may have

attempted suicide if it were not for her partner's love and support. I began to notice that while perhaps less dramatic, this theme emerged throughout many of the interviews. Participants mostly tend to rely solely on their partners for support, even when they have a social network. Many are unsure as to how they would cope were their partner not around.

Some participants say they know they have friends who they could ask for help, but since they have both a partner and best friend in their intimate relationship, they look to each other for strength in coping through hard times. Dawn says,

We have people.... it's just whether we call them or not. It's nice to know they're there, but mostly we just rely on each other. We spend lots of time just together.

Sarah and Kate also acknowledge that they do not call on their friends for support as much as they could. Sirshu and Hazel reflected that they do not think they have *ever* tried to rely on other people for help - even though knowing the help is there is important. Of caring for Hazel, Sirshu remembers that she "tried to do it as much on my own as possible... besides, there's no one she really would have been comfortable with to do some of those things."

Relying solely on each other as partners while going through a health crisis may not be the most effective way to cope. Firstly, a couple that does not reach out for, or accept help from the outside begins to be isolated from their networks. Charmaz writes that people who become immersed in chronic illness often experience a "pulling in," or "shrinking" of their social worlds. Dawn admits this happened with hers and Leigh's friends. "Sometimes we feel ostracised from all the friends we had." If contact becomes sporadic, friends and families may drift away (Charmaz, 1991). The women may also

begin to feel that the load which was once manageable may become too heavy after awhile, and it may feel like there is no one left to call on for help, since they have distanced themselves from their networks.

On a very intense personal level, women spoke to me about the very frightening, serious phases of their own and/or their partner's illness. When asked how their illness experiences might be different without their partners' support, many women became overwhelmed with an outpouring of strong emotions. Many of the participants share very strong commitments and deep love for one another. In times of crisis, many of these women do give up their own lives and interests in order to focus on their partner's health issue. While many women articulate both how important it is to be a healthy individual within a relationship, and to access support from outside the relationship, when it comes to facing a serious health issue, most women come to a point at which individuality and separateness may be overlooked for a time. Participants admit that during some points, they became completely involved in the care of their ill or disabled partner. Sandy describes this shift in Cancer In Two Voices:

I am excused. I excuse myself. Cancer is what I do now. Cancer is my work. Barbara's mood swings, doctor's appointments, medicines. My feelings. Our writing together. All of it has become my central activity. Cancer swallows up the air of my life and insinuates its presence everywhere. Nothing remains untouched. Inviolable. So I am excused. I don't want to be separate now. Time is too valuable. I will be separate soon enough. I am excused. I excuse myself from autonomy. I need to yield, to allow the dependence on this woman who has become my life. (Butler & Rosenblum, 1991: 48)

Many of the women say they could not bear to think about what the experience of illness would have been like without the support of their partners. A few even credited their partner's support as the one thing that

kept them alive at various points. When I asked Adrienne how she thought it would be different if Dar's support had not existed in her life, she immediately responded,

I think I would have had a nervous breakdown a long time ago if I ~~hadn't met her. If she wasn't here, I don't think I would be able to~~ function emotionally...I don't know if I could go on.

Ann answered quietly and seriously about Diane's support, "She's my support and vice versa. If she wasn't there, I wouldn't be alive today. I'd just be a shell. Partners and the support they provide are crucial for many women who cope with serious health issues. With partners as the main providers of support, many participants feel they could not have made it through the experience without their partner.

Participants cite several kinds of support that they provided or received in the face of a serious health issue. Women's partners were usually the main source of support, providing emotional, instrumental, informational and appraisal support (House, 1990). Not surprisingly, several women said that their well-being depends largely on the support of their partners.

The most common type of support discussed by participants was emotional support. Most participants felt that the existence of emotional support is extremely important to their general well-being. Emotional support is most often provided by partners. For the women who were involved in relationships that they considered positive and supportive, it was a comfort simply knowing that they had that one person there with whom they could talk, cry, and face daily challenges. Even while enduring stressful health conditions, women expressed being comforted by knowing their partners loved and cared for them.

While Rene was undergoing treatment for cancer, her emotional

connection with Jamie increased tremendously.

Just being together with her was...wow. She was just there... all the time, you know? We hadn't been together that long before all this happened, and uh....even though you talk support and all that stuff, and 'I love you,' and whatever... you don't know until you go through something like this, how much is there? And uh, the caring and support... And like, I think the hugs are important - telling each other you care, and stuff...And hearing "I love you," every day is great! It was so good to have her there. A lot of her being there helped me to maintain my life... I think if I didn't have her, um, I might have found myself going to my parents, and I don't think that would have been a positive situation at all.

Adrienne and Dar both deal with health issues. Adrienne revealed her method of being emotionally supportive and keeping communication open in the relationship with Dar.

Sometimes she'll say she's okay, but I know underneath she's not. And it's hard to be supportive in a way so that the other person doesn't feel like you're prying or pushing or trying to pull stuff out of them that they don't want to talk about. I've learned to kind of let it be if she doesn't want to talk. She'll talk when she's ready. So, my approach to Dar now is compassion, support, patience and love... and just being there if or when she wants to talk.

Lesbians participating in the study confirm that illness and disability are easier to deal with if one has a partner who is emotionally supportive. Emotional support from a partner was described as being more significant than having extra money, a nice home, or having tasks done for them. Those women who did not receive what they perceived to be adequate emotional support from their partners found that absence difficult to deal with, and to talk about. Theresa is not satisfied with the support she receives from her partner. While her partner provides some types of instrumental support, there is no emotional availability. Theresa explains what it feels like to be in this relationship:

No.....I don't feel satisfied at all. It's like, sort of, "Do you accept what's happening in your life?" I need to accept what's happening, because I've tried many times to leave, and thought about all the options, and you know, (sigh) I'm here only because I need to be here. Because I've looked at all the other possibilities and can't do it right now.... So, no, it's not great, but you know... I'm grateful that she's here and I have a roof over my head, and....but no, it's hasn't been a satisfying coupleship for a long time.

Along with emotional support, the women in the study mentioned instrumental help as something that their partners most often provide. Participants found that the various instrumental supports provided by their partners (e.g., cooking, cleaning, grocery shopping, and taking on more duties with the children) helped them to carry out day-to-day living.

When Ann was in hospital, Diane helped her with the financial costs of being ill, and took over some of Ann's shifts at work. When Hazel was disabled due to her ankle, leg and hip, Sirshu cooked all the meals and cleaned their home. Sirshu also assisted with Hazel's mobility issues, including taking her to and from the bathroom, and in and out of the car if Hazel had to leave the house. Jill looks after the yard and the major cleaning in the house, while Jane cooks the meals. When Penni was dealing with mental health issues, Rosie took the children for drives or to the park in order for Penni to have some quiet time in the house. When Rosie herself was struggling with her addiction, Penni looked after Rosie's children, and helped Rosie manage her household.

Many women in the study found it helpful when their partners accompanied them to medical appointments. Driving and accompanying one's partner to an appointment is not only an instrumental support, but also often makes it easier for patients to remember the information given to them, to make sense of that information, and to feel more comfortable asking

questions of medical professionals.

Another important type of support is providing information and resources. When Ann was in the hospital, Diane searched for information about Ann's condition in the biology textbooks she had used in university a few years earlier. Ann and Diane were better able to speak with and understand doctors once they were prepared with the knowledge that Diane sought. Likewise, Jamie located information about the different types and stages of lymphatic cancer, and shared it with Rene. Rosie found it helpful to meet with people at the Addictions Foundation of Manitoba to learn more about the effects of addictions on families both for her own benefit, and so she could share that valuable information with Penni.

Appraisal support includes affirmation, feedback, and social comparison. The women in the study thought of many examples where their partners were able to offer this kind of assistance. After Ann was released from hospital, Diane continuously reminded her not to worry about money, bills, or work, saying: "Don't worry about it - just get better. That's your job." Sarah, who lives with a chronic condition, finds it helpful that during her low times, Kate provides positive affirmation, such as: "You're doing a good job. It's not your fault that you're sick. It's not a personal failure." As Dawn had dealt with her own mental health issues for many more years than Leigh, she was able to draw upon her own experiences to help Leigh make sense of some of the feelings and questions she had about depression. Most of the women find that appraisal support goes along closely with emotional support. A partner who is able to be emotionally supportive is more likely to offer appraisal and positive encouragement to the partner who is sick.

The existence of social support from partners is critical to maintaining

a healthy relationship.

Participants say it can be overwhelming to cope with the sudden changes of a health crisis. Couples describe the tensions of dealing with illness, and they portray the challenges they face when each partner copes differently. All the women discussed the impacts of health changes on their careers and education. Participants share a mix of emotions about the future, including frustration, hopelessness, worry and fear.

All of the women interviewed agree that the onset of an illness or disability interrupts a couple's life for better or for worse. Despite differences in style and coping, all say that when a health crisis occurs, the balance in the relationship and in every day responsibilities needs to be shifted. The partner who is well must take on more roles, and when balance and power are changed, both partners may face some stress or anxiety. There were many depictions of "shifts" in power between partners, and feelings of dependence. Relating these shifting notions of power and dependency to me in the interview setting came easily for many, as most of the women had already articulated these feelings, patterns and dynamics to their partners.

Many women "took the role of the other" when shifts occurred in their relationships, and tried to make their partners feel more secure about losing some power or becoming dependent in some way. Many shifts have to do with one partner's health condition and its effects on the sick woman's abilities.

Women in the study like Adrienne, Jamie and Sarah spoke about being overwhelmed by the initial diagnosis of their own or their partner's serious acute illness. Jamie recounts the moment Rene was diagnosed with a serious type of cancer. She describes her immediate feeling of a need for a shift in

balance.

I just remember feeling really overwhelmed! I felt, you know, like, I've got to take care of everything, I got to take care of her, I've got to take care of you know, all the menial tasks in life. I've got to work still, and you know, continue and put on a smiley face and - and.....I just.....remember feeling, yeah.... really overwhelmed...

Sirshu echoes the feelings of Jamie, feeling stress that what was once divided evenly in the relationship now fell solely upon her, when her partner, Hazel was injured. "Usually we shared tasks, and then, all of a sudden, I was doing it ALL. And yeah... that caused some stress."

Ann and Diane say that when Ann became seriously ill in a very short period of time, the balance was quite disrupted. Diane began to work around the clock, heading towards exhaustion. She took over Ann's tasks at home and at their common workplace, organizing information regarding Ann's condition, and spending every possible moment at the hospital. Once home from the hospital, Ann remembers how hard it was not to step up to do her equal share of the work. Since Ann was so ill and her recovery so slow, the pair negotiated that Ann's primary "job" at that point was to focus on getting well, and not to worry about other tasks.

In Good Days, Bad Days, a book about living with chronic illness, Charmaz says that "immersion in illness means experiencing the vulnerability of one's body: facing dependency" (Charmaz, 1991: 80). Several of the women said that it is difficult to feel as if one is dependent on another person, thus it is helpful if the well partner is understanding, and realizes that this imbalance in power needs to exist during the acute stages of an illness or disability, but is, in most cases, temporary.

Sarah and Kate jokingly report that their lives have been filled with

crisis since they began to see each other four years ago. They have had several different periods in their relationship when dynamics shifted dramatically, due to their health conditions. Sarah recounts a time when she says the dynamics of power and dependency changed. She and Kate verbally negotiated what this change in the balance of their relationship would look like. Sarah expands,

This question takes me back, too, to the beginning of our relationship, when Kate entered into a kind of personal crisis and we tried to be really explicit at that point, that we were setting up some dynamics that we didn't want to be permanent in our relationship. So, it was clear for a given period of time, and we don't know how long there's going to be a power imbalance for a whole bunch of reasons. Like, because I'm working and she's not. Because she's in an emotional crisis and I'm not, like for a whole bunch of reasons.

When partners feel they can relate somehow to the person going through the health crisis, it is easier for them to provide support. Understanding that one person is more vulnerable, and articulating that the relationship's balance might be disrupted for awhile is important when supporting a partner through a health crisis. Adrienne and Dar understand this, as they had a dramatic change in their lives when Dar stopped working.

Finances have been hard... Dar's not working. She declared bankruptcy.... Sometimes it's hard being the sole wage-earner. It's a little better now because she is getting money from EI. She was on Social Assistance for awhile which just tore her apart - right apart. I can understand that. If I was on Social Assistance after years of earning money as a nurse I would feel the same way. And so, I'm telling her, "It can happen to anybody," that kind of thing.

For Sarah the hardest thing about having balance shifting around is the feeling of powerlessness. Whether one is the ill partner who cannot maintain the same tasks and responsibility in the relationship, or one is the well partner who has no power to improve life for the other, it is difficult to adapt

to these types of shifts. As Dawn says of her experience with her own and Leigh's depression, "It's awful, like you can't just give your partner an ice pack or an aspirin to make her better." Living with a partner who is ill can be frustrating on many levels. Shifts to the balance of a relationship may be frightening and challenging for lesbian partners.

Many participants who are dealing with their own health issues feel that they do reciprocate support to their "caretaking" partner, and many of the same types of supports already discussed emerge (i.e., emotional support, instrumental help). Louise experiences severe chronic pain, and admits the balance is not even in her relationship with Thelma because of Louise's limitations. However, Louise relates that she tries to reciprocate support for her partner in whatever ways she is able:

Well, I think I'm there for her emotionally pretty well all the time. At times, when she's not feeling that great, I try, you know, to keep Jen [teenage daughter]away from her, let's say, or distracted. Or just let her know, you know, "Jen, she's not feeling good. Maybe you could leave her alone. You don't need to call her every five minutes..." Stuff like that. And if she [Thelma] needs to come home from work and vent and stuff.... absolutely. And I'll like come and make supper, whatever. Keep the peace.

At times the stress of the relationship and a breakdown in communication may make it difficult to support a partner. Taking the role of the other, and trying to understand how one's partner is feeling may be difficult, especially if one has never experienced a chronic health problem. When we talked about support in their relationship, Jill acknowledged frustration with Jane, and Jane responded, "I think the difficult thing is that I live with this illness every day and she doesn't," and Jill replied, "That's not true, I do, too!" Jane proceeded to explain, "Well, you do, but you don't live with it in my body." Jane's partner Jill has a difficult time understanding the

nature of the Jane's chronic illness. During the interview, both women are clearly frustrated as Jane tries to explain what it is like to deal with an illness. Jane describes Jill as "emotionally unavailable," and Jane says she is unable to communicate effectively how draining the illness is in her daily life.

Jane I've been fatigued since April, and Jill knew that. So, I figured it was a little redundant to say, every day, "Well, I'm tired. I've been tired for this many months now." It seemed obvious to me.

Jane's experience is evidently not as clear to Jill, who replies,

Jill Well, obviously it wasn't that obvious to me. Fatigue goes up and down - it's not constant.

Jane Well, it feels constant to me.

Jane realizes that her illness "is real, and it's not going away, and it's impacting," while Jill seems unable to accept this fact and move on with it. Because the two are at different places in their acceptance of the health issue and its impact on their lives, it makes it very difficult to support each other emotionally and deal honestly with issues together. Their lack of communication and understanding leads to great frustration for both of the women. Each said that she finds it difficult to provide emotional support for the other.

Participants agree that a supportive partner is very beneficial during a difficult health experience. Since having the experience of supporting each other emotionally through a health crisis, many couples even find that their relationships are solidified. Jamie shares,

It's a positive....I can't think of a negative thing that you know, had an effect on our relationship. It's brought us closer together, and I just feel like we can conquer anything now. You know, we'll get through... hey, honey?

Diane said, "I didn't think I was able to love her any more than I had prior to the illness but it just keeps on growing...."

While some couples find their commitments solidified and strengthened by coping through a health problem together, some relationships become very strained from the extra stresses associated with dealing with serious health issues. The stress on an individual or couple dealing with a difficult health condition may result in fears about the stability of the relationship. Some participants say that the experience of an illness, and needing to communicate and be supportive causes them to see their relationship in a more realistic, and sometimes more negative way.

Jane and Jill each describe different tensions they face around relating as a couple. When I asked Jane and Jill how Jane's illness had affected their relationship and commitment to each other, Jane responded matter-of-factly, and without hesitation, "Oh, I expect her to leave me any day." Jill was shocked, and repeated the phrase in question form back to Jane. At this point in the interview, Jane and Jill entered a dialogue among themselves, and Jane shared with Jill some of her fears around this issue. She told Jill that she sensed Jill's frustration and anger at her for being sick. Jill did not deny these feelings.

In this sample, the majority of participants say it would have been harder, lonelier, more devastating, and more draining had they gone through their health crisis without the support of their partner. Some women are quite certain that without their partner's support in their relationship, they would either be in hospital, more ill (physically and mentally) or dead. Indeed, many women say their well-being is due in large part to the support of their partners. This finding, that people in positive marriage-type

relationships feel a greater sense of well-being, and cope better than individuals, is similar to classic studies of social support with heterosexuals, such as Lin & Westcott (1991). While many women say it is important to maintain individuality when possible, in times of crisis, couples may become focussed only on their immediate situation, i.e., serious health issues.

Summary

The stress faced by these lesbian couples dealing with illness is quite high, and having to take time off of work or school is incredibly difficult for many of the women. Not only did taking time off work add strain to their lives, but it was demoralizing for some women. In general, lesbians face a double-bind because they do not conform as stereotypical women. If they are not out in the workplace as lesbians, they are often viewed as “single” women, due to a cultural lack of understanding of the experiences of lesbians and their lives. Thus, the demands on lesbians’ time due to illness or caregiving may not be recognized, and they may find it difficult to take time off work. If they are out at work as lesbians, then they may fear losing their jobs, or dealing with discriminatory attitudes from co-workers, clients and supervisors.

Stress is compounded when lesbians feel they are unable to talk with others about their situations and find outside supports. When lesbians experience stigmas and do not feel comfortable being open about their lives, it becomes highly stressful for them to cope. While heterosexual couples may take for granted receiving family support, and speaking openly without fear about their experiences, these are not guaranteed to lesbians. Worries and fears escalate when a lesbian couple faces illness, and when nothing feels

secure, stress increases.

Women did a great deal of thinking about what it means to be healthy as an individual and as part of a couple. A strong relationship often buffers the additional strain that illness places on people's lives. Participants described the qualities and actions that they believe make relationships healthy, including communication and support. Many lesbians recognize and acknowledge the steps they take to maintain healthy relationships, particularly after the balance has been shifted due to illness. Couples also identify factors which complicate the process of restoring balance in a relationship. Some women come to see that their relationships are not healthy, and they are unsure about their futures.

Participants' relationships have all been tested after facing major health crises. In coping with this stress, what women say is that where there is emotional support exchanged between partners, the strain of illness is buffered. Couples facing futures with chronic illness deal with their own unique questions around identity. Social support within lesbian relationships is essential to coping effectively with stress and illness.

While this discussion points to the importance of a foundation of support in the couple, lesbians facing health issues also need the support of others. It is to a discussion of the many types of social supports and the various sources of support outside couples' relationships that I will now turn.

Chapter Six: Social Support and Social Networks Outside of Women's Primary Relationships

A social network is described by McKinlay (1980: 82) as "that set of contacts with relatives, friends, neighbors, etc. through which individuals maintain a social identity and receive emotional support, material aid, services and information, and develop new social contacts." I asked women about the contribution of different types of networks and support to their various experiences of health and illness. Participants share some negative and positive experiences with regards to their social networks and the support they provide.

Lesbians' Networks

Most often, women in this study cite other lesbians as the main source of support in their informal social networks. More specifically, most participants' friendship networks involved other lesbian couples. Once they had come out, participants say they met other lesbians through sports, support groups, and community groups. In almost all cases, lesbian friends were mentioned as people who ranked higher in social networks than family, and lower than partners. Some participants were distant from their families because of the family's inability to accept their sexual orientation or their health condition (e.g., mental illness). Some women, like Rene and Kate, describe long histories of family conflict that has little to do with sexual orientation, but which has a lasting impact on the family's ability to support them. Other women, like Jane, were not too involved with their families simply due to geographic location. Some women, like Dawn, Louise and

Penni, remained close to their families of origin.

Most participants said that to have a supportive social network including non-family members is extremely important, especially during health crises. When lesbians come out, they may create a “family of choice” made up of other community members of varying ages and genders. If they have been isolated from their family because of sexual orientation, the support from this family of choice becomes especially important. Most of the participants had social networks made up of close friends. Each network ranged in size (from two to over 20 people) and type of support provided. Even when family of origin support was present, many women say they are emotionally closer to their “chosen family” than they are to their families of origin.

In this sample, most families of choice included other lesbians almost exclusively. Almost every one of the women mentioned how satisfying it is to have friends to talk to, go out with, or depend on for other types of support. In general, friends in participants’ social networks provided the entire range of supports. Rene and Jamie’s friends offered a variety of supports during Rene’s illness. Dealing with cancer, Rene found she often needed different types of support from the network than did Jane. While Rene wanted to go for coffee with friends and be able to laugh and make light of the cancer, Jamie needed friends’ emotional support and appraisal to help deal with her own fears. Rene depended on Jamie for emotional support, but Jamie turned elsewhere for this type of support. The network they shared was good at assessing what the partners needed and when, without being asked. Members of the network were able to offer different types of support to Jamie and Rene at varying points throughout the illness.

Dar and Adrienne, along with Sarah and Kate, also find that their informal friendship networks consist mostly of lesbian friends. They say that this group offered the most valuable types of supports. Kate describes the kind of support she appreciated receiving from her friends.

People who could come and REALLY talk about it. People who were stressed by the entire experience were not helpful, but generally it was the people in our lives who were fairly grounded that were helpful. The people who were stressed from their own lives were not really so helpful, nor were the people who needed to be made feel better by the situation.

Sarah also commented that while their lesbian friends are helpful in the sense of being emotionally supportive, those friends who are childless did not recognize the added stress of looking after kids when one is sick, and did not think of providing instrumental support such as child care.

Most of the women say they share the same network of friends as their partners, although they may have a couple of individual friends from work. While couples most often share one network, sometimes one partner is more social by nature, or calls on the network more frequently for support. For example, Kate says she is better at reaching out for help, while Sarah, who describes herself as an introvert, prefers to depend only on herself and Kate. Likewise, Dawn is less apt to use the network of friends that she and Leigh share, partly because she does not drink socially, as the group does. However, Dawn does feel supported by the group, and is getting better at calling on the group for help.

Leigh has the support of the friends that we have, and she draws on that more than I do so that's okay, I mean, she's allowed to do that. And that actually helps me, I mean, if I ever need it I just tell them, "Could you come over and help me?" you know, or I go, "Could you come over and look after her?" And in the last six months, we've had to draw from our support network extensively....like spending the

night, going to the hospital...

Jane does not seek out a great deal of support from her network, and prefers not to dwell too much on her illness. She realizes that in a crisis, she and Jill have a strong social network to depend on, and although she chooses not to access help from the group at this time, she acknowledges the support.

I do feel that they are supportive and they would be very supportive in very concrete kinds of ways, instrumental tasks and stuff. They would really be quite supportive, and some of them even now, around the emotional stuff, are okay.

Kate reflects on the difficulty for lesbians in having a social support network of other lesbians, given the stress they are all faced with in daily life:

~~The world is still kind of set up assuming that we have family support~~
They're assuming you can go home and be cared for by your family.
And for a lot of lesbians, they don't have family support because of ~~their orientation. And then,~~ friends are great, but you know, so many of our friends are in their own crises and... I think it's just hard to be a lesbian. I just think that I've worked really hard to try and have a supportive community around me and it's hard to sustain that and there were a lot of supportive people around me when I was sick and that was great. I sort of compare it, you know, how poverty impacts on well-being because you don't have so many resources in your life. Well, I wouldn't say that I'm like a poor person, but there is a poverty of resources when you're a lesbian. You have to work hard to make your own community. It's not built in. And when you're tired, or sick..... it's even harder.

Support from Families of Origin

Even when women had contact with their families, and support was available, most women still tended to rely first on partners, then on friends, and then on family for social support. Thelma explains:

It's interesting about the friends thing, because... I am really close with my mom and my brother, and they're very supportive.... but it's the friends that I go to.

Only one couple had adult children, and Diane says that her daughter was wonderful during the time that Ann was ill. Ann boasts

she took over everything - the laundry, she drove when Diane had no sleep and was afraid to drive because she was so tired. She worked and helped out as much as she could... She was there. She ignored her life and came to her mom's side.

There seemed to be a clear division between friends and family, and the types of support provided by each. According to the women in this study, friends generally provided adequate emotional support and appraisal support, while families, if in the picture at all, were more apt to provide instrumental supports such as child care, meal preparation, and driving. A couple of participants cite family members who are supportive in different ways, including searching for information, and spending time relaxing with participants. However, most women in this study had little to say about the support of family during health crises and its impact on their well-being. Either families were out of town, participants were not emotionally close to them, or families were close by but were simply not able to provide the most effective social support for participants.

Some women do not have any family support during a time of crisis for themselves or their partner. Jamie almost lost her entire family when she came out to them several years ago. She informed them later that she was not a lesbian, and the family welcomed her back. Then in 1999, unprepared to lose family ties again, but faced with a partner whose illness was terminal, Jamie had no support. Jamie was not out to her family, thus she could not access the same types of support that may be taken for granted by some other couples.

Leigh's family does not know about her mental health issues. Her parents responded very negatively and with judgment when a family

member was dealing with depression, and so Leigh has felt unable to talk about her own depression openly with them. However, she finds that although her partner Dawn's parents live in another province, their emotional support in phone calls and letters, and during holidays is quite valuable. Even the perception that support exists is an important feature of feeling supported. Leigh illustrates this when she speaks about Dawn's family:

Her family, actually, is an extension of Dawn, and also, her family has been a big support to me. Yeah, it's just like unconditional support from her and her family. I know they will always be there...

Sometimes, even when a couple is not certain how family members will respond, the need for support becomes too important to worry about secrets. In their attempts to have a child, Dannie and Sam negotiated who they would tell, and how, as they became engaged in the process.

~~There was a bit of talk on whether we would tell our moms because they would worry, but we did.... and a lot of it was that it felt like it was an emotional journey that we were going on, and what if it doesn't work? We need the support of our friends and families, and if they don't know what's going on in our lives - our friends and family - then how can we expect them to support us? And so, we decided to tell them.~~

In sum, while families offered some types of support to many participants, they were never considered the main source of support.

Weak Ties Who Provide Unexpected Support

Many participants received surprises in terms of social support coming from a person or group from which support was not expected. Such support is very meaningful when one is trying to make it through a crisis. Almost every woman who participated could think of at least one "weak tie" (Granovetter, 1973) that helped in some way while she or her partner were dealing with the

stress of a difficult health condition. Weak ties were co-workers, relatives, and friends from out of town. The women had either not seen the weak tie for a long time, or were not usually very emotionally close with them. Participants themselves say they would not have called upon these weak ties for support. Jamie was not out at work, but found that her supervisor was quite supportive and understanding:

I was pretty sure he was on to me and stuff, and he suggested that I switch over to another site so I would "be able to run home at a moment's notice if your roommate got sick." And when he knew - like the day we were waiting for the news to come in, and I got there to show up for the beginning of my shift and he sent me home like an hour into it. He said, "Take the whole day off - you'll need it."

Penni and Rosie say that despite the fairly regular homophobia they experience in their small town, there were two weak ties who proved to be supportive in significant ways: the minister, who provided counselling for them for a short time (even though they do not have any religious affiliation), and the wife of Penni's manager at work. Penni describes a feeling of relief that at least two people were willing to provide emotional and appraisal support to help the couple deal with their problems.

Many women's weak ties helped out financially. Rene and Jamie were experiencing some financial difficulties, and when two acquaintances learned of this, they gave Rene and Jamie a cheque for \$1,000. The couple was quite shocked, as they were not close friends. Rene explains her relationship with these women:

They're not close friends or anything, they're just acquaintances, you know...I used to be closer to them, but um.....it just slacked off. They are sort of the kind of people that take people under their wing, like when I first came out and so then I was a little closer to them and then as I got more comfortable with the community and coming out and whatever, they just sort of...you know, went back into the woodwork....and I

mean, they're just good people.

Ann and Diane work together, and once the word spread that Ann was sick, something surprising happened. A group of women in the community, only some of whom were friends of Ann's, raised money through their informal network to help with some of her medical costs.

Siblings and other more distant relatives were often weak ties who provided important social support. Sarah's brother and his partner came to visit from during a time when both Kate and Sarah were unwell. They offered a fun time without the constant focus on illness, looked after the children, and took care of household duties for a week.

Jane says that what she finds quite comforting is the understanding and a sense of a shared experience she finds when she occasionally visits with her friend from another province.

~~I do have a friend who lives out of town who has a chronic illness, and I find her good to talk to, you know... when I feel like really shaking someone..... part of it is I don't have to say a lot. She's been chronically ill for a very long time. So, you can say like whatever. It's nice to have someone who knows where you're coming from. Or, I went for a walk with her and it was like a really short walk, and I didn't feel like we had to turn around just because of me. I felt that we both needed to turn around because it was enough.~~

Another group that often provides social support as weak ties are ex-partners. Several women noted that ex-girlfriends, and in one case, an ex-husband, were extremely supportive in helping to deal with the effects of the health condition. Past partners, having known participants over a longer period of time, are able to provide some emotional support, appraisal, information sharing, and instrumental support. In several cases, past female partners are included in the lesbian couple's shared friendship network.

The appearance of weak ties and the support they offered for these participants is beneficial not only in terms of whatever immediate relief the support provides, but also because they offer emotional satisfaction to participants. Each participant identified at least one weak tie. Participants say they felt surprised and pleased that support was received from someone from whom there was no consideration or expectation of support.

Disappointments from Social Networks

Along with surprises in support which pleased participants, a few women also experienced disappointments in informal support systems. Women in the study may feel let down when expected supporters do not respond at all to their health condition, or do so inappropriately. One male friend of Kate's was unable to come to terms with the seriousness of her illness and did not visit her even once after hearing about her health condition. She says that the news of her illness elicited quite a range of responses from her friendship network:

It really brought interesting responses from people, and some of it was kind of sad, you know... especially because some of my friends are in the ministry.... and seeing them not respond, well... that was really disappointing.

Rene also found that some people responded inappropriately to her while she was undergoing treatment. She wanted to maintain a positive outlook, and to not focus on the negative aspects of her cancer. Some people she encountered and hoped she could count on to be positive with her wanted only to cry with her, tell stories about others who had died from cancer, and speak in very "negative, dreary" terms.

Jane is also disappointed and uncomfortable when people do not

respond appropriately to her illness. She considers her illness a very personal aspect of her life, and does not share details about it openly with those close to her or with strangers. People who attempt to be supportive by talking about illnesses all the time only irritate and disappoint Jane. In her goal to to continue working, and to be as independent as possible, she does not appreciate help which she sees as undermining her ability to do things for herself.

When support is expected but is not carried through, participants felt sad, confused and disappointed.

Social Networks Respond Differently to Chronic Illnesses

Women spoke differently about support from their networks depending on whether their illness was chronic or acute. In general, women report that they receive more help during acute or crisis periods of their illnesses, and that support fades if conditions persist in a chronic nature. Women who experienced chronic illnesses, or whose acute conditions took longer than expected to heal often experienced disappointment that the support they received at the onset of their health struggles faded and in some cases became almost non-existent the longer the illness progressed.

When Ann was in the hospital during an acute period in her illness, she received much support from lesbian and gay friends. Rene was also well-supported while going through cancer. However, Jane, Kate, Louise, and Adrienne, who deal with long-term chronic conditions, experience support from the network differently. During the flare-ups, exacerbations, or hospitalizations due to their illnesses, they are certain they would be able to access support. In the non-crisis times, though, that support is not so clearly

defined. Sarah is not surprised at the variations in support.

I know this is not ~~uncharacteristic~~, but I think our experience was that in the crisis, in the worst crisis, we got quite a lot of support. Once the immediate crisis had passed, people were kind of not so supportive, but that's human nature... When you phone someone and say, "We're on our way to the hospital - could you please come over?" they tend to respond. When you say, "Kate doesn't feel well and is on the couch for the ninth week," they're like, "Oh, that's too bad." It's not quite the same response of, "Well, can we bring dinner?" or, "Can we take the kids?"

Sirshu was disappointed that as Hazel's long recovery period went on after her fall, fewer friends came to visit. Sirshu would have liked it if people came over to spend time with Hazel so that she could have some space alone:

I would have preferred a little more time just to do my own thing - ~~read a book or whatever~~, and not worry about her. Like that one time, when I went out... she fell. And if somebody had been there.... well then... I wouldn't have worried.

Women who live with a chronic illness are frustrated that the nature of chronic illness is not widely understood. Participants say their entire life is put on hold as they try to stay well while living with a chronic illness. When friends and family members do not understand that chronic illnesses are not going away, it can be frustrating. It is often a challenge to remind friends about fatigue, the difficulty of making plans in advance, and the consequences of overextending oneself. Often, Charmaz says, while people begin to cope, they often "tighten their essential relationships and loosen problematic bonds and casual ties" (1991: 82).

Living in a Rural Area Affects Support

Another factor that affects support is the experience of living in rural Manitoba. I interviewed two couples and one single woman from rural areas,

and there were some clear similarities, particularly around the issues of support. In rural communities, which are often more conservative and homogeneous, anyone who does not conform to the norms, like lesbians, may face predictable sanctions. "They are gossiped about, shunned, ostracised, encouraged to leave, and they may face acts of violence." (Tiemann, Kennedy, Haga 1998: 63). Some researchers even describe being lesbian in a small-minded rural community as a health risk. "Because negative attitudes about lesbians and gays are normative in rural locales, being a known lesbian is potentially hazardous to one's health (Tiemann, Kennedy, & Haga, 1998: 65; Herek, 1991).

Penni and Rosie say that people in their small town are less open-minded and more conservative. Tolerance of gays and lesbians may not exist in some rural areas. However, Penni claims that after living in her town for a number of years, people got to know her, and she gained their respect. Gradually, her sexual orientation has become less of an issue, and she feels she is now judged on her character and not her sexual orientation. Penni and Rosie like where they live and speak of the benefits of raising children in a small town. She relates that because "everyone knows" that her children's mother is gay, and there are not a lot of people moving in and out of town, at least the children do not constantly meet new people and have to explain the family situation over and over again.

Some people, like Theresa, feel isolated living in rural areas, and rarely find other gay or lesbian people with whom to socialize. She wishes she had a social network she could count on for support. However, while rural women said that having a social network in close proximity was important, particularly when they are unwell, they do not expect to have many other

lesbians in their networks. They agree that it is rarely possible to have a network of other lesbians in a rural area. Most often, women travel to larger towns or cities to see lesbian networks, however, if one does not have a car, or money for child care, this is a luxury that is not possible. The few rural participants in this study have mostly heterosexual networks.

Summary

Social support means different things to different people. For this sample, the existence of emotional support is key to maintaining well-being. Partners of ill women are most often cited as the main providers of support. Participants also receive support from their networks, which most often include other lesbians, and sometimes family or heterosexual friends. Support may fail or change if an illness is chronic rather than acute, or if people in the network are unprepared for dealing with the serious nature of an illness. Lesbians in rural areas do not find as much support, particularly from other lesbians as participants from the city. Clearly, social networks and the support they provide are important when trying to deal with a serious health issue, although the support of a partner is considered more important. While most participants admitted they tend to rely primarily on their partners for support, they admit that it is still helpful for all of them that they also be in, and have access to support from, a social network.

Participants who are ill or disabled will also come into contact with and rely on support from health care and social service providers. The next chapter examines women's varied experiences and interactions with health care professionals in Manitoba.

Chapter Seven: Interaction with Health Care Providers

When a person is ill, often they must be in contact with health care professionals more frequently. Women in this study had mixed experiences when they sought support from formal services such as health care providers. Some participants report fairly positive experiences, but most cited at least one negative experience with a health care provider in which they feel they were discriminated against because of their sexual orientation. Some theorise that they were treated poorly because of homophobia, heterosexism, and/or sexism. All of the participants agree that there is a need on the part of service providers for greater understanding of lesbians' lives, and a need for acceptance and inclusivity.

Positive Experiences with Health Care Providers

Some lesbians in the study say they have had positive experiences with health care providers. Some women expect and demand this type of treatment, while others are surprised when it occurs. When Adrienne had a supportive, positive experience with a nurse during one of Dar's hospitalizations, she was totally caught off guard. Adrienne sought out the nurse later and thanked him for the care and respect he gave them. He shrugged and replied to her matter of factly, "I was just doing my job."

Ann and Diane say they never experienced any homophobia during Ann's lengthy hospital stay. They recall letting care providers know from the beginning that they were a couple:

There was no response, really. It was just fact. Or, I suppose, I did come out to them, and explained that Diane was my partner, and the response was... we were treated normally.

Ann continues:

I kept on saying *partner* and they confirmed, "When you say partner...?" and I would say "Yes, my life-long commitment." They just asked for confirmation that I was gay, and that was it. I think it was for clarity or curiosity. I would ask if I was in their shoes. I mean... they don't want to make wrong assumptions. They needed to assess the situation, and realize who the important people in my life are. It wasn't like it was something hidden. We were open.

Only a few women relayed positive experiences in response to questions about experiences with health care practitioners. Several women provided accounts of feeling disrespected and invisible in health care settings.

Negative Experiences with Care Providers

It was easy for most of the women to recall times when experiences with health care providers have been uncomfortable. It is not surprising that some lesbians feel invisible when they seek formal supports (individually or as couples), as much of their lives remains ignored and excluded. Our language is not yet inclusive so that it allows lesbians and their families to be acknowledged. Health care providers ask lesbian patients questions about partners and family which are heterosexist, or assume that everyone is heterosexual.

Some women report that it is in the emergency room where they experience the greatest lack of respect or understanding. Usually, the problems occur with the very first person they contact, the intake nurse. When Jill broke her ankle, Jane accompanied her to the emergency room, and spoke to the nurse with her. Jill recalls,

Jane wheeled me in and is standing next to me. The nurse is taking all of the information down, and she goes, "Next of kin?" And I gave them her [Jane's] name. And the next question is, "Relationship?" I

said, "Partner." She says, "Friend?" I say, "Partner." Again, "Friend?" And then the third time we correct her and we say, "PARTNER!" And then she writes F-R-I-E-N-D on the chart!

This example and others make it clear that there is not always recognition of lesbian patients and their significant relationships by health care providers. Some women like Kate are less comfortable disclosing to strangers personal information about the nature of their relationships with their partners. Nonetheless, Kate says the treatment she and Sarah received from the intake nurse in the emergency room was terrible.

You know, in the initial intake when they're asking you who brought you in, and what you're in for? I said, "My house-mate, Sarah." I didn't know whether I should say partner or not. I was worried about negative reactions to that and also because of Sarah's profession, like, your people are everywhere, and I don't know that the files are that confidential. And so I said, "house-mate" and you know, like just rude response.... people were just rude to me about what that *meant* and who she was.

A heterosexual person may have their support person accompany them while waiting in the emergency room. By contrast, a lesbian cannot, due to the "family only" policy. Jane sees this as homophobia.

They certainly saw [Jill] as a friend that brought me in. They didn't see her as a significant other - they wouldn't. That was definitely an act of homophobia. I learned from this experience a few months later. I was part of a study, had to go to the hospital. I know that they don't understand the word partner, so I thought, "Okay, I'm going to be really clear." So, they give me the form, to fill out, and I'm very happy there's a blank. And so I write *same-sex lover* because I want them to understand the relationship of my next of kin. Then they finally get to the marital status and they have the usual choices, and I go, what the heck, *common-law*, so I write that in, and I give it to the receptionist, and she looks at it, and says, "Oh... we call that single."

Again, even though pertinent information about her life and her supports might be revealed through Jane's responses, her and other lesbians' lived

realities are invisible and ignored by the health care system.

Heterosexist questions which use exclusive language are easy to identify during interactions with health care providers, and some people can stand up and correct them with ease. Homophobia itself, however, which may manifest itself through heterosexism, is a less visible form of discrimination which is sometimes harder to identify or name.

Adrienne had been seeing a doctor who had always been quite supportive of her lifestyle, or so it seemed. On one visit, Adrienne decided to bring Dar into the examining room to talk with the doctor about Adrienne's depression and plan of care. The doctor was very awkward and short, and would not look at or direct conversation to Dar. The visit ended abruptly, in a different fashion than normal, Adrienne says. When the couple talked about the incident after, both shared that they had felt very uncomfortable, and decided it might be homophobia coming from the doctor.

What exactly is homophobia, and how can participants be sure that is what they were experiencing? Some of the women discussed these questions, in attempts to explain how a person knows when she is a victim of homophobia. Adrienne thinks back to her experience with this particular doctor, and describes a sort of intuitive knowledge or feeling a person gets when she encounters any kind of homophobic response:

Well... initially, I thought I was imagining it.... I thought of writing a letter, but how could I prove someone is homophobic? That's the whole thing. It's so insidious. That's what I'm finding. It's like, how do you know when someone's a dyke? What substantive evidence do you have? Same thing when you know someone is homophobic. You just feel it.... you know it. But, then, what is that....?

Jane and Jill say they have dealt with a great deal of homophobia on the part of health care providers. Jill reminds Jane, "They always had

problems with me going into the office with you." Jill adds:

Other times people have said, to me, "Well, what are you doing here? Like the nurse will call her in, and she'll go in and I'll go with her, and the doctor will come in and give me a glare, and you know, like, "Who are you?" In the meantime, I'm thinking, "Well, [Jane] knows I'm here. What's the difference who I am? She obviously had no problem with it." But twice that's happened. And the other times, it's "Who are you?" And I said, "I'm her partner," and one of them gave us a really annoying response. One doctor was obviously very uncomfortable, and the other one just totally ignored me.

Sometimes homophobia is subtle, and sometimes it is more overt. In another example from Jane and Jill's life, even though a care provider was gay-affirmative, members of a support group were less accepting of Jane and Jill as a couple. When the couple decided to attend a monthly support group for couples dealing with chronic illness they called the group facilitator ahead of time to let him know that they were a lesbian couple, and to ask if he thought that would pose a problem within the group. The facilitator assured the couple that all couples are welcome, regardless of factors such as sexual orientation, age, or class. When they introduced themselves as each other's partner during check-in every week, other group members' reactions seemed fine. However, during one session, when Jane and Jill were absent, the group watched, "Towards Intimacy," a film about couples who deal with chronic health issues in their relationships. The group leader phoned them shortly after this meeting to alert them to the fact that during a segment which depicted a lesbian couple discussing the impact of illness on their lives, there was a great deal of overt verbal homophobia from the group members. Jane and Jill were invisible as a lesbian couple, despite all their efforts to be open and honest, and had been sharing details of their lives and trying to seek help from a group which was included individuals espousing

ignorant, homophobic attitudes.

Sometimes the attitudes of health care professionals are blatantly discriminatory. Jill relates what happened during another trip to the hospital,

~~So the nurse says, "I'm going to wheel her into the hallway over here, and the doctor is going to see her right away." So she grabs my wheelchair, and I say, "Well, I want her to come with me." And the nurse says to Jane, "No, no, she's not going to be very long. You can just wait here. It's very crowded back there. There's no room to have a whole bunch of people back there, all waiting in the hallway." So she wheels me into the hallway, and I'm sitting there waiting for an hour, and there's basically just a wall separating us. And like the whole wall was littered with people waiting, and they all have two people with them - someone who has brought them in, whoever they are, and the injured person. And I'm sitting there all alone. And so every time the nurse would come by, I'd say, "Can't I have Jane come back with me and wait?" And she'd say, "Well, you're going to see the doctor in a few minutes." After about three hours, the nurse came back and said, "Oh, your friend Jane asked how you were doing."~~

While several women experienced inappropriate and offensive treatment from health care providers, some are unsure whether it is because of their sexual orientation or another factor. Penni is puzzled about the awkward treatment she received at a small town crisis stabilization unit. "I don't know if it's because it was a mental health issue, or because I was an out lesbian, but the staff was really weird." When Diane and Ann were thinking of past negative experiences with care providers, they thought of this particular issue. Diane remembers

~~The only complaint I have was that one doctor not taking the time to explain as much to me as I would have liked, because I'm more familiar with the terminology. And I realize that Ann had the illness, but if she's on heavy medication, and I'm the one who will be providing home care for her once she gets back.... I sometimes felt I should have been included more. A lot of doctors do that, just assume that you won't understand, so they don't bother trying to explain it. They always assume it's beyond you and I find that a little.... annoying.~~

Some participants in this study (whether or not they are out as lesbians) feel as if they are treated condescendingly by male doctors, and some say they are made to feel as if they are wasting physicians' time. Some think that if they were (heterosexual) male patients, their feelings and medical concerns might be taken more seriously by physicians. Kate remembers with irritation the way she was treated before she was diagnosed with a serious degenerative kidney disease.

All the emergency room doctors and the cardiologists I spoke to were all very patronizing, but I'm clear, I don't think they even bothered thinking about whether I was a lesbian or not. They just treated me like it was all psychosomatic and I was a complete idiot and just wasting their time. I'm sure they get the odd crackpot. But from what I could tell, nobody who was at the hospital was there just for fun. I don't understand why people treat you with that sense of, I mean, the assumption out of which they function is that you're trying to hoax them somehow.

Participants feel that women's concerns about health are often overlooked or dismissed as invalid. Dawn, who has been dealing with mental health issues for over 10 years, was recently put on a drug which causes sexual dysfunction, or a marked decrease in her sex drive. When Dawn recognized this side effect and brought her concern to her psychiatrist, she was told that it was likely the only drug that would work for her illness, and she had little choice but to continue taking it. She seriously considers that if she were a male, and in particular, heterosexual, and had complained that this side effect was unacceptable, her concerns would have been heard, and more would have been done to help salvage her sex drive.

Feeling diminished, invisible or disrespected by a health care provider may lead to serious consequences, where women say the experiences with doctors have been so bad that they do not want to return to seek medical care.

Kate felt this way after her visit to the emergency room:

~~It was terrible treatment. The last time at the hospital, I said, "That's it. I'm never going back. I'm just not going to go again, because it was so bad." I didn't care if I died.~~

Strategies Lesbians Use to Achieve Better Health Care

Many participants went on to tell me about the strategies that they now use to avoid future disappointing interactions with health care providers. The strategies revolve around three main ideas: being assertive as a patient, being out and open as lesbian couples, and locating services that are lesbian-positive.

After experiencing negative treatment by health care professionals, many women like Adrienne are learning to become more assertive and proactive in demanding good health care, and negotiating their way through the system as women, and as lesbians.

~~This is probably the case with a lot of health things, but I'm finding more and more that if I do go and see a conventional doctor, I have to be very assertive and almost, not exactly rude, but quite vocal, and I have to ask a lot of questions and make sure I understand things. I have to be my own advocate and I found with Dar's illness, I have to be her advocate, too.~~

Through her assertive communication skills, Adrienne hopes to send the message that she will not be treated as anything but an equal. After a homophobic experience with her general practitioner, Adrienne switched doctors. She remembers the tone on which she began a relationship with her new doctor. "The new doctor asked why I was coming to see her. I told her, 'Because the other doctor is homophobic. I won't tolerate that.'" Adrienne says that being assertive "scares" doctors, but when a patient is assertive,

doctors will respond in a more appropriate and respectful way.

Dawn shares the same attitude, saying: "I don't like to see people as higher than me, I see them as human beings. They have no power over me... but I know other people feel that."

Some women say that being proactive and assertive is helpful in creating good relationships with health care providers. Even if the first visit is awkward or uncomfortable, they consider that may be typical for any patient. Starting off the interaction in a proactive manner, though, will lead it more quickly into a positive relationship with which patients are comfortable, and are treated with more respect by doctors.

Dawn and Leigh find they must be assertive about demanding good care as lesbians. They must also deal with mental illness which brings up a whole host of other issues. Dawn needs to make it very clear when she sees a new psychiatrist that being lesbian is not her reason for seeking help. If she is not understood or respected, she will not continue to seek services from that doctor. She explains:

Being gay is not my central focus when I see a psychiatrist, but it often is for them. ~~On the first visit, psychiatrists often think you are there because of problems with your sexual orientation, like it must be so hard or traumatic to deal with. I tell them openly right away. If a doctor was going to get stuck on that, I would just leave.~~

Each participant recognizes the barriers and the extra strain of being assertive, but all say it is essential in maintaining good health care.

Being out in the world as a lesbian couple is another strategy that Dannie and Sam and some other couples find is extremely helpful when dealing with a major health issue, and navigating through the health care system. Being out as lesbians works together with being assertive. Sam says

the health care system always makes us give over power to them. Our approach, though, is to be really pro-active about setting the tone, going to every appointment together, and being visible as a couple. If we push the fact that we're a couple, they have no choice but to see us that way.

Dannie and Sam find that these strategies have worked, and feel very comfortable with the doctors and nurses with whom they have frequent contact. Sam jokes that she and Dannie are informal educators about lesbian life when they meet with doctors and social service providers, and they say they are patient as health care practitioners come to understand their positions. Dannie says that after being challenged or puzzled initially about their situation, most health care practitioners are now usually relaxed and treat them with respect and dignity. Dannie and Sam are also comfortable being out, and neither woman is worried about losing her job or family based on sharing this information. The couple goes together to appointments with a sense of entitlement. They are assertive health care users, proud of their relationship, and happy with their decision to conceive. Dannie and Sam "never wanted to compromise our identities as lesbians in order to be parents."

For some women, being out is not as comfortable or as simple an option. Sarah still worries about being out in her profession, as do Sirshu and Jamie. Lesbians in this study who are not out say there is greater stress and anxiety around the whole process of interaction with health care providers. Medical visits may be less honest, and patients may have to deal with all sorts of questions (e.g., "Are you married?" "Are you using birth control?") and procedures (e.g., pregnancy testing) that may not be relevant to their lives.

Each person's comfort level with coming out to health care providers

will be different, and fears and concerns are based on varying factors in each individual's life. Those women who are still in the closet have valid reasons for not coming out. Sarah shares her concerns:

I didn't come out ~~explicitly~~ because I was worried, and I wanted her to get good care, and I wanted to know what was happening. But.... I wasn't in a place where I was going to work on justice issues.

Coming out to doctors is generally thought of as positive by the women who have done so, and who have had at least one positive reaction. Sometimes being out means one is faced with homophobia. For couples like Dannie and Sam, it becomes an opportunity to educate others. They certainly do acknowledge the barriers involved in being two women accessing care and support from health and social services, but they feel that by being out as a couple, they are the ones who can begin to break down these barriers.

In this study, participants who were out (like Dannie, Sam, Ann, Dawn, Adrienne and Diane) *expected* to be treated fairly and with respect, and for the most part, they have cultivated satisfying relationships with their health care providers. By contrast, the women who are more closeted (like Sarah and Sirshu) and worried about receiving a homophobic response from health care providers more often report recent negative experiences. The fear that keeps people in the closet is intense, but perhaps it can lead people to self-fulfilling prophecies. It is no doubt difficult to be out, assertive, and demand fair health care when you are sick, but those who have done it say the results are worthwhile.

The third main strategy that the participants use is to locate services that are "lesbian-friendly." This strategy is one employed in particular by those women who are less comfortable being out as lesbians seeking care from mainstream services. In Winnipeg, women say they go to community

health centres like Klinik, Village Clinic, The Fort Garry Women's Resource Centre, and The Women's Health Clinic for medical care and counselling. Each of these is known to be a clinic welcoming of diversity. Sarah, Kate and Jamie all feel that going to a place which is known to be affirming takes away some of the stress that is already associated with going to the doctor. Some women asked other lesbians for advice on gay-positive doctors and health care providers, or consulted a list kept by the Winnipeg Gay/Lesbian Resource Centre.

Summary

When participants say they have had negative experiences with homophobia on the part of health care providers, their stress and anxiety around the whole visit increases. It is often difficult enough to communicate with health care professionals without worrying about whether you will receive sub-standard care based on their judgments of your lifestyle. When lesbian couples are made to feel invisible, different, or unwelcome, this creates tension and awkwardness, and obviously makes it difficult for both partners to feel like they are being included in the plan of care. As Jill describes, even when some women are assertive and demand that their partners be present with them throughout medical visits, this is not always met with understanding.

Even with all the strategies that women employ to achieve better health care, their responsibility also needs to be met with effort on the part of health care providers. Many women say they have endured awkward, uncomfortable situations with health care providers. Feeling invisible or disrespected are not feelings which support positive health care. Even when

care providers are known to be positive, the women in the study say that it is not enough. There are too few resources for lesbians in Winnipeg.

Chapter Eight: Discussion and Conclusion

I am an invisible man. No, I am not a spook like those who haunted Edgar Allen Poe; nor am I one of your Hollywood-movie ectoplasms. I am a man of substance, of flesh and bone, fiber and liquids - and I might even be said to possess a mind. I am invisible, understand, simply because people refuse to see me.

I am not complaining, nor am I protesting either. It is something advantageous to be unseen, although it is most often rather wearing upon the nerves. Then too, you're constantly being bumped against by those of poor vision. Or again, you often doubt if you really exist. You wonder whether you aren't simply a phantom in other people's minds. Say, a figure in a nightmare which the sleeper tries with all his strength to destroy. It's when you feel like this that, out of resentment, you begin to bump people back. And, let me confess, you feel that way most of the time. You ache with the need to convince yourself that you do exist in the real world.... And alas, it's seldom successful. (Ellison, 1994: 3-4)

Lesbians, like Ellison's "invisible man," are invisible in mainstream society. Lesbians are stigmatized because of their sexual orientation, and they face daily challenges, living in a heteropatriarchal world. When a lesbian is dealing with daily life as an invisible minority, other strains such as illness can be an unwelcome interruption, as it brings even greater challenges and obstacles.

This thesis examines the experience of lesbian partners coping through major health issues together. Other oppressions, stress, quality of relationships, social support, social networks, interactions with health care providers, and the lessons learned throughout the process all affect lesbians' experiences of well-being. This chapter reviews the impact of the study, followed by a discussion of the findings of the study. Then, the limits of the study are assessed, and areas requiring further investigation are discussed.

The Impact of the Study

To begin, it is important to discuss the impact of the study for me and for many of the women who participated. Lesbians who shared their stories were given the rare opportunity to discuss their concerns together about support and well-being as women, as lesbians, and as partners. The process of participating in the research was not only empowering for some, but refreshing for others, and a reminder of the important things in their lives.

Completing this research has had effects on me personally and will endure, I believe, throughout my life. Learning about the women's lived realities proved to be extremely profound. With each interview I realized that there was so much that needed to be said. It was often overwhelming and difficult as I tried to organize the stories without losing the authenticity of the participants' meanings of events. Participants had a great deal to say about relationships in particular, and the nature of social support within relationships. I was continually amazed at how much participants learned from their experiences of being ill, and humbled at the fact that I was privy to these lessons. The experience of being engaged in this work was, while difficult at times, quite positive.

It is clear from the foregoing chapters that this study provided voice and visibility to the experiences of lesbians who deal with health issues. Their everyday experiences were shared, as were their unique and often uncomfortable interactions with the world around them. Their stories make visible the nature of the problems with which they often deal silently - sexism, heterosexism and homophobia. Heterosexism is the most commonly faced obstacle, and it manifests itself in a variety of ways in their dealings with family, friends, co-workers and health care providers. Heterosexism leads

some of these women to remain closeted to the outside world even though hiding the true nature of their lives exacerbates the stresses associated with illness and/or caring for a partner facing health problems. Lesbians' experiences with heterosexism can affect their relationships, their own identities, their networks, and their access to health care and social support. "The heterosexism of the broader culture manifests itself within families in a range of strained and stigmatizing dynamics - whether in the form of silences, social distance, and disapproval, or of complete rejection and hatred of lesbian family members" (Aronson, 1998: 161). Few of the women in this study - even those with supportive networks - were immune from the adverse effects of this type of bigotry and discrimination.

Gender and sexual orientation are closely linked, and each can be dangerously oppressive to varying degrees. When compounded by other stigmas, the experience of oppression is even greater. Living as lesbians within heteropatriarchal society demands of lesbians a sense of hyper-vigilance to the world around them. Lesbians may feel forced to stay in the closet, because they feel threatened by homophobia. Some women shield others from knowing about their lives in order to protect themselves and their families. They then face the consequences of being closeted. When women are in the closet, the stress of caring for a partner and being invisible to outsiders becomes overwhelming. When lesbians do come out and speak the truth about who they are, the fact that there are many barriers in place to finding acceptance and respect, creates feelings of invisibility, isolation, and stress. These women are in some cases constantly being "bumped up against" by a mainstream culture that is ignorant or indifferent to their needs and concerns.

Clearly, there are distinct power differences between many groups in society. Many lesbians are aware of these differences, and recognize that based on the categories into which they do/do not fit, their lives may be rendered invisible, and their realities ignored. Having lesbian couples' experiences and lives recognized is critical, particularly when a serious health crisis or death occurs.

From this research, it became apparent to me that lesbians' experiences are different from those of heterosexual women because they face negative societal attitudes, the possibility of family rejection, homophobia (including internalized homophobia), and the struggles involved in continually having to come out. The double burden of being women and being lesbians means that lesbians have even less power in society than heterosexual women do. If they are poor, non-white, or old, their power is diminished even further. Living as a stigmatized person, with very little power, and no voice in mainstream society impacts negatively on health and well-being. As one participant, Sarah, said, "There is a cost to being lesbian in this society." The strength of patriarchal and heterosexist oppression against lesbians can be overwhelming for some women, and this has been shown in the stories women tell about their experiences.

Lesbians' everyday lives and experiences are excellent starting points for creating theory and action. To date, much theory describing women's lives is androcentric. When theory is male-defined, patriarchal, and heterosexist, lesbians' realities of oppression and exclusion are ignored. Feminist theory and methods support exploring women's experiences of oppression, and include methods which allow women to openly discuss their day-to-day realities. Standpoint feminism acknowledges the multiple oppressions faced

by lesbians in normative society, and calls for change to try and end injustices faced by lesbians.

One of the main benefits emerging from this study is that lesbians did have their stories told and their voices heard. Telling stories is a form of taking action and empowerment. Participants' stories offer insight into many different aspects of coping with illness, dealing with inadequate access to care, and maintaining supports and relationships. Most notably, the women's stories demonstrated that, even in the face of extreme stress, lack of support, and barriers to adequate health care, lesbians did find ways to stay strong, to survive, and to actualize their own sense of agency. The support they received from partners and others is crucial to them staying well and maintaining a positive identity. The strength of women's love for each other is powerful. Many feel stronger having gone through this, though each can think of very necessary changes that need to be made to ease the experience of illness for lesbians and their partners. Many have now learned lessons that they will use to guide them throughout their lives.

That said, even the strongest of women and the support networks were challenged as they struggled to support their loved ones who were dealing with illness. When a person's status is marginalized, they may have fewer supports to begin with. In this study, whether or not women were out, they almost always sought support from partners first, then friends (mostly other lesbians). Choosing partners and lesbian friends for support indicates that these lesbians are more comfortable sharing stressful and personal aspects of their lives with those who they are certain can relate, and who will not judge or question them. Some of the women in this study are not using mainstream support services, which they view as inaccessible or

unwelcoming. As a result, some lesbians rely almost exclusively on their partners for support, which may place tremendous burdens on the individual women, and therefore intensify stress in this important relationship. Throughout this experience, couples work at staying well together, but it is clear that this is often difficult.

Couples cannot face illness alone, and need support from outside their relationship in order to maintain well-being and protect against the risks imposed by homophobia and intolerance. Lesbians are often invisible to the outside world, and even to each other. The experiences of not receiving adequate support might be reflected upon and understood as a call for development and social action in the lesbian community so that all lesbians begin to consider how to provide social support as a community, and to fight for appropriate access to supportive and appropriate health care. There is also a need to educate service providers about anti-heterosexist attitudes and procedures.

Learning from the Experience of Illness / Disability

Through the difficult periods of being unwell, lesbians and their partners in this study learn great lessons about life, love, relationships, support, and well-being. The illness, then, becomes a sort of "interruption" to their life, and offers them important insights they otherwise may not have acquired. Illness is transformative for many of the women in this study (Frank, 1995) and it allows them to re-evaluate their lives, and teaches them a new way of living in the world.

There are a lot of lessons that come with this disease, or maybe it's just that you learn to make them into lessons. I am a very different person now: more open, much more righteous, much more honest, and more self-knowing. After getting cancer, I saw that being a sociologist was

just the smallest part of who I am. There are so many riches, so many interests, so many other parts of myself. Instead of losing myself, instead of being consumed by this disease... I grew. I turned it into a possibility for opening up to myself, for discovering, and for exploring new areas. (Butler & Rosenblum, 1991: 160)

Barbara's words in Cancer in Two Voices are echoed by many of the women who participated in the study. They have stories to tell, and lessons to share about their own identities, health and well-being, and the importance of finding and giving positive support.

In The Wounded Storyteller, Arthur Frank (1995) describes the transformative nature of illness, and how ill people come to find their voices through story telling. Sharing stories about illness is very important to many who have suffered through a difficult health issue, but people who have experienced suffering are often denied a chance to talk about their experiences. While empowerment can manifest in many ways, one way is giving people who may have been silenced a chance to speak about their lives. "One of our most difficult duties as human beings is to listen to the voices of those who suffer" (Frank, 1995: 7).

Frank (1995: 118) says that many people feel transformed by illness, that they emerge from it with new knowledge. Women in the study describe thinking about well-being in multidimensional terms, particularly after being faced with a serious health issue. Most of the participants reflected on their emotional, mental, psychological, spiritual and physical health. Almost every woman says she learned something new from the journey of being ill, and each began to view health differently afterward. Many come to re-define the meaning of well-being, and to take health less for granted.

For both the woman who is ill and her partner, often the meaning of

well-being changes. Rene reminds me that physical health can go far sooner than you are ready for it to go. After Jane's decrease in physical ability due to her illness, she began to value all the other factors that contribute to being healthy, and focussed less on the physical aspects of health. She speaks at length about being transformed by illness, re-defining health, and understanding a new way of living with chronic illness, while still maintaining well-being.

Women in this study also say that well-being means feeling comfortable with yourself and the path that you have chosen. Some women re-examine their identities, and call into question the importance of being out versus being in the closet. Lesbians in this study often say that the stress of being closeted adds tremendous pressure to an already strained situation. Kate finds she is more out now that she is sick, and that being out is one stressor she does not have to think about: "I can't add to my life the stress of hiding. I need to speak the truth." Sarah is still closeted, but recognizes the value in not having to hide, especially during a crisis. She says that "there is a limit to how long you can hide [your] sexual orientation when things are falling apart around you." Rene said that when she was sick she started to care less about who knew that she was in a lesbian relationship. She had previously been quite secretive about this. Through their stories, she and some other women who are closeted offer encouragement for other women to come out. Many participants recognize the stress of hiding one's identity in order to avoid potential negative situations, but they also come to realize that it is a burden too big and unnecessary to carry forever.

Placing significance and value on positive relationships is another lesson that becomes much more clear for many women. Women who are ill

and their partners come to recognize that life is short, and it is important to prioritize things. Rene and other women say that their partner relationships are so important, and need to be celebrated, even or especially in the face of the stresses lesbians experience in the outside world. As outlined earlier, some women feel that living through a health crisis has brought them closer together, and they feel as if nothing could break the bond that secures their relationship. Many describe having a renewed sense of relationships. They value their partner more than ever before. Regrettably, however, some couples in this study found the stress of illness to be too great, and were not able to overcome the challenges together.

Some women feel that a positive way to take action is to offer advice to others who may be sharing the same experience. Women gave advice about how to stay healthy in relationships, how to maintain individuality, how to deal with doctors effectively, and how to make your life meaningful even in the face of illness. Kate shares that well-being means living the best that you can each day, and finding both internal and external peace. Rene suggests living life as fully as possible, enjoying small things, and not taking for granted the things that you can do. Sharing these words of wisdom allows women to speak of the lessons that they took from their own illness stories.

A final main lesson participants share is to seek help outside of the relationship, and to not rely only on one's partner. Surrounding oneself with positive support is essential to feeling cared about and to maintaining well-being. For some couples, dealing with illness becomes a "wake-up call" that they cannot rely solely on each other, and that they need to speak honestly of their health issues and their relationship to others in order to receive support. Some women also say that coming through the experience has made

them more aware that they need to extend their support to other lesbians who have limited supports, (e.g., young lesbians who are struggling to come out, other sick lesbians, and those who are senior citizens).

Women in this study did not always receive appropriate, supportive responses from health care and service providers. Many participants claim that they have experienced homophobia, heterosexist assumptions about women's health issues, and negative treatment based on their gender. Homophobia and heterosexism are indeed health risks for lesbians, and barriers to lesbians receiving good health care. Sometimes, the women "bump back." Heterosexism was confronted by the women, particularly in regard to heterosexist policies (e.g., not allowing a same-sex partner to sit in the emergency room), medical assumptions (e.g., if a woman has stomach pains, there is always the possibility that she might be pregnant), or in-take forms (e.g., there is no language or category for same-sex partner). Some women work hard at accessing positive, sensitive health-care, working as "informal educators" in each encounter. This hard work at making the system work for lesbians takes a toll on women when they do not see long term results, and when they are facing illness, it is hard to maintain this attitude. Lesbians' lives and needs are invisible in both mainstream society, and within the realm of health care.

Health care professionals need more education around homophobia and the lives of lesbians, so that they can move beyond stereotypes rooted in sexism and heterosexism, provide appropriate responses to women who do come out, and adequately address lesbians' health care needs and concerns. Physicians must educate themselves with regards to sexual orientation in its application to specific lesbian health issues, and become aware of the overall

stresses of lesbians' lives in heterosexual society (Mathieson, 1998).

Lesbians in this study had many ideas about where the gaps are in service, and how services to lesbians could be more appropriate. Forms and procedures need to be inclusive of all different types of relationships. One simple way of creating inclusive in-take forms is to use language like "partner" instead of "spouse" and to ask about a person's support network instead of assuming that everyone is in a heterosexual relationship. In-take nurses in particular must be trained to be non-judgmental and supportive, as they are often the first person with whom a patient deals. (See Appendix F for Policy Recommendations made the the PWHCE.)

Women in the study would like to see more out and open lesbian health care providers. As it stands now, there are no out lesbian doctors commonly known in Winnipeg. Participants say there are barriers everywhere if you are not heterosexual, and sharing one's sexual orientation with a health care provider might make health care interactions more comfortable. Heterosexual physicians need to be gay-positive, meaning that they are "open-minded, knowledgeable about lesbian health needs, and able to create and sustain a safe place for disclosure" (Mathieson, 1998: 1637). They can make this obvious through posters and magazines in the waiting rooms, and the use of appropriate language on all patient information forms. There is a lack of service and sensitivity for those who are mentally ill, and in particular, for the many lesbians who deal with mental health issues. Similarly, there is a need for services for lesbians and their families who deal with addiction issues. Lesbians facing addictions and mental health issues are often overwhelmed by judgment and discrimination. Illness-specific groups for lesbians might be beneficial. Support groups for lesbians with cancer,

chronic illnesses, those who are mothers, disabled, and non-white may also be of value to members of the lesbian community.

As the participants in this study indicate, some women are becoming more assertive and proactive with regards to their health. The data suggests that some lesbians are better able to negotiate their way through the system together, developing strategies for how to deal with health professionals together. However, several of the women in this study indicated that during times of extreme stress (e.g., dealing with a serious health issue) it was more practical to neutralize the issue of their sexual orientation, and focus all of their attention on what they can do to help themselves and/or their partners become well again. They may also downplay the issue of their orientation in hopes of maintaining the best quality care. This notion of neutralising sexual orientation supports countless other studies which suggest that lesbians still do not feel safe being open about their lives (Stevens, 1993: 2). In this respect, they are like Ellison's invisible man. Lesbians fear receiving inadequate services, having their lives ignored, or becoming the target of judgment and violence if they do come out. Lesbians' double-burden as women and as lesbians diminishes the quality of their lives, and their power in this society.

Summary

The experience of lesbian couples who deal with health issues, and their experiences of social support in this case has not been widely studied. This study provides empirical data on a small sample of lesbian couples' experiences of social support from partners and others, and the ways in which they were treated by formal helpers. It contributes to the research on lesbian health, and adds diversity to studies of social support. The themes emerging

come from the women's lived realities, and while no two participants share the exact same story, there are some themes that are similar throughout.

Lesbians' lives still remain unacknowledged by medicine and research, and the realities of lesbian life in Canada are still not recognized or valued. Being a lesbian makes the experiences of relationships, illness, social support and interaction with health care providers different. Along with the social identity "lesbian" comes invisibility, ignorance, stigma, social pressures, the question of whether or not to come out, incorrect assumptions, and very often awkward interactions with health care and social service providers.

While there is some positive change, and hope for a future that is inclusive and welcoming of diversity, work still needs to be done. The gaps (particularly with regards to heterosexism) need to be filled. Many of the lesbians in this study are persisting to make their voices heard, and to get their needs met. Perhaps the sample in this research is unique, in that it showed us the experience of couples. It seems that couples who have been together for a few years, and who have faced some challenging issues in their relationships already, learn to negotiate the system *together*, and to create strategies to cope. Lesbian partners, and one hopes, lesbians in communities can learn to exchange help and support together as they try to seek care, and to stay well together in the process.

Women took action by sharing their important stories. Telling ill people's stories in their own words gives voice to an experience that medicine, politics, and others could never describe (Frank, 1995). As Frank (1995) suggests, we often deny a voice to those who have been marginalized, and I am glad that this study offered even a small venue for some women to reclaim their voices and tell their stories. This study, then, becomes the

interruption that allows participants, the researcher, readers, and future researchers to think about lesbians couples' lives a bit differently. The new knowledge generated will assist in the creation of policies and practices that will benefit lesbians and their families in the future.

Limits to the Research

The limits to these data must be acknowledged, as this sample was self-selected, and included the typical people who respond to calls for participation in research, i.e., those who are well-educated, middle class, and in this case, out about their sexual orientation. While many participants may still struggle with some internalized homophobia, or are out only to some people, they are dissimilar to very closeted lesbians. There are very real concerns that those particular women who are closeted both from the mainstream community and from other lesbians still feel the effects of external and internal homophobia, and may avoid seeking necessary health care based on long-held fears that they will be discriminated against based on their sexual orientation.

Further research on lesbians in couples, and as individuals, including efforts to access those who would not typically volunteer for a study, are critical in order to learn more about lesbians' lives, and to improve the health of lesbian communities. Further study of lesbians who deal with mental health issues is also warranted. Similarly, there are few studies which examine the effects of chronic illness on lesbians' lives and relationships. A longitudinal study following lesbian couples coping through health issues would contribute substantially to our understanding of social support, health, and health care.

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Appendix A: Interview Guide (Couples)

As you know from the letter of introduction and consent form, the goal of this study is to hear from lesbian couples who have been through a serious illness, disability or chronic condition together. I am interested in learning about your experiences of coping, and of giving and receiving social support. I am going to ask you some questions about the support you provide to each other within your relationship, as well as some questions about the support from people you would consider to be in your informal "support network." I will also ask you about what it means to be "well," and about how the support you receive from each other impacts on your well-being.

First of all, I want to remind you of the consent form you signed. You have the right not to answer any of the questions I may ask. This interview is not intended to bring up any issues which one or both of you are not comfortable talking about. If anything comes up which does not feel good to talk about, please let me know, and we can turn the tape off. Or, I can give you two a chance to privately discuss how you want to handle the disclosure before we return to the interview. Do you have any questions at this point?

—> talk briefly about my position in this research: lesbian, provider of social support, graduate student

—> my interest in this research project: lesbian health interests, how the process came about, my hopes for outcomes (i.e., social action - workshops, publications, etc.)

1. First of all, can you tell me a bit about your relationship? How did you two meet? How long have you been together?
2. Collect demographics: age, ethnic background, SES, education, occupation, any children?
3. How long have you each been "out" as lesbians/gay women/bisexual/two-spirit women in a same-sex relationship?
4. First of all, can you tell me: what does it mean for you to be "well" or "healthy" lesbians?
5. What does it mean to have a "healthy lesbian relationship"?
6. Can you describe to me briefly what kind of health issue you are coping with in your relationship?

7. What kinds of effects has the illness/disability/chronic health condition had on your relationship? Has it had positive effects? negative effects? How have things changed? (e.g., emotions, sex, finances etc.)

Have any issues of power or dependency come up?

8. Have any conflicts emerged in your relationship, while you try to cope with this illness/disability/chronic health condition and re-negotiate your lives around it? Do you see each other differently now? Has the illness had any effect on your commitment to each another?

9. Is there any advice you would give to other lesbian couples facing an illness or health condition together?

10. Some researchers have described "social support" as including everything from emotional support, to financial support, to information giving, to feedback on experiences or decisions, to instrumental tasks like driving or making meals. How do you provide support for each other while coping with this illness/disability/chronic health condition?

11. How has your relationship and the support your partner provides contributed to your well-being?

12. How did/do you negotiate support in your relationship, or "who does what," in terms of balancing life with this illness/disability/chronic health condition?

13. We have talked a bit about the support that exists within your relationship. Now, could you tell me, who else provides social support for you as a couple?

→ Do you have a network of friends or family who have also been around to provide support? Are you satisfied with the size of your network, and the types of support they provide?

→ For example, if you needed a ride to the hospital in the middle of the night, do you

have someone who could take you? Do you each have friends or family members who you could call or visit at any time just to talk, or to get a hug?

→ Are your families of origin in the picture? Do they support you? How?

14. Has being in the closet to others (i.e., friends, family) about your sexuality/relationship ever affected the amount or quality of support you have experienced? has homophobia?

15. Have you found that there are some people who were helpful during your illness who you weren't ordinarily that close with?

—> For example, are there any people, say, who live out of town, or who you do not have frequent contact with who have turned out to be helpful with some aspect of coping with your condition?

16. (To rural couples) Do you think there are differences between the possibility of forming informal social support networks in rural as opposed urban settings? Do you feel isolated at all living in rural Manitoba? Would you prefer to have a broader social support network?

17. Is there any advice you would give to those people around them who could be supportive, but aren't sure how?

18. What would you say to others about how support from your partner and your network helped you both to deal with the experience of an illness/disability/chronic health condition?

19. Do you think that the existence, or the lack of social support in your life contributes to your earlier definition of a well/healthy lesbian? (remind them of their definition..) How does it relate to your experiences?

20. Is there anything else you wish to add about anything we've discussed?

Appendix B: Interview Guide (Individuals)

I've talked to you and your partner together about the experiences of social support during an illness, disability, or chronic condition. Now I would like to ask more in-depth questions about your experiences of social support and wellness. Some of the questions will be very similar to those asked in the "couples" interview, however, I am also interested in hearing about your thoughts individually. Do you have any questions, or comments you want to make about the last interview?

1. Have you done any more thinking about what "well-being" means to you? Do you want to add anything to what you said last time?

2. When you learned of your/your partner's illness etc., did your concept of what it means to be "well" change at all? Did your perceptions or your expectations of your partner's role in the relationship change at all? How?

We talked a little bit in the first interview about how social support can impact greatly on a person's well-being.

3. (to care giver (CG)) How do you think that you support your partner? What impact do you hope this support has on her ability to cope with her illness, and on her well-being?

4. (to CG) What kinds of stresses do you face as a lesbian supporting a lover/partner who is ill/disabled?

5. (to CG) How does your partner reciprocate support for you? What happens to the balance of support awhile coping with one person's illness?

6. (to care receiver (CR)) How does your partner support you? What does she do that makes her supportive? What does it mean to you to feel "supported" by her? What impact does her support have on your well-being?

7. (to CR) Do you think your illness places any kinds of extra stress on your partner?

8. (to CR) In what ways can you reciprocate support for your partner? What happens to the balance of support awhile coping with one person's illness?

9. What kinds of conflicts can arise in a relationship when dealing with a serious health condition?

10. Is there anything more you want to say about how your/her health

condition has affected other parts of your relationship, like your financial situation, intimacy, emotions, or work?

11. (to CG) Has there ever been an incident when you simply could not provide the support your partner needed at a particular time? What happened?

12. (to CR) Has there ever been a time when you really needed your partner to be supportive, and she couldn't be? What happened?

13. How did you negotiate who would be involved in the informal support network? Were there ever any conflicts about the balance of support between that provided in the relationship, and support from others?

14. How have people in the support network been helpful for you AND for your partner in dealing with this illness/disability/chronic health condition?

15. In general, how does it feel to be a woman supporting another woman dealing with a serious illness? Do you think gender has an impact - like, do you think if you were two men it would be any different?

16. Finally, I'll ask again: have you come to any conclusions about the support in your life how it impacts on your ability to cope, and on your feelings of general well-being?

Appendix C: Advertising Sites

1. Aboriginal Aids Task Force
2. Addictions Foundation
3. AIDS Brandon
4. AIDS Canada
5. The Alternative (publication of the WGLRC)
6. The Aquarian (newspaper)
7. Augustine United Church
8. Big Ruby's Restaurant
9. Brandon University Gay/Lesbian group
10. bulletin boards in Wolseley area (a neighbourhood populated by a large number of lesbians)
11. Canadian Cancer Society
12. Canadian Mental Health Association
13. Canadian Paraplegic Association
14. Centre Plurielle
15. Coalition of Lesbians on Support and Education)
16. Deaf Centre Manitoba
17. Family Centre of Winnipeg
18. First Universalist Unitarian Church
19. Fort Garry Women's Resource Centre
20. RA Steen Community Centre
21. Gay/Lesbian/Bisexual Caucus
22. Gay Pride Day celebration
23. Giovanni's Room (gay bar)
24. Gays/Lesbians of Brandon and Elsewhere
25. Happenings Social Club (gay bar)
26. Harvest Collective
27. Hope Centre
28. Independent Living Resource Centre
29. Immigrant Women's Resource Centre
30. individual feminist counsellors/therapists in Winnipeg
31. Kali Shiva AIDS Services
32. Klinik Community Health Centre
33. Lavender Rose Books
34. Manitoba Advisory Council on the Status of Women - Brandon
35. Mediation Services
36. Metropolitan Community Church
37. Miriam Centre
38. Ms. Purdy's Women's Club
39. P - Flag (parents/friends of lesbians and gays)
40. Prairie Sky Books
41. Select family doctors/ clinics

42. Seneca House
43. Sexuality Education Resource Centre Winnipeg & Brandon
45. Society for Manitobans with Disabilities
46. Sum Quod Sum
47. Sunrise Health Food Store
48. Swerve Magazine
49. University of Manitoba - Gay and Lesbian Association of Students and Staff, Womyn's Centre, Women's Studies Program, and selected faculty
50. University of Winnipeg - Women's Centre, Lesbian/Gay/ Bisexual/ Transgendered/ * Centre, main buildings, and selected faculty
51. University of Winnipeg Interfaith Pastoral Institute
52. U of W Students' Association
53. Village Clinic
54. Weetemah (Aboriginal newspaper)
55. Women's Health Clinic

**Are you a lesbian/dyke/bisexual/queer or
two-spirit woman involved in a
same-sex relationship?**

**Have you or your partner experienced a
major illness, disability or chronic condition
during your relationship?**

If so, a lesbian graduate student in Sociology
(University of Manitoba), in partnership with the Winnipeg
Gay/Lesbian Resource Centre, is interested in talking with you.
Interviews will inquire about a variety of experiences couples share -
ranging from types of support partners provide, to the amount of
social support available, to what *well-being* means for couples
dealing with illness/disability/chronic conditions.

**Please call Jan at 453-6383 for more information.
(Confidentiality assured)**

**This research is supported by the Prairie Women's Health Centre of Excellence
(Women's Health Bureau, Health Canada)**

**Are you a woman involved in a
same-sex relationship?**

**Have you or your partner experienced a
major illness, disability or chronic condition
during your relationship?**

If so, a lesbian graduate student in Sociology
(University of Manitoba), in partnership with the Winnipeg
Gay/Lesbian Resource Centre, is interested in talking with you.
Interviews will inquire about a variety of experiences couples share -
ranging from the amount social support couples receive, to the
amount of support available in rural areas, to what well-being means
for couples dealing with illness/disability/chronic conditions.

**Please call Jan collect at (204) 453-6383 for more
information.
(Confidentiality assured)**

**This research is supported by the Prairie Women's Health Centre
of Excellence (Women's Health Bureau, Health Canada)**

Appendix E: Letter of Introduction/ Consent Form

Hello! My name is Jan Mitchell and I am a graduate student in the Department of Sociology at the University of Manitoba. I am currently doing a thesis research study to gather information from lesbian couples regarding their experiences of social support in the face of a major illness, disability or chronic condition. I am interested, both as a researcher, and as a lesbian, in learning more about the support that lesbians provide for each other in this context. I would also like to gather information about the support lesbian couples receive from informal social networks (that is, friends, family, co-workers, etc.), and about their experiences of accessing support from formal systems (e.g., the health care system). I would like to interview lesbian couples of various backgrounds in an effort to understand some of the ways in which support from partners and others acts to provide a buffer when coping with a serious illness, disability, or chronic condition. This proposed research has been approved by the Department of Sociology Research Ethics Review Committee, and has been funded by the Prairie Women's Health Centre of Excellence.

Your participation in this study is voluntary. There is no obligation for you to participate, and you will not receive any financial reward; however, any information that you provide may help other lesbian couples in the future who might be coping with a similar situation. I will begin by interviewing you and your partner together, and this will take approximately 2 hours. You have the right to stop the interview at any time throughout the process, and the right not to answer any questions that I may ask. You also have the right to withdraw from the study at any time. The interviews will be tape recorded. All of the information you provide during the interview will

be kept confidential, and no results will be released which could identify you personally. All of the tapes and other information provided will be stored in a locked filing cabinet at the University of Manitoba. After the data is analysed, it will be made available to you so that you can see that your information has been accurately portrayed. A copy of the findings will be made available to all participants at the time of completion of the study by calling the researcher at the Winnipeg Gay and Lesbian Resource Centre.

Any questions or complaints you may have concerning the project can be directed to me, at 779-7191, to the Winnipeg Gay/Lesbian Resource Centre at 478-1160, to the Head of the Department of Sociology at 474-9260, or to Dr. Karen Grant, my thesis advisor at 474-9912. Thank you very much for your time and information. I appreciate your participation in this study.

Sincerely,

Jan Mitchell

I understand that my participation in this study is voluntary, and that I have the right to withdraw at anytime, without prejudice or consequence. I have the right not to answer any questions in the interview, and if I have any questions or complaints, I can call the researcher, the Ethics Review Committee, the WGLRC, or Dr. Karen Grant at any time. The information I provide will be kept confidential, and, at the time of completion of the study, I may obtain a copy of the research findings by calling the researcher. I will not be remunerated for my time.

Date: _____ **Respondent's Signature:** _____

Date: _____ **Researcher's Signature:** _____

Appendix F: Recommendations made to the Prairie Women's Health Centre of Excellence

1. Increase the education for service providers on the concept of heterosexism and its existence in policy and practice, and its effects on patients (e.g., having to explain about the nature of a relationship to doctors or others, when there is a larger issue at hand adds extra stress to patients).
2. Increase education and access to resources regarding the use of inclusive language in both practice and policy of health care. For example, the language of intake and history forms could be changed to include a term such as "partner," "same-sex spouse," "domestic partner." Same-sex partners should be allowed to wait in emergency rooms, just as other family members are.
3. Increase research on women's health issues generally (i.e., social, physical, mental, emotional health), with the inclusion of the specific health needs of lesbian and bisexual women. Women's health centres such as the Women's Health Clinic should do more education to service providers about the unique concerns of different groups of women, including lesbians.
4. Information and education must be targeted to lesbian communities to make women aware of health care providers and support programs that are accepting of diversity. Lesbians, like all women, must be encouraged to take their health into their own hands, and persist to find positive health care.
5. It is recommended that further research be done, which attempts to locate those lesbians (single, or in couples) who are closeted and unlikely to come forward to participate in interview research.