

**THE LIVED EXPERIENCES OF WINNIPEG
WOMEN WITH HIV/AIDS**

by

SUZANNE NICOLAS

**A THESIS SUBMITTED TO THE FACULTY OF GRADUATE STUDIES OF
THE UNIVERSITY OF MANITOBA IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE OF**

MASTER OF NURSING

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ISBN 0-612-13404-0

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SUZANNE NICOLAS

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

MASTER OF NURSING

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ABSTRACT

The purpose of this phenomenological study was to explore and describe Winnipeg women's experiences living with the human immunodeficiency syndrome (HIV) and the acquired immunodeficiency syndrome (AIDS). An interpretive research approach provided the basis for the research design. The Mandala Model of Health was used as the framework for the study.

In-depth interviews were conducted with five Winnipeg women living with HIV/AIDS. Data collection consisted of unstructured face to face interviews. An interpretive or hermeneutic method provided the basis for the data analysis. Six major themes emerged following analysis which included: health related issues, marital/partner relationships, child and family issues, occupation, social network, and coping with the illness. These issues and concerns are not necessarily specific to women, however, women's experiences with HIV and AIDS are inseparably linked to their experiences as women.

Implications for nursing practice, education, and research were discussed. The study revealed the need to provide more knowledge based care and support to women living with HIV/AIDS. Continuing education, increased curriculum content related to this topic, and keeping current with the latest development in the management and treatments is needed. Further research is necessary in all domains of women's health as it relates to HIV/AIDS.

DEDICATION

This thesis is dedicated to the five women who allowed me to become a part of their world for a short time. I am grateful to them for sharing their stories with me. I recognize the courage needed to go through the interviews and I deeply appreciated their openness throughout the research process. I thank them for trusting that I would tell their story the way they would have. I would like to recognize one woman who will not have the opportunity to reap the rewards of her contribution to this thesis, as she passed away during the research process. Also, I am greatly indebted to another woman who enriched this study by writing a poem of her lived experiences (Appendix F).

ACKNOWLEDGMENTS

There a number of individuals I wish to thank for their genuine concern, support, and guidance through my thesis research.

To my thesis chairperson, Dr. Erna Schilder, my deepest appreciation and thank you: for your patience, understanding, and flexibility; for always being present when I needed support; and for taking the time to re-familiarize me with the phenomenological research process. Most of all thank you for your tremendous sense of humor, I would not have survived without it.

To my internal thesis advisor, Dr. Eleanor Adaskin, thank you for your editorial expertise and for being so accommodating. I greatly appreciated your interest and encouragement.

To my external thesis advisor, Dr. Shurjeel Choudhri, thank you for your support, your enthusiasm, and encouragement throughout this process. Your commitment to this research inspired me to persevere.

To my second external thesis advisor, Jocelyn Preston, thank you for your caring, compassionate concern. Thank you for the support throughout the Master of Nursing program as well as through my thesis research. Your "human" expertise in the field of HIV/AIDS was invaluable.

To my husband and children for their caring and loving support, thank you. Thank you for always being there and for your understanding and

acceptance of thesis related priorities. I could not have done this without you.

To my family and friends, thank you for your encouragement and your acceptance of my temporary absence in your lives.

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CHAPTER I

INTRODUCTION

In Canada the history of the human immunodeficiency virus (HIV) and the acquired immunodeficiency syndrome (AIDS) began just over a decade ago. The first case of AIDS was reported in Montreal in 1979; the disease did not have a name or a cause, but many Canadians were carriers of HIV. In the early 1980's the Centre for Disease Control in Atlanta, Georgia began reporting rare forms of cancer and unusual lung infections. These diseases usually occurred in people with a weakened immune system however, in these instances the target population were young healthy gay men in Los Angeles, San Francisco, and New York. By the end of 1981 the disease had a name and AIDS became a new fact of Canadian life (Health & Welfare Canada, 1990).

HIV/AIDS is having a tremendous impact on Canada's social character. Powerful emotions are being unleashed. AIDS in Canada continues to be thought of as a gay disease, causing a great deal of anxiety, misinformation, and prejudices against persons infected with HIV. Canadians are faced with difficult social realities such as discrimination, human rights, ethical and legal questions relating to issues of access to social services, health services, jobs, housing, and schooling. On an individual level, Canadians are challenged on their strongly held personal values (Health & Welfare Canada, 1990).

HIV/AIDS

AIDS is a communicable, fatal disease. It is associated with socially stigmatized groups: homosexual men, intravenous drug users and ethnic and some racial minorities. This disease has attracted moral disapproval, negative societal attitudes and there is a tendency to blame the infected person for having the disease (Flaskerud, 1987; Flaskerud & Ungvarski, 1992). The persons living with HIV/AIDS, from the time of diagnosis through to the end stage of the disease are faced with unpredictability and uncertainty. As the disease progresses it becomes a fight for survival, since the diseases which are related to AIDS can be debilitating, deforming and relentless (Health & Welfare Canada, 1990). The person living with AIDS becomes vulnerable to unique physical, social and emotional threats and the disease presents a medical and psychosocial crisis of unparalleled proportions (Buckingham & Rehm, 1987), not only for the person living with the disease, but for the community at large.

Defining HIV/AIDS

HIV is the causative agent of AIDS. HIV's main target is the CD4 lymphocytes (T4 helper cells) which play a major role in the body's immune system and defend the body against invasion by organisms such as bacteria, parasites, fungi, and viruses. Once the CD4 cell is infected with HIV it cannot function properly. When an appropriate stimulus activates an infected cell, there is

an active production of the virus. The host immune response to this process results in CD4 cell destruction. This process is mediated by CD8 (T-suppressor cells). As the immune system begins to break down, the body becomes more susceptible to infections and cancer (Flaskerud & Ungvarski, 1992).

HIV begins its attack on the immune system long before the development of signs and symptoms. The course of the HIV infection is unpredictable. Within three to eight weeks after the initial infection, the person may develop flu like symptoms. Following the patient may remain asymptomatic for many years. Following this asymptomatic period the person may develop symptoms accompanied by a low white cell count. Common symptoms are : persistent swollen lymph glands, fever, fatigue, night sweats, weight loss and diarrhea (Flaskerud & Ungvarski, 1992).

HIV is contagious and spreads from an infected person to someone else through the exchange of semen, vaginal fluid, blood, and breast milk. HIV is transmitted though sexual intercourse, sharing needles, contaminated blood products, perinatal transmission, and breast feeding (Flaskerud & Ungvarski, 1992).

AIDS is diagnosed when a person's CD4 count is $200/\text{mm}^3$ or less. AIDS is characterized by a series of specific opportunistic infections: such as pneumocystis carinii pneumonia, Mycobacterium avium complex, Cytomegalovirus, non-

Hodgkin's malignant lymphoma, Kaposi's sarcoma, disorders of the nervous system and cervical cancer (Appendix A). AIDS or perhaps more appropriately HIV infection is considered one in which a cure may not be possible, but early intervention can improve survival. HIV infection is now seen as a chronic disease requiring health care planning and management along a chronic disease continuum (Flaskerud & Ungvarski, 1992).

Background information

As of late 1994, the global figures for the reported number of AIDS cases worldwide is estimated at over 4.5 million cases in adults and children, the majority of cases occurring in sub-Saharan Africa and the Americas (Health Canada, 1995). As reported in The Weekly Epidemiological Record (1995), it is estimated that around 18 million adults and about 1.5 million children have been infected with HIV since the beginning of the pandemic, that is from late 1970's to early 1980's (cited in Health Canada, 1995).

Currently, of all AIDS cases and HIV infected people in the world, 39 and 42 percent respectively are women (Hankins, 1995). This translates to 250,000 women living with AIDS and an additional 3 million who are positive for HIV infection (Easton, 1992; Williams, 1992), 80% of whom live in sub-Saharan Africa (Williams, 1992). The World Health Organization predicts that by the year 2000, ninety percent of all new cases of HIV infection in the world will be contracted

through heterosexual activity and that more women than men will be living with HIV infection (Hankins, 1995).

Wofsy (1992) stated that in major cities in the Americas, Western Europe, and sub-Saharan Africa, AIDS has become the leading cause of death for women in the 20-40 age group (cited in Houde-Quimby, 1994). In the United States, the percentage of female AIDS cases doubled from 6 percent reported in 1982 to 12 percent of all cases reported for 1990. By the end of 1991 AIDS was one of the five leading causes of death for all women of reproductive age in the United States (Williams, 1992).

At the end of June, 1994 , 576 Canadian women were reported to have AIDS, representing 5.6% of the total number of AIDS cases in the country (Health Canada, 1995). Heterosexual transmission accounts for 64% of all cases of AIDS in Canadian women and two-third of the women worldwide (Hankins, 1995). In 1995, the proportion of Canadian women diagnosed with AIDS increased to 7% (Hankins, 1995).

In Manitoba although the number of cases of HIV/AIDS appear to be relatively small, the numbers continue to increase. The first woman infected with HIV was reported in 1983; since then as of June 8, 1995, 38 women were diagnosed as HIV positive and 3 have AIDS. This represents 6.48% of all HIV/AIDS cases reported in the province (Manitoba Health Report, 1995).

Purpose of the study

Little research has been conducted on the experiences of women living with HIV/AIDS. In Canada, the literature is limited to anecdotal articles on the topic; no formal research studies have been done. More specifically, in Manitoba, no literature exists to describe the particular experiences of this population and whether the issues of Winnipeg women are comparable to issues of women in other geographical areas.

To date, the voices of HIV positive women in Manitoba, more specifically in Winnipeg have not been heard in the HIV/AIDS epidemic. Health care providers and the public at large are not aware of the impact of HIV/AIDS on the lives of women. HIV disease continues to be thought of as a disease of gay men and health professionals continue to be uninformed of the manifestations and impact of the disease in women (Easton, 1992; Haynes, 1993; Johnston, 1994; Smeltzer, 1992; Taylor, 1990). Consequently little attention has been directed to meet the needs of Manitoba women living with HIV/AIDS, and most particularly, their human experience has not been heard.

The purpose of this study is to obtain an understanding of the unique issues faced by Winnipeg women living with HIV/AIDS. More specifically, the objectives of the study are to explore in the Manitoba context: a) women's experiences surrounding living with HIV/AIDS, b) the needs of women living with

HIV/AIDS, and c) women's perceptions as to whether their needs are being met, and/or how their needs could be met.

Significance of the study

Women living with HIV/AIDS continue to be invisible and extremely vulnerable. Nurses need to become advocates for HIV positive women; they must play a role in moving these women out of isolation and integrating them within the AIDS community.

Nurses are in pivotal positions to have a positive effect on the health care of women living with HIV/AIDS. They are familiar with the health care system and have the advantage of being aware of women's health care issues. Nurses must assume a greater role in women's advocacy, be proactive in shaping health policy and promote education about HIV/AIDS. To facilitate this process, nursing research aimed at understanding HIV/AIDS in women is necessary.

The findings of the study may provide a basis for program development and services which will be sensitive and responsive to the needs of this population. In addition, the findings will serve to increase the public's and health care providers' awareness to the unique and complex issues faced by Winnipeg women living with HIV/AIDS.

Conceptual framework

The Mandala Model of Health

The mandala model of health (Figure 1) is particularly well suited to the study of women living with HIV/AIDS. The model incorporates all aspects of the human ecosystem, that is, the interrelationship of human beings and their environment. In this model the individual is viewed in its totality, incorporating and integrating mind, body and spirit. All aspects of the individual such as self-concept, self-worth, coping skills, biological functioning, lifestyle, influences from the physical, psychosocial, political, economic, and cultural environment. The individual is considered not in isolation, but always within the context of the family, the community and society (Hancock, 1985; Hancock & Perkins, 1985). The definitions of the major concepts follows this section.

The community includes the social and political nature of the health care system, the work life, and all aspects of the human mandala environment. All these factors are situated within the individual's context, which will influence values, attitudes and beliefs, which in turn will determine how individuals will perceive health and illness. The biosphere, which incorporates all of these dimensions of the human being in constant interaction with the environment, is the ultimate determinant of health. This model is dynamic and interactive since the health of the individual is influenced by any or all factors in the model and each factor can

FIGURE 1: MANDALA MODEL OF HEALTH

From "The mandala of health: a model of the human ecosystem" by

T. Hancock, 1985, Family and Community Health, p.2

be influenced by the individual (Hancock, 1985).

To fully understand the lived experiences of Winnipeg women living with HIV/AIDS, the problem must be situated within the broader context of the biosphere. HIV/AIDS affects more than the physical aspect of the person; the disease has an impact on the individual in her/his entirety. Individuals go through their illness within the context of the world around them, that is, the interaction and influences of the culture, society, community, and the family. The woman's culture, socialization process, her economic, social, physical environment, lifestyle, self-concept, self-worth, and coping skills, all will affect how she will perceive and live with her illness. The mandala model of health provides the framework necessary to address this problem.

Definitions of major concepts

1. mandala: a circular symbol of the universe;
2. individual: comprised of body, mind and spirit, is seen at the center of the universe; always exists within the context of a family;
3. family: refers to the nuclear and or extended family; family plays a vital role in establishing health values, attitudes, and habits and continuously influences the health of its members; the family acts as the most important mediating structure between persons and social institution;
4. human biology: the genetic traits and perception; the competence of the

- immune system, and the biochemical, physiologic, and anatomic state of the person and the family;
5. personal behavior: dietary habits, including smoking and drinking; driving habits, including use of seat belts; general risk-taking and preventive behaviors;
 6. psychosocial environment: socio-economic status, peer pressure, exposure to advertising, social support systems and related factors;
 7. physical environment: adequacy of housing and the physical state of place and the immediate environment;
 8. lifestyle: this is personal behavior as influenced, modified and constrained by a lifelong socialization process as well as by the psychosocial environment, including family, community, cultural values, and standards;
 9. sick care system: refers to the medical care system; this system exists within a community of which it is a part and to which it is accountable; this system is concerned almost exclusively with human biology and personal behavior;
 10. work: is an important determinant of health; both physical and mental health are influenced by the physical state of work, including the work role, social relations, and the quality of work life;
 11. community: each community has its own values, standards, support

- systems and networks; it is a major influence on health;
12. human-made environment: includes all of the above mentioned components;
 13. culture: includes cultural beliefs, values and attitudes; influences how people perceive health and how they react to illness;
 14. biosphere: incorporates the community, all components of the human-made environment and the culture; it is the ultimate determinant of health.

Summary

HIV/AIDS presents a unique medical and psychosocial crisis (Buckingham & Rehm, 1987) for the individual, the family, the community, and society at large. To date most studies on the psychobiological and spiritual responses to HIV/AIDS have been on white middle-class homosexual men (Chung & Magraw, 1992; Pinch, 1993; Quinn, 1993; The AIDS Report, 1993; Wofsy, 1988). There is only a scant amount of literature addressing how women live with the disease.

Although the person's gender does not altogether determine the psychobiological responses to the illness, gender does contribute in shaping the responses to the illness (Clarke et al., 1993; Chung & Magraw, 1992; Denenberg, 1990; Smeltzer, 1992). Women living with HIV/AIDS are faced with unique physical, social, and emotional threats (Buckingham & Rehm, 1987; Clarke et al.,

1993; Chung & Magraw, 1992; Denenberg, 1990; Hutchison & Kurth, 1990; Smeltzer, 1992). Researchers and health care professionals acknowledge the lack of research addressing the full range of unique and complex issues faced by women living with HIV/AIDS; hence the reason for this study.

CHAPTER II

LITERATURE REVIEW

Minimal attention has been given to the increasing number of women exposed to HIV (Buckingham & Rehm, 1987). The stereotypes of AIDS as a homosexual disease and AIDS as a prostitutes' disease prevail (deBruyn, 1992; Taylor, 1990). The reality is that world wide, women constitute the fastest growing segment of persons with HIV/AIDS (Christiano & Susser, 1989; Chung & Magraw, 1992; Haynes, 1993; Stuntzer-Gibson, 1991; Whipple, 1992; Williams, 1992). In the United States, from 1990 to 1991, a 17% increase in diagnosis of AIDS in women was reported, and in 1991, the number of women dying of AIDS had increased by nearly 100% since 1984 (Houde-Quimby, 1994). This growing epidemic poses a serious threat to women's health and well being.

A review of the literature was conducted to explore and describe the unique issues and concerns faced by women living with HIV/AIDS. Due to the paucity of research findings, it was necessary to rely on anecdotal articles, reports of clinical observations, and related or peripheral research studies.

The social dimension of AIDS

Fineberg (1988) describes AIDS as the modern day affliction; a contemporary disease recognized as an urgent problem in both industrialized and

less developed countries. Fineberg adds that the AIDS epidemic has touched almost all aspects of society, from every social institution to businesses, courts of law, the military, and Federal and local governments. In addition, AIDS has had a significant impact on the way science, medicine, and public health are practiced in the world.

Fineberg (1988) states that AIDS is associated with sex, blood, drugs, and death; the disease therefore evokes basic human fears and inhibitions. AIDS is considered morally and literally contagious. The contagion is compounded by the stigma attached to the behaviors most often associated with the HIV infection, that is, homosexual intercourse and intravenous drug use. Fineberg adds that "AIDS exposes the hidden weaknesses in human society" (p. 128), and prompts society to further reflect on the concepts of relationships, love, and sexuality. AIDS has prompted acts of human kindness and generosity, but the disease has also provoked mean-spirited and irrational responses.

AIDS has increased society's awareness of homosexuality as well as having promoted an understanding and tolerance of different sexual orientation (Fineberg, 1988). However, the spread of the disease continues to be blamed on the powerless individuals in society (Faulstich, 1987; Shroff, 1991). Societal sexism, racism, and classism have influenced the public's perception of HIV and AIDS in women (Mackie, 1993; Shroff, 1991; Wiener, 1991).

AIDS disproportionately affects disenfranchised women in our society (Chung & Magraw, 1992; Health and Welfare Canada, 1990; Mackie, 1993; Shroff, 1991; Smeltzer, 1992). Although women in Canada have made some advances toward equality, they continue to have less power and fewer opportunities than men (Health and Welfare Canada, 1990). Many remain socially, educationally, and economically disadvantaged (Smeltzer, 1992). As a result, they tend to have less access to educational, social and health resources needed to protect themselves from HIV infection and to receive adequate care if they become infected (Chung & Magraw, 1992; Easton, 1992; Haines, 1991; Health and Welfare Canada, 1990; Mackie, 1993; Shayne & Kaplan, 1991; Nyamathi, Bennett, Leake, Lewis, & Flaskerud, 1993; Smeltzer, 1992). AIDS is said to be contributing to the increased feminization of poverty (The AIDS Report, 1993).

Women and HIV/AIDS

Although women share similar concerns and needs to those of men living with HIV/AIDS, there are important considerations which uniquely affect women (Easton, 1992; Chung & Magraw, 1992; Hutchison & Kurth, 1991; Shroff, 1991; Smeltzer, 1992; Taylor, 1990). From the biophysical dimension, HIV infection manifests itself differently in women (Clark, Hankins, Hein, Mitchell & Williams, 1993; Denenberg, 1990; Mackie, 1993; Semple et al., 1993; Marte & Allan, 1991;

Taylor, 1990). Women may also experience a variety of psychosocial issues that are not comparable to those of HIV positive men (Chung & Magraw, 1992; Semple, Patterson, Temoshok, McCutchan, Straits-Tröster, Chandler, and Grant, 1993).

Chung and Magraw (1992), collected clinical data identifying psychosocial problems and concerns encountered by women living with HIV. Nineteen HIV positive women primarily of lower and middle class urban neighborhoods attended group therapy for a period of three years. The age range of the participants was 21 to 48 years of age. All women had a history of substance abuse, or had received psychiatric treatment, or had a partner with substance abuse problems. Clinically, three women were described as having AIDS and the remainder of the participants had a symptomatic HIV infection.

Chung and Magraw (1992) noted that the areas of concern most frequently raised by group members were: isolation, stigma and shame, medical issues, relationships, children, gender, and sexuality. The researchers acknowledged that these concerns were not necessarily specific to women living with HIV/AIDS however, they stressed the importance of situating illness within its social context. They further emphasized that women's experiences of HIV was inseparably linked to their experiences as women. Although there was no scientific basis in the collection of this clinical data, the findings were further validated in another study

by Semple et al. (1993). These researchers were the first and only researchers to use empirical data to address the full range of issues and concerns experienced by HIV infected women. They described the major psychobiological life stressors of HIV positive women. This research indicated that there are multiple stressors related to being HIV positive, some are common to both sexes and others may be viewed as being unique to women.

Semple et al.'s (1993), longitudinal cohort study consisted of a sample of 31 Caucasian HIV positive women, infected primarily through heterosexual contact. The age range for the participants was 24 to 53 years of age. Two hour semi-structured interviews were conducted with each participant and evaluations were performed semi-annually for five years. The interview consisted of detailing the circumstances, context, and consequences of all stressful life events and difficulties experienced in the preceding six months.

Primary HIV related stressors were defined as problems arising directly from being HIV positive and secondary stressors were those related to stressful life events and difficulties occurring in other role areas. Primary stressors consisted of health-related problems, including gynecological problems, and general symptoms of HIV infection such as fatigue. Secondary stressors related to child and family, marital/partner relations, occupation, economic problems, and social network events.

Semple et al. (1993) also described other non-related HIV life stressors. These were defined as everyday life events which have the potential to adversely affect women's health and well being. The participants in the study reported almost equal numbers of HIV related and non-HIV related life stressors. Everyday life stressors do not disappear when one is infected with HIV although, as women progress through their illness HIV related stressors begin to outnumber other life stressors.

The primary and secondary stressors or major themes identified by Semple et al. (1993) are pervasive throughout the literature. In the following pages each theme will be further described and supported by related or peripheral studies, as well as anecdotal literature which has addressed specific concerns or issues related to women living with HIV/AIDS.

Health related problems

Historically, within the male medical model, women's health care issues have received less attention than those of men. This trend has prevailed throughout the HIV/AIDS pandemic (Denenberg, 1990; Mackie, 1993; Marte & Allen, 1991; Smeltzer, 1992). HIV disease continues to be thought of as a disease of gay men and the medical definition of HIV/AIDS has been based on the illnesses common to men (Buckingham & Rehm, 1987; Easton, 1992; Taylor, 1990). Until 1993, the Centers for Disease Control (CDC) definition for HIV/AIDS did not include any of

the female manifestations of the disease (Holloway, 1994; The AIDS Report, 1993; Whipple, 1992; Williams, 1992). This led to under-recognition and under-reporting of AIDS cases (Buehler, Hanson, & Chu, 1992; Schoenbaum, Mayris & Webber, 1993). Women were often not treated until serious complications arose (Denenberg, 1990; Holloway, 1994). Berkelman (1990) suggested that as many as 65% of women with HIV were dying without receiving an AIDS diagnosis (cited in Williams, 1992).

Some studies demonstrate that HIV infection is more severe, progresses much faster, and has a higher mortality rate in women (Mackie, 1993; Williams, 1992; Schoenbaum et al., 1993; Smeltzer, 1992). A prevalent explanation for this phenomenon is the lack of access to medical care. In the United States, gender differences may be related to unequal access to treatment experienced by women (Hankins, 1995; Schoenbaum et al., 1993). Hellinger (1993) concluded from his study that even after women have been diagnosed they continue to receive less medical services than men.

Recent comparative studies demonstrate that when age, diagnosis, and treatment are matched, gender differences in prognosis and survival rate are virtually identical to those of men (Clark, Hankins, Hein, Mitchell, & Williams, 1993; Hankins, 1995; Mackie, 1993; The AIDS Report, 1993; Wofsy, 1988).

Hankins further describes that in Canada, the potential delays in diagnosis due to "either patient or physician factors" may affect the survival rate of women.

Hankins (1995) reports that as many as three out of four women with HIV infection may experience one or more gynecological problems. Semple et al. (1993) reported that 35% of the participants in their study reported gynecological problems such as yeast infections, irregular menstrual bleeding and abnormal pap smear. In addition to these problems 64% reported physical symptoms that are typical of HIV infection; fatigue and sleep disturbances were most frequently reported. These health related events as described by Semple et al. (1993) were identified as primary stressors.

Another high stress event in the lives of women was learning of one's HIV seropositivity (Buckingham & Rehm, 1987; Semple et al, 1993; Gaskins & Brown, 1992; Jones, 1991). Semple et al. (1993) described women as shocked and completely surprised to learn of their HIV infection, because they did not consider themselves in a high risk category.

Women often do not perceive themselves at risk (Christian & Susser, 1989; Glenn, Nance-Spronson, McCartney, & Yesalis, 1990; Haynes, 1993; Crouse Quinn, 1993; Shayne & Kaplan, 1991; Kinsey, 1994; McNicol, Hadersbeck, Dickens, & Brown, 1991; Nyamathi, Leake, et al., 1993; Smeltzer, 1992; Stuntzer-Gibson, 1991; Williams, 1992). Glenn et al. (1993) demonstrated that even though

women did perceive themselves at risk, virtually none of the participants in their study reported it likely that they had HIV at the present time, or would contract it in the future. Sex workers who are at great risk for contracting HIV infection usually will perceive themselves at risk from their clients rather than from their husbands or boyfriends (Dorfman, Derish, & Cohen, 1992).

Glenn et al. (1993) concluded that women may be experiencing a great deal of fear and denial concerning their risk of contracting AIDS. Williams (1992) states that two out of five women seem to be unaware of their risk for HIV, or fail to inform the health care provider. She further adds that in 1989 and 1990, 80% of one million women tested for HIV at voluntary counseling and testing centers, did not admit to any behaviors that put them at risk, yet one percent of these women were HIV positive. Stuntzer-Gibson (1991) proposes that women's ability and willingness to protect themselves from HIV infection may be related to socio-cultural pressures.

The false notion that women of reproductive age are not at risk of contracting HIV is further promoted by society and health care providers (Carovano, 1991; Easton, 1992; Krieger & Margo, 1991; Levine & Neveloff Dubler, 1990; Shayne & Kaplan, 1991; Taylor, 1990). Society does not generally perceive women at risk unless they are involved in prostitution (Carovano, 1991), or are intravenous drug users (Stuntzner-Gibson, 1991). There is a persistent

attitude among physicians and health care providers that most women are "good girls" and they do not get AIDS (Denenberg, 1990; Krieger & Margo, 1991). Some health educators assume lesbian women are not at risk (Denenberg, 1990; Easton, 1992; Stuntzer-Gibson, 1991); they are given messages that their sexual preference protects them against HIV (Denenberg, 1990). Women are often discouraged from being tested for HIV infection and the HIV symptoms are attributed to other causes (Taylor, 1990). Thus, as described in the American Public Health Association Report (1991), women may be vulnerable to misdiagnosis and not receive the proper care until late in the disease (cited in Hellinger, 1993).

The lack of empowerment of women in the health care system, the lack of knowledge about the disease, available resources, empathetic and effective treatments, and the perceived loss of control over their lives, promotes further problems and concerns for women living with HIV/AIDS (Chung & Magraw, 1992; Hellinger, 1993; Hutchison & Kurth, 1991; Johnson, 1994; Smeltzer, 1992; Williams, 1992). Due to the lack of attention given to women's health care needs, women may become distrustful of the health care system (Levine & Dubler, 1990; Pinch, 1993; Crouse Quinn, 1993). Women feel they may not be believed and may be suspicious of medical interventions and fear coercion and discrimination, for example: compulsory sterilization, criminalization of childbirth, coerced termination of pregnancy (Arras, 1990; Hutchison & Kurth, 1990). Women feel

they may be denied benefits and services, which leads to delays in accessing health care thereby, increasing the risks to themselves (Easton, 1993; Haynes, 1993; Johnson, 1994; Smeltzer, 1992; Taylor, 1990).

Child and family

Child and family issues are of paramount importance in the lives of HIV positive women (Arras, 1990; Hutchison & Kurth, 1991; Levine & Dubler, 1990; Pinch, 1993; Semple et al., 1993; The AIDS Report, 1993; Wofsy, 1988). Chaplain (1993) states that family issues are among the most difficult and complex problems faced by HIV positive women (cited in The AIDS Report, 1993). Disclosing HIV status to children and family members, child rearing problems, issues with the future guardianship of children, reproductive choices, HIV related illnesses of family member, and the death of a family member of AIDS, all are high level stressors in the lives of HIV positive women (Semple et al. 1993).

Although fathers are becoming more involved, women have, traditionally, been the primary caretakers of their families (Chung & Magraw, 1992; Clark et al., 1993; Health Canada, 1995 Krieger & Margo, 1991; Norr, McElmurry, Moeti, & Tlou, 1992; Pinch, 1993; Crouse Quinn, 1994; Shroff, 1991; Smeltzer, 1992; Wiener, 1991). Women have played key roles as educators of their children and as health guardians (Flaskerud & Thompson, 1991; Health Canada, 1995).

When a mother is HIV positive or has AIDS, it can have devastating effects

on the integrity and strength of the family unit because of her crucial role as the primary care giver. This is especially true if the woman is a single parent and the sole source of financial support for her family (Health Canada, 1995; Mackie, 1993). As the disease progresses, the mother's decreasing ability to be the nurturer, the caregiver, and the breadwinner may eventually cause disintegration of the family. Even though the woman may be very ill, she is still expected to care for the children, other members of the family and herself (Denenberg, 1990). Children and other family members lose the comfort and support which is greatly needed as the family struggles to live with the disease (Health and Welfare Canada, 1990; Mackie, 1993; Smeltzer, 1992; The AIDS Report, 1993).

Women must display remarkable strength in caring and supporting their families even though their own needs for care and support are not being met (Pinch, 1993). Often, women find it easier to care for their children or other family members than to care for themselves (Clark, Hankins, Hein, Mitchell, & Williams, 1993; Hutchison & Kurth, 1990; Pinch, 1993). As a result of their roles, women often fear becoming more ill and are fearful of being dependent on their partner, family, or even their children (Chung & Magraw, 1992; Flaskerud, 1987; Health and Welfare Canada, 1990). This may lead to devastation and depression, as women feel an increasing sense of helplessness, hopelessness, and powerlessness (Health and Welfare Canada, 1990; Taylor, 1990). Semple et al. (1993) add that

the physical and emotional demands exerted on the woman may further jeopardize her health and well being. The lack of self-care and the long term consequences may lead to a shortening of the woman's lifespan (Hutchison & Kurth, 1990).

Semple et al. (1993) reported that the most stressful experiences reported by HIV positive women is the care of a young child with HIV infection. Women harbor a lot of guilt in regards to their children if they are infected (The AIDS Report, 1993). Chung & Magraw (1992) reported that the mother-child relationship poses a significant concern for HIV positive women. Women need to cope with their own illness and care for themselves as well as dealing with the chronic illness of their child (Chung & Magraw, 1992; Mackie, 1993; Pinch, 1993).

Semple et al. (1993) reported that women in their study dreaded having to tell their children of their status. Women wanted to protect their children from suffering and worries about the future, as well as the social stigma and ignorance associated with HIV infection (Clark et al., 1993; Pinch, 1993; Semple et al., 1993). Some participants reported significant behavioral changes in their children after their disclosure which made child rearing even more difficult for HIV positive mothers (Semple et al., 1993).

Semple et al. (1993) described the issue of guardianship of young children and elaborated on the stress involved in making decisions and concrete plans for

the future of their children. Women must plan for the future needs of their children. Children may have to be placed in foster homes, and/or sick children may have to be hospitalized (Pinch, 1993). This results in complex decision making as the mother tries to deal with the separation from her child (Pinch, 1993).

Reproductive choices

Typically, the topic of reproductive choices is complex, difficult, and generates a great deal of conflict and controversy. Women who are HIV positive have an even greater struggle with this aspect of their lives. Not only are they living with the implications of their diagnosis for their own lives, but its potential impact on a child. HIV positive women may feel a heavy onus of moral responsibility when making reproductive decisions (Pinch, 1993). This may pose a threat to a woman's sense of self (Hutchison & Kurth, 1991). Normally the decision to have a baby is filled with love and hope for the future, but for HIV positive women, the decision is filled with guilt and anguish at the prospect of infecting their child with a deadly disease (Arras, 1990; Bradley-Springer, 1994).

The focus of HIV positive women and childbearing is on the risk of perinatal transmission of the virus. HIV positive women have gained attention not for their own sake but because of their potential for transmitting the virus to their fetus (Levine & Dubler, 1990; Holloway, 1994; Shroff, 1991; The AIDS Report, 1993). Women are often labeled as vectors of the virus to children and men

(Bradley-Springer, 1993; Clark, Hankins, Hein, Mitchell, Williams, 1993; Denenberg, 1990; Marte & Allen, 1991).

Hubbard (1993) states that pregnant women are said to have a legal and moral duty to avoid anything that could damage the fetus. The woman is expected to do whatever the experts consider best, not for the woman's sake, but for that of the fetus and the woman's moral obligation to society. She adds that no questions are asked about circumstances or opportunities that define women's lives and the influences these will have on the growth of the baby pre and post-natally. Women are seen as threats to the well-being of their fetus (cited in *The AIDS Report*, 1993), and are being blamed for the epidemic (Bradley-Springer, 1993; Pinch, 1993).

HIV positive women are faced with wondering if they will be able to conceive, if they should conceive, or if they should continue a pregnancy or abort their fetus. Culture, class, and race, are important factors which influence reproductive choices and may determine the woman's perception of herself and her role in society (Hutchison & Kurth, 1990). In most cultures motherhood is very important (Carovano, 1993; Hutchison & Kurth, 1990 & 1991; Levine & Dubler, 1990; Wosfy, 1988). In some cultures motherhood elevates the status of the woman in the community (Carovano, 1993; Levine & Dubler, 1990), for others it provides a sense of pride, self-expression self-esteem, social respect (Arras, 1990,

Hutchison & Kurth, 1990 & 1991), security, and validation of the woman's sexuality and often her life (Carovano, 1993; Mackie, 1993; Wofsy, 1988). For many women, having a baby is an opportunity to have someone to love, and/or having someone to love them (Levine & Dubler, 1990); it becomes a source of pride, it reinforces one's identity, and it gives reason to go on living (Hutchison & Kurth, 1990). Motherhood can be an empowering experience.

As a result, HIV positive women often choose to become pregnant or to continue a pregnancy. Women may feel coerced in terminating their pregnancy, although few choose that option (Arras, 1990; Bradley Springer, 1993; Jones, 1991; Wofsy, 1988). Jones (1991) states that this is related to the cultural values placed on childbearing and women's fertility. Nevertheless, HIV positive women who choose to initiate or continue a pregnancy are seen as being selfish, irresponsible, or immoral and are often treated with disdain (Arras, 1990; Bradley-Springer, 1993; Levine & Dubler, 1990).

Although there is conflicting data about birth outcomes, in North America asymptomatic HIV positive women have a 15 - 40% per cent risk of vertical transmission; 50% of this risk is due to breast feeding (Arras, 1990; Jones, 1991; Hankins & Lapointe, 1990; Wofsy, 1988). The uncertainty of infecting one's child promotes tremendous ambiguity and may be even more difficult to resolve than an AIDS diagnosis (Hutchison & Kurth, 1991; Jones, 1991; Taylor, 1990). This is

accentuated by the mixed messages from society that stresses freedom of reproductive choice while emphasizing the irresponsibility of conceiving when infected with HIV (Arras, 1990; Levine & Dubler, 1990). Hence, HIV positive women may experience rejection from significant others (Jones, 1991), family (Hutchison & Kurth, 1990), and may feel intimidated by the negative societal attitudes (Clark, Hankins, Hein, Mitchell, & Williams, 1993; The AIDS Report, 1993).

The decision to have a child leads to additional stresses as the woman wonders if her baby will be infected and if she will live to care for her children and see them grow up (Williams, 1992). Semple et al. (1993) describe women's fear and uncertainty of having infected their child through pregnancy or breast feeding. In addition, Semple et al. elaborate on how HIV positive women are forced to deal with personal losses. HIV positive women report that the father or significant other are rarely seen as support persons (Arras, 1990; Hutchison & Kurth 1990). HIV positive women identify themselves as the decision agent and they view themselves and their children against the world (Hutchison & Kurth, 1990).

Marital/Partner relations

Relationships, responsibilities, and understanding the circumstances of the moral situations are important in the moral orientation of most women (Gilligan, 1982). Generally, women place a high value on the development and preservation

of relationships (Kline, Kline, & Okin, 1992; Levine & Neveloff Dubler, 1990; Pinch, 1993). Hence, many women gain a sense of self through relationships. Relationships with men are particularly important. Traditionally, women have been socialized to believe that they must have a man in their lives, otherwise they have no life (Shayne & Kaplan, 1991). This concept is further reinforced by society's value of monogamous, gender structured families as a core institution (Pinch, 1993). Culturally based gender roles continue to greatly influence how men and women view and interact with each other (Kline, Kline, & Okin, 1992; Stuntzer-Gibson, 1991).

For HIV positive women, many factors come into play which may create havoc in their relationships. Women struggle with issues of disclosure, fear of abandonment, loss of traditional social roles, and issues related to self-concept, self-esteem, love, sexuality and intimacy.

The disclosure of women's seropositivity may jeopardize their relationships. Buckingham & Rehm (1987) state that disclosure is a twofold consideration that is the decision to protect the image and reputation of the partner as well as her own. Disclosure then becomes a stressful event in the lives of HIV positive women (Semple et al., 1993). They may fear the loss of their relationship, abandonment, rejection, and in some instances disclosure may lead to domestic violence (Pinch, 1993; Stuntzner-Gibson, 1991; The AIDS Report, 1993). Semple et al. (1993)

reported that women who were not married, but living with a male partner reported that over time the act of disclosing had either changed a good relationship in a negative way, or had made a poor relationship even worse.

Haynes (1993) states that some women are so dependent upon their relationships that they would rather face death than to be without a man. Pinch (1993) add that HIV positive women put themselves in second place when caring for significant others with AIDS, to the point of sacrificing their own health and safety. Gilligan (1982) reinforces that care orientation of women is at the core of the considerations for relationships and responsibilities. Six of the eleven married couples in Semple et al.'s (1993) study had husbands who were also HIV positive. The women in this study reported having to provide considerable care and support to their ailing husbands, causing a great deal of stress in their lives and placing them at risk for their own physical and emotional well-being.

For other HIV positive women, their social role is disrupted and there may be a role reversal in the relationship (Buckingham & Rehm, 1987; Chung & Magraw, 1992). Semple et al. (1993) reported that married women appeared to have good relationships. The spouse of HIV positive women were emotionally supportive at the time of disclosure and throughout the course of the illness. In one situation the husband stayed home to care for his ill wife. Buckingham & Rehm (1987) describe that under certain circumstances some marriages will disintegrate,

or the illness may create a turning point in the relationship, leading to the resolution of emotional conflicts.

Fifteen of the women in Semple et al.'s (1993) study reported living with a male partner in what the women considered to be an exclusive relationship. The women reported that initially the men were more supportive than they had expected, but eventually the relationship deteriorated or was terminated. Partners, lovers, or spouses may face intense feelings of helplessness, grief, and shock, as well as conflicts between their fear of infection and their desire for love and intimacy (Semple et al. 1993; The AIDS Working Group, 1992). This may cause them to withdraw from the relationship (AIDS Working Group, 1992).

HIV positive women may question their femininity (Buckingham & Rehm, 1987). They may feel unattractive, feel they have lost their sexual appeal even though they look healthy (Chung & Magraw, 1992; Clark et al., 1993). They may have difficulty with their self-image, they may be confused about whether sexual activity is safe, or they may feel guilty about their desire to have sex, love, and intimacy (Chung & Magraw, 1992; Clark et al., 1993). They may begin to question their adequacy as a woman and feel they cannot compete for the men in their lives (Buckingham & Rehm, 1987). Women may become dependent on men to validate their self esteem (Levine & Neveloff Dubler, 1990), for women are taught to gain self esteem from significant others in their lives (Brody, 1992). Although a

monogamous relationship may be highly valued, one might not be available for HIV positive women leading to considerable frustration (Buckingham & Rehm, 1987; Levine & Neveloff Dubler, 1990).

Occupation

Occupation is another area of concern for HIV positive women, as they may have difficulties maintaining their job (Mackie, 1993; Shroff, 1991; Summers, 1994). A number of factors as reported by Semple et al. (1993) contribute to this issue. Some women reported a lack of concentration on the job, frequent absenteeism, and lower quality of work due to chronic fatigue and a lack of stamina. As a result, some women expressed feelings of inadequacy and were concerned with job security. Since the majority of these women were heads of household and had several dependent children to support, the fear of losing their employment was particularly stressful.

Economic

HIV positive women tend to be poorer economically than men infected with the virus and therefore may be limited in their access to housing, food, clothing, social, and medical services (Health and Welfare Canada, 1990; Mackie, 1993; Norr et al., 1992; Stuntzer-Gibson, 1991). Women may be underpaid and work in low level employment (Summers, 1993), or may be dependent on social assistance or social security benefits for their livelihood (Pinch, 1993). Poverty combined

with the lack of economic alternatives may create more dependency on their male partner for economic stability (Health and Welfare Canada, 1990; Kline, Kline, & Oken, 1992; McCoy & Inciardi, 1993; Novello, 1991; Pinch, 1993). Economic dependency on men leads to further impoverishment if women lose their partner (Norr et al. 1992).

Semple et al. (1993) describes that seropositivity may impact finances through income loss and increased expenses. Income loss may be associated with health related absenteeism and the necessity to resign permanently from paid employment (Bradley-Springer, 1993; Health and Welfare Canada, 1990; Semple et al., 1993). In addition, the loss of group health insurance further promotes financial strain related to major increases in expenditures, to medical care, and treatment (Semple et al. 1993).

Social Network

HIV positive women are a very diverse group culturally, economically, and spiritually, and have a wide range of sexual gender roles and family configurations (Stuntzer-Gibson, 1991; Summers, 1994), making it difficult to organize a social or political community (Stuntzer-Gibson, 1991). Women often perceive AIDS agencies as being for gay men and feel the services are not appropriate for them, causing further isolation (Stuntzer-Gibson, 1991).

HIV positive women are closeted, secretive and prefer not to be visible

about the disease (Wofsy, 1988). Generally they do not like to come together in social ways to talk about their illness.(Wofsy, 1988). For some women social contacts become maladaptive; they will lie to keep their secret and use denial as a coping mechanism which serves to isolate them further (Pinch, 1993). For some women secrecy may be imposed upon them by their partner or family (Summer, 1994). Eventually, living in secrecy and the pervasive feeling of being alone may lead to depression, lack of hope, and feeling of shame. Thus HIV positive women become more fearful, isolated, and powerless to change their circumstances (Shayn & Kaplan, 1991), and become more vulnerable to discrimination by family, friends, and the community (Shayne & Kaplan, 1991).

Semple et al. (1993) found that HIV positive women in their study reported disclosures to friends and co-workers as stressful events, although less emotionally charged than the disclosures to family members. However, for some, disclosure of their seropositivity often aggravates the isolation; they may be abandoned or rejected by friends and family (Buckingham & Rehm, 1987; Shayne & Kaplan, 1991; Stuntzer-Gibson, 1991; Williams, 1991). Lin et al. (1994) concluded from their study that women needed continual support from their family, friends, and co-worker in order to promote psychological health of HIV positive women.

Since HIV positive women lack a community in which they can share their experiences, fears, and grief, they may experience a much more profound isolation

than that experienced by gay men (Shayne & Kaplan, 1991; Taylor, 1990; Wiener, 1991). They may experience a tremendous sense of aloneness and isolation from family, community, and support structures (Bradley-Springer, 1993; Chung & Magraw, 1992; Health and Welfare Canada, 1990; Hutchison & Kurth, 1990). Women from other ethnocultural communities may experience further discrimination and isolation from their own communities as well as from the mainstream society (Health and Welfare Canada, 1990). Stigmatization and discrimination lead to a greater sense of isolation and vulnerability (Mackie, 1993; Wiener, 1991).

Summary

Although few empirical studies address the holistic experiences of HIV positive women, a number of recurrent themes are pervasive in the literature. Women remain an invisible and vulnerable group. Women are faced with unique psychobiological and social issues. In addition, women living with HIV/AIDS are faced with overcoming the hurdles of a patriarchal health care system, socio-economic and political issues and gender biases (Crouse-Quinn, 1993; Holloway, 1994; Hutchison & Kurth, 1991; Johnston, 1994; Smeltzer, 1992; Stuntzer-Gibson, 1991; The AIDS Report, 1993; Wiener, 1991).

CHAPTER III

METHODOLOGY

This chapter describes the method used to conduct the present study. An overview of qualitative research design is presented so as to situate the study within the proper context. A discussion ensues regarding the interpretive research approach. The role of the researcher and the sample are described. Methods of data collection and data analysis are delineated. The issues related to rigor in qualitative studies is addressed. A discussion of ethical considerations concludes this chapter.

Qualitative design

Qualitative design involves the systematic collection and analysis of subjective data. Flexibility in the data collection methods promote a holistic approach to understanding the human experience. Qualitative research recognizes that people construct meaning in their lives within the context of the world in which they live, work, learn, and play. The researcher strives to collect data which describes the experience under study (Lobiondo-Wood & Haber, 1990; Polit & Hungler, 1991). More specifically, in this study, hermeneutical phenomenology is used to describe the human experience of women living with HIV/AIDS.

The interpretive research approach

Hermeneutical Phenomenology

Hermeneutics, an ancient discipline that can be traced back to the early Greeks provided a means of understanding language (Benner, 1994). This approach was used in the systematic study of biblical texts, and more recently in historical research and literary criticism (Benner, 1985). Hermeneutics has its roots in Heidegger's work; that is, understanding the essence of human beings and the human experience (Benner, 1985). Heideggerian phenomenology has emerged as the philosophical underpinnings of the qualitative research method in the social sciences (Benner, 1985; Taylor, 1985) and has been accessible to nursing as a research method (Benner, 1984a, 1984b; Carter, 1989; Chelsa, 1988).

Oiler (1981) states that "phenomenology is a philosophy, an approach, and a method" (p. 178). Phenomenology attempts to describe the human experience as it is lived, within the context of the perceived world (Cohen, 1987; Benner, 1985; Oiler, 1981 & 1986; Omery, 1983). Phenomenologically speaking, world is defined as "the meaningful set of relationships, practices, and language that we have by virtue of being born into a culture (Benner, 1994 p. 47). Heideggerian phenomenology is grounded in a view of humans that support the possibility of shared understandings of the world, shared concerns and practices.

Intersubjectivity is the basis of phenomenology (Anderson, 1989; Benner, 1985;

Cohen, 1987); generating meaning is determined by being in relation with people and being in the world (Anderson, 1989; Oiler, 1981 & 1986; Benner, 1985; van Manen, 1990).

Humans are essentially self-interpreting; they are the kind of beings for whom things have significance and value. Meanings or self-interpretations are embedded in the person's cultural background; that is language, skills, and practices (Benner, 1985; van Manen, 1990). It is this background that individuals cannot make fully explicit, but which allows individuals to come to a situation with a story (Benner, 1985). What matters to human beings therefore, may change with the context and reveal a different kind of understanding (Benner, 1994). Lived experiences are therefore layered with meanings related to being in the world and they are limited by particular language, culture, and history (Benner, 1985; Benner, 1994; Oiler, 1981). It is of significance to note that phenomenological reflection is a retrospective process; reflection on lived experience is always recollective since the experience is already passed or lived through (van Manen, 1990).

In the phenomenological view individuals actively become involved in their world. The type of involvement that is shaped by concern is existential rather than spatial. For example, one can be "in" a place, but existentially only "in" love. Only persons can be existentially involved (Heidegger, 1962). Therefore to understand

an individual's behavior or expressions, the person must be studied within the context of the situation. What the individual values and finds significant will show up only in the context of that situation (Benner, 1994).

In the interpretive view, humans have an embodied intelligence; that is a bodily way of knowing, perceiving, grasping, and interpreting the world in relation to cultural background practices and meanings (Benner & Wrubel, 1989; Carter, 1989). Meanings are grasped in relation to context, surroundings, and functions (Benner & Wrubel, 1989). There is an important distinction between practical or bodily knowing and theoretical knowing. Practical knowing is the primary way of knowing and precedes the abstract knowing. Abstract knowing requires an individual to take a step back from the situation in order to understand what is happening (Benner, 1984a).

This qualitative study is an approach to understanding human behavior and meanings through text interpretation. The purpose of hermeneutical phenomenology is to illuminate human practices that evidence the background meanings and concerns of the persons under study. The goal in this study is to give an adequate account of the perspectives of women living with HIV/AIDS, regarding the issues of concerns for them. Benner (1985) states that "the task is to uncover the meanings in everyday practice in such a way that they are not destroyed, distorted, decontextualized, trivialized, or sentimentalized" (p. 6).

Role of the investigator

Keen (1975) describes three strategies to enable the investigator to understand and to reveal the meaning of the human experience in a phenomenological study. These are phenomenological reduction, imaginative variation and interpretation (as cited in Knaak, 1984).

1. Phenomenological reduction refers to setting aside any preconceptions or notions to more fully understand the meaning of the phenomenon to the individual; this has been achieved by bracketing.
2. Once bracketing had occurred, imaginative variation allowed the imagination of the phenomenon against the background of various meanings of experience to determine what the phenomenon really meant.
3. Interpretation is the articulation of meanings as they emerge in the phenomenon. The investigator avoided categorizing a phenomenon within the context of a known theory, concept, or personal preconception.

Research design

Sample

The purposive sample was comprised of five Winnipeg women living with HIV/AIDS. The inclusion criteria were quite broad, related to the inaccessibility of that population and the small number of women living with the disease. Criteria

for eligibility were women having a confirmed diagnosis of HIV infection or AIDS; they may or may not have been symptomatic. The participants required the ability to speak English or French and had to be able to articulate their experiences.

Health care organizations and physicians were contacted and encouraged to collaborate in selecting participants for the study. Health care providers were asked to distribute a letter of invitation (Appendix B) to potential participants describing the nature of the study, with a request for voluntary participation. A letter of access permission (Appendix C) was sent to health care facilities in order to have access to the subjects.

Data collection

Data collection consisted of in depth unstructured interviews with five participants over a period of four months. Two interviews were conducted with four of the participants; the fifth participant died prior to the second interview. The duration of each interview ranged from one and a half to three and a half hours, for a total of 19 hours of interview time.

Prior to the first interviews, a camera was offered to all participants. Two participants consented to use photography as a means of additional data collection. The participants were instructed on the use of the camera and they were asked to photograph any meaningful events in their lives for a period of six weeks. In the

end, only one participant actually used the camera. Wagner (1979), states that photographs may hold the promise for investigating the meaning of social life. Indeed, the photo interview provided in-depth information on the participant's personal and social life.

During the first interview the participants were asked open-ended questions such as "Describe what it is like for you to be living with HIV/AIDS? ". From that question the participant directed the conversation. Probes were used to obtain more or extended information such as silence, uh-huh, umm, waves of the hand, or simple calls for more (Could you tell me more about...), or (Do I understand you correctly?), or paraphrasing the words of the participant. Dexter (1970) states that interviews are conversations with a purpose (as cited in Lincoln & Guba, 1985).

Photographs served as the basis for the second interview for only one participant. During the photo interview, the participant was asked questions such as "What does this photograph mean to you?" or "What is the story behind the picture?" or "What were you wanting to capture with this photo". This process encouraged sharing of additional information which had not previously been discussed and allowed for more in-depth sharing. This process also permitted the investigator to validate themes from the first interview.

For the three participants who did not consent to photography, the second interview consisted of reviewing and validating the interpretations made during the

first interview. The additional time provided an opportunity for the participant to further elaborate on previous discussions. To bring closure to the interviews, the participant's key points were summarized. This process encouraged member check as well as allowing participants to add new materials (Lincoln & Guba, 1985).

The interviews occurred in the participant's home. This promoted ease and comfort for the participant, and increased the investigator's awareness and understanding of the participant's environment. With the participant's consent, the interviews were audio-taped and later transcribed. The investigator personally transcribed the first set of five interviews. Field notes were maintained by the investigator following each interview, in which all thoughts, observations, and feelings were recorded. This became an integral component of the data analysis. In addition, one of the participant wrote a poem which was included in the text interpretation.

Data analysis

Data were analyzed using a systematic interpretive approach. The field notes, verbatim transcriptions of the audio-taped interviews and the poem provided the text for analysis and interpretation. Benner (1985) describes the interpretation process as "a systematic analysis of the whole text, a systematic analysis of parts of the text, and a comparison of the two interpretations for conflicts and for understanding the whole in relation to the parts, and vice versa" (p. 9). Benner

adds that during the process of text interpretation the shifting back and forth between the parts and the whole may reveal new themes, new issues, and new questions.

The three strategies, or interrelated processes as described by Benner (1994) were used to guide the text interpretation: (1) thematic analysis, (2) analysis of exemplars, and (3) the search for paradigm cases.

1. Thematic analysis: All interviews and field notes were read several times to arrive at a global analysis. Notes, questions, and interpretations were made. Themes emerged from the data. Each interview was then reread for indications of newly emerging themes. All whole cases were further subjected to additional interpretive analysis. The outcome of this process was the identification of general categories that formed the basis of the study's findings.
2. Analysis of exemplars: The second stage of the interpretive process involved the analysis of specific episodes or incidents. All aspects of the specific situation and the participant's response to it were analyzed together. The analyzed event includes the individual's situation; her concerns, actions, and practices, and not her opinions, analyses, or ideology. This resulted in stories or vignettes (exemplars) that captured the meaning in a situations in such a way that the meaning could then be

recognized in another situation that might have very different objective circumstances. An exemplar is "a strong instance of a particularly meaningful transaction, intention, or capacity" (Benner, 1985, p. 10)

3. Paradigm cases: The last aspect of the interpretative analysis was the identification of paradigm cases. Paradigm cases are strong instances of particular patterns of meaning. They "embody the rich descriptive information necessary for understanding how an individual's actions and understandings emerge from his or her situational context: their concerns, practices and background meanings. They are not reducible to formal theory, to abstract variables used to predict and control" (Benner, 1994, p. 59.)

Rigor in qualitative studies

Rigor is paramount in qualitative studies. Throughout the study measures were undertaken to enhance the rigor of the research process. Lincoln and Guba (1985) identify four criteria to ensure rigor in qualitative studies: credibility, transferability, dependability, and confirmability.

Credibility parallels internal validity; this was achieved by:

1. two interviews were conducted with four of the participants, the use of photographs with one participant; this prevented misinterpretation and distortion of data;

2. interviews were transcribed verbatim; this provided a true and faithful description of the lived experiences of the participants;
3. regular debriefing sessions with the thesis chair person, this promoted intersubjective agreement;
4. member check with participants; and
5. bracketing preconceptions and biases prior to data collection and analysis; this was achieved by setting aside as much as possible the investigator's pre-existing theoretical and practical understandings.

Transferability parallels external validity and generalizability; this was accomplished by:

1. providing thick, rich descriptions of the data;
2. providing quotes or excerpts from the data to support the findings; this provides the reader with information to validate the process by confirming the interpretations and confirming the analysis based upon their own experiences; and
3. presenting the results of the study to a public audience.

Dependability or audibility parallels reliability; this was ensured by:

1. maintaining a copy of the coding procedure; and
2. maintaining a detailed journal of events used in the study.

Confirmability or objectivity is achieved when there is freedom from bias in the

research process; this was accomplished by addressing all of the above mentioned criteria which are essential in maintaining rigor in a qualitative study, that is credibility, transferability, and dependability.

Ethical considerations

Following the proposal defense with the thesis committee, ethical approval was obtained from the Ethical Review Committee of the University of Manitoba Faculty of Nursing (Appendix D). Upon approval and prior to data collection, a letter of invitation describing the nature of the study was sent to health care providers for distribution to potential participants. This process ensured confidentiality and anonymity of the subjects. Voluntary participation and the right to withdraw from the study was emphasized.

A written consent (Appendix E) was obtained from all participants. Each participant was given a copy of her signed consent. The consent consisted of a description of the study, the role of the investigator, the role of the participant, the risks and benefits of participating in the study, confidentiality and anonymity, voluntary participation, and the right to withdraw from the study. The name and phone number of the researcher as well as the thesis chairperson's name and phone number were provided, whereby either one could be reached for clarification or questions about the study.

Confidentiality was maintained by assigning a code number to each study participant. This code was known to the investigator only. The code number was used in the field notes, audio-tapes, and in the transcribed data. Only the investigator and the thesis chairperson had access to this data. All sources of data will be kept in a locked file for seven to ten years and then destroyed.

participation in the study. Participants were forewarned that they may experience some loss of privacy or feelings of being uncomfortable through the interview process related to the intimate and sensitive nature of the topic. In the event of distress, participants were informed that appropriate resources such as a counselor would be available to them.

Participants were made aware that there may be no direct benefits to participating in the study, but the results may help to increase the health care providers' and the public's understanding of the unique issues faced by Winnipeg women living with HIV/AIDS. They were informed that this study may promote the development of more appropriate and sensitive services to Winnipeg women.

Summary

In this chapter the research method was described along with the philosophical background for the methodology. Characteristics of the research design were presented including the sample, procedures for data collection, and

data analysis. Issues relating to the rigor is qualitative and ethical considerations were addressed. In the next chapter the findings are presented.

CHAPTER IV

FINDINGS

This chapter presents the findings of the study on the lived experiences of Winnipeg women with HIV/AIDS. The sample characteristics and the interview context are described. The six major categories that have emerged from the thematic analysis of the data: health related issues, marital/partner relationship, child and family issues, occupation, social network, and coping with HIV/AIDS are elaborated upon.

Sample characteristics

The sample consisted of five Winnipeg women living with HIV/AIDS. Two of the participants were Caucasian and three were from a visible minority group; one having newly immigrated to Canada. Participants were not clustered in any specific geographical area in the city. One participant was married, four were single. Three of the subjects had children although, in two instances the children were not living with their mother. Two participants had a history of sexual abuse.

The participants' age ranged from 24 to 41 years of age. The education level varied from no formal education to college prepared individuals. Three of the five participants received social assistance as their main source of income and one was receiving disability insurance, and the other woman was being supported by her family.

Four of the subjects contracted HIV through heterosexual relationships, one through intravenous drug use. Out of the five participants, four had been diagnosed seropositive for two to six years and one for three months. Two of the participants were diagnosed with full blown AIDS.

Interviews

All interviews occurred in the privacy of the participant's home. The majority of the interviews were rescheduled when no children, family, or friends were present. On two occasions interviews were reschedule due to unexpected visits. The majority of women in this study felt more comfortable and at ease in sharing their stories with the investigator when they were alone.

Interviews with one participant were held in the presence of her husband. These interviews were difficult for both the participant and the investigator. At times the participant appeared hesitant to verbalize her feelings, concerns, or fears. In mid sentence she would often glance at her husband, pause, then resume her sentence. She appeared to be guarded and nervous. The physical environment was also unpleasant as the participant's spouse was a heavy smoker. Smoke quickly consumed the entire apartment to the point where it became difficult to breathe. Richness and depth of information was limited.

One participant consented to using photography as an additional means of

data collection. The participant took 48 photographs. The stories related to each of these photos were shared with the investigator during the second interview.

Photography provided a powerful medium from which data was generated. The information shared by the participant came to life through the photographs. The photo interview promoted an in-depth sharing of information.

All women welcomed the opportunity to participate in this study. The majority of women were able to share intimate details of their lives with the investigator. The participants' stories, the investigator's field notes, the photographs, and a poem written by one of the participants provided the context in which the data was collected, analyzed, and interpreted.

Health related issues

Medical issues

In the domain of health care, participants were able to share some vivid stories of their experiences. In one particular instance the participant was not diagnosed until she was admitted to the hospital with AIDS. She had seen her physician a number of times and was even referred to a specialist. She was never considered to be in a high risk category and was therefore never tested for HIV.

Three of the participants had experienced no difficulties in being tested for the virus. They simply asked their physician to be tested. They did not experience

any hardships in securing adequate medical treatment post diagnosis. One woman was tested for the virus without her consent. She believes this happened because she was "a junkie, a heroin user" and therefore had no control over what happened to her.

The majority of participants generally believed they were being discriminated against in the health care system because of their disease. Women were able to relate specific events during the course of their illness, whereby they felt abused by the system, treated as less than human, and reported incidents where staff were rude and uncaring. Painful experiences with hospital admissions and interactions with physicians and nurses promoted a negative attitude in these participants. The general feeling amongst these women was that health care providers are "afraid of the disease and they just don't want to deal with it". One participant stated "I think this is happening because I'm unique, I'm not gay and I'm not Native".

Upon diagnosis of their seropositivity three of the five participants described their experiences with health care providers as frustrating. They were unable to obtain the necessary information to help them deal with their circumstances. One participant obtained most of the information from out-of-province contacts. Two of the other participants went to the library and read as

much as they could on HIV/AIDS and women. Two women relied on information provided to them by their primary physician or nurse.

Learning of one's seropositivity

Being diagnosed as HIV positive was a trying experience for all participants. The majority of women were in a state of shock and disbelief. The overriding feeling was that of "HIV = AIDS = Death". The responses were that of anguish and shattered dreams. This participant's words sums up the reactions of all the women who participated in the study.

All of a sudden I was paralyzed with fear. I couldn't move, I couldn't make a decision. I couldn't think straight. I was just devastated, I mean I couldn't even breathe. I was just, I was like, "well what does this mean?" Its just like a nightmare. I mean it can't possibly be true. I mean this can't be happening and yet there's this sort of feeling like deep down like I knew it, I knew it. And I walked out of that doctor's office and I was not the same person. You know, and I was in so much pain, and I was so tormented by everything. You know this is it, my life is over, I'm as good as dead. This is a death sentence. After the diagnosis like I slept for hours and hours on end and it was hard for me to even get out of bed. It was hard for me to convince myself that there was a reason to even bother. You know that for the longest time I didn't even know if I wanted to live.

The majority of participants felt that physicians were honest and straight forward in informing them of their diagnosis. Physicians admitted not knowing a great deal about HIV disease in women, but were willing to share the information they had. For the most part when women got over the shock of the diagnosis they were able to understand that it was not necessarily an immediate death sentence.

Perception of risk

Participants did not perceive themselves at risk for contracting the virus. All participants acknowledged that they were not informed about HIV/AIDS; had they been so informed, they would have taken precautions. One participant's words reflects how these women felt. She states "I didn't know. I could have done something about it had I known, but I did not know."

In retrospect, once they were diagnosed women were able to verbalize that in fact they had placed themselves at risk. Three of the five participants stated they were careless and did not take the necessary precautions to protect themselves. All but one participant thought it could never happen to them. The disease was considered to be a homosexual disease; women did not become infected with this virus.

Reproductive choices

Two of the five participants interviewed described their anguish related child bearing issues. For one participant, once informed of her seropositivity and

the potential risks of infecting her baby, she categorically refused to bear another child. She stated that she could not live with the responsibility of bringing an infected child into the world. She added that she could never forgive herself if that ever happened. She felt torn and distraught about having to make that decision, but adds " this is the way it must be". She had resigned herself to not having any more children.

For another participant, her first reaction to her diagnosis was to inquire about being able to have children. She describes her becoming "obsessed" about having a baby and elaborates how devastated she became in thinking that she could never have a child. She adds that all of her dreams for having a family were gone.

Marital/partner relationships

Three of the four single women in this study felt there was no hope for an intimate relationship in their life. They described the futility in even thinking of having a relationship. They perceived themselves as being dirty, unattractive, asexual, and having nothing to offer. One participant summarized by saying "who the hell would want me, I am damaged goods".

These women also felt strongly that men would not be interested in them as women. There would always be the overriding concern of the risks of sexual intimacy. Men may fear contracting the disease and would not, nor could not enjoy

them as women. One participant described that men would not take those kinds of risks. Women were also preoccupied with transmitting the virus to a partner even though precautions would be taken. Essentially, they were afraid to "hurt" their potential partner and felt a strong need to protect these men.

The other dimension that was brought to the forefront for four of the participants was the loss of anonymity. Even if these women were interested in an intimate relationship they were not prepared to risk their anonymity. The fear of being discovered as being HIV positive was a grave concern for these participants. None of them were convinced that the potential loss of anonymity, the pain, and suffering they may experience upon disclosure to a partner was worth the effort.

One participant shared the above mentioned views but she realized that intimate relationships in her life could continue. She was surprised that the men in her life did not seem to mind her HIV status. She adds however, that she always acknowledged her responsibility in protecting her partner; that she could not live with herself if she placed him at risk.

The single mother on the other hand, responded by being adamant about not being involved in a relationship. She acknowledged that she would greatly enjoy an intimate relationship but would not venture to take the risk of infecting her partner. She was quick to add that a relationship is not for her at this time; that she

is content to spend the time with her children. She reinforced that she did not have the time to develop a relationship, that her children needed her at home.

The married participant in this study is thankful that she has such a "loving supportive husband". Although there is no sexual intimacy between them she feels that they can still maintain a positive relationship. She insists that she must protect her husband and refuses to be sexually involved because she could not tolerate the thought of infecting her husband and seeing him suffer.

Child and family issues

Children

For the HIV positive mother in this study, her three children became the centre of her world. The burden is heavy for the young single mother. She has the total responsibility for her children with no support from the father of her children and little encouragement from her family. She vividly described the trials and tribulations she had experienced with her children, including the difficulties she had in disclosing her status to them. She further explained how she wanted to protect her children against the stigma of having an HIV positive mother. She elaborated on the subtle ways she tried to inform her children about the disease and she shared her preoccupation about dying and having to leave her children behind. She adds that she would like her children "to die with her so they wouldn't have to

go through life without her". She describes her pain when thinking about those issues and states that she would rather not think about those problems. She prefers to focus on the "good times" she has with her children.

The other participant with children has resigned herself to not being a part of her children's lives although, she continues to grieve their loss. The small children are living with their grandmother in another country. Even if her children are not with her, this mother constantly worries about her children. She worries about their health, about their schooling, and generally about everything in their lives. She misses them and cries when talking about them. She adds that she must be strong and that one day she may be reunited with them. Until that time she has resigned herself to her fate.

Family issues

Family relationships were significant issues in the lives of participants. All participants highly valued family relationships, but have had to compromise a great deal in order assert themselves as HIV positive women. Three of the five participants chose to distance themselves from their family because family members made life too difficult for them. One participant had not informed her family because she felt she needed to protect them. One family reassured the participant that they would always be there for her; that she need not worry about

how she would survive, they would see to her needs. Although her physical needs have been met, other psychological and emotional needs remain unmet.

Disclosure to family members was a difficult process for all participants. At the time of this writing, one participant had not been able to inform her family. All participants were fearful of being blamed for contracting the virus. They were afraid of being rejected, judged, and abandoned by their family. In the four instances of disclosure all participants were initially blamed by family members. In three instances family felt the participants were being punished for past behaviors.

Initial responses by family members in all cases was disbelief, as AIDS is perceived as a disease of the homosexual population. Women do not get this disease. This was followed by a bombardment of questions as to how, when, and with whom they contracted the virus. Denial became a coping mechanism for many family members. Four of the participants were rejected by their family and/or were tolerated as long as HIV/AIDS was not discussed. Two participants found their family was supportive upon disclosure, but later abandoned them.

One participant was responsible for caring for her aging husband and her elderly mother-in-law. Even though she was ill at times, the expectation remained that she would do the housework, prepare the meals, and provide direct physical care to her mother-in-law. The husband refused to provide any assistance. The participant described this situation as acceptable since that was her role. Although

she does not want to become a burden to her husband, she worries about the time when she will become debilitated and unable to maintain her role. She is also concerned that no one will be there to care for her. Nevertheless she states that life must go on and she will deal with those issues when they happen.

Occupation

None of the participants in the study were employed. Three participants expressed the desire to get back into the workforce. They add however, that they are unable to work full time because they don't have the physical stamina to do so. They are fearful that workplaces will not be understanding of their circumstances. They feel they will have to lie about their disease so as not to be discriminated against.

Two of the participants were concerned about being on social assistance. They stated that people don't necessarily understand why apparently young healthy women need to be on welfare. There is no tolerance in society for this. These participants felt that they were considered lazy and not wanting to help themselves. For one participant in particular this issue was of great concern. She had been active in her career and had achieved a certain status in life; she found that being on welfare was almost an unbearable situation for her. Nevertheless, all participants reported having a satisfactory standard of living.

Social network

Isolation

All participants reported feeling isolated and alone. Feelings of loneliness were paramount in four of the five participants. This was particularly evident when participants described their reaction to the diagnosis. Participants were embarrassed and ashamed of themselves. Two participants stated they hated themselves and did not want to see anybody. They chose to isolate themselves; to go "in hiding" to protect themselves. They were afraid that people would find out; they feared they could not deal with the stigma attached to living with HIV/AIDS. One participant summarizes this isolation by stating "It's not fair that gay people are able to come out of the closet and I'm straight and I have to jump into the closet".

The extreme isolation is still ever present in the daily lives of all participants. Even though they have all stated that they would enjoy a more active social life, all describe the need to remain alone; to protect themselves. All participants continue to be afraid to reach out to people, they feel people will know that they're HIV positive. Two participants stated that it "seems as if it's written on my forehead that I'm HIV positive." Participants do not want to be hurt by the "ignorant" reactions of people. They state that in general people are rude and they

don't care whom they hurt. Participants in this study believed that society is uninformed about women living with HIV/AIDS and as a result women feared being categorized as prostitutes or intravenous drug users. All participants feel that they've had enough pain in their lives that they do not want to submit themselves to being further stigmatized.

Three of the five participants indicated there was no place for them to go for support. They only had their primary physician or nurse. They felt strongly that the existing support groups for gay men did not meet their needs. They expressed their uneasy feelings about being in groups with these individuals. They described themselves as not a "groupie type of person". They felt they could not relate with gay or Native men. One participant summarizes the participants' general feelings, that is "they have nothing to give me and I have nothing to offer them".

Disclosure

Three of the participants found it easier to disclose their diagnosis to their friends rather than family. With friends they could choose whom to tell; they had a choice. With family, they did not have that choice; they felt pressured to disclose. Generally speaking, these three participants found that their friends were initially shocked and afraid, but gradually, as they were provided with information, these friends were supportive. The select few individuals who were informed of the participants' illness were close friends, so participants felt confident they could

disclose to these individuals and not be judged or criticized. There remains however, one outstanding issue. No matter how close these friends became, HIV positive women still felt a need to protect them. They were reluctant to really tell them how things were; they did not want to overburden their friends or scare them away.

Two participants simply did not want to confide in any other individual. They were quite prepared to live in secrecy for the rest of their lives. They simply did not want anyone to know. They were afraid to be hurt and were not prepared to take any chances. They chose to lie about their disease rather than face the consequences of the truth. Lying about their disease however, was not uncommon amongst all participants when dealing with family, friends, or acquaintances.

Two of the participants had befriended other individuals living with HIV/AIDS. These relationships were a great source of support for them. However, these relationships became particularly difficult when the friend was afflicted with a debilitating disease or when the friend died. Both women stated they could not visit these individuals in hospital, nor could they attend the funeral. It became too difficult for them to cope with their own disease. They identified with these individuals and it became a destructive force in their lives.

Coping with HIV/AIDS

All participants dealt with their disease by "taking it one day at a time". There were "some good days and bad days", but all believed in a power greater than themselves, which made difficult times easier to live through. All participants turned to prayer or meditation in one form or another as a means of transcending the disease. One participant described being grateful for her disease because it had allowed her to "more fully realize herself".

Another participant grieved her losses. She described that she would never be the same. She stated that she "felt beaten and other times just destroyed". She added "I'm not the same person; I'm not as outgoing as I was, and I don't participate in life any more". Nevertheless, she stated that if this is God's wish then so be it. She would accept what she must live through and God will help her through it.

Throughout the interviews with all the participants, it became evident that they had come to terms with dying. Upon the initial awareness of their disease there was considerable fear of dying, but as their illness progressed there was an acceptance that death was a part of living. The acceptance came about in part because of the uncertainty and unpredictability of the disease, but mostly because they had placed their lives in the hands of a greater being.

Summary

The thematic analysis of the verbatim transcripts of HIV positive women allowed the investigator to capture the essence of the lived experiences of Winnipeg women living with HIV/AIDS. The lived experience was described in terms of health related issues, marital/partner relationship, child and family issues, occupation, social network, and coping with HIV/AIDS. The insight gleaned from the in-depth analysis of each of these major themes promoted a greater understanding of realities faced by HIV positive women.

One participant summarized these realities in stating "It doesn't matter if it's cancer, or MS, or AIDS, you inevitably are left holding the pieces of your shattered dreams, and you're looking at things in a totally different perspective and what was important to you then, isn't now, and what you think of as being important now, are not the values that everyone else holds; it's not what everybody else thinks you should be doing, it's what you feel you need to do for yourself".

CHAPTER 5

DISCUSSION

This chapter will focus on the discussion of the themes as presented in the previous chapter. Results reported in the literature will be further discussed in relation to the findings of this study. The relationship of the conceptual model to the findings of the study will be addressed. Limitations of the study will be recognized and recommendations for nursing practice, education, and research will be elaborated.

Health related issues

Findings from this study partially substantiate the concept that is pervasive in the literature. More specifically that women's health care issues have received less attention than those of men, in particular as it relates to HIV/AIDS (Denenberg, 1990; Makie, 1993; Marte & Allen, 1991; Smeltzer, 1992).

According to the literature, women are often not diagnosed (Buehler, Hanson, & Chu, 1992, Schoenbaum, Mayris & Webber, 1993), or treated until serious complications occur (Denenberg, 1990; Holloway, 1994).

It was shown in this study that an individual had not been diagnosed until she was admitted to the hospital with complications of AIDS. Two and a half years later, in January 1996, this individual died. Based on her history, it was suspected that she might have been infected four to five years prior to her diagnosis. This

individual had a long history of blood dyscrasia. She had been closely monitored, but in fact had not been tested for AIDS. One can only hypothesize that her survival rate would have increased had she received treatments in the early phase of the disease. It is interesting to note however, that this individual never blamed the health care system for the misdiagnosis. She recognized that this situation could have happened to anyone, whether male or female.

In the unfolding of the data analysis it became apparent that the majority of women felt that health care professionals were uninformed of the manifestations and impact of HIV/AIDS on women's health. It should also be emphasized however, that the findings demonstrated that this was true of health care professionals four to six years ago. It would appear that specialists in the field have gained significant knowledge in the domain of women and HIV/AIDS. Women with a more recent diagnosis believe that specialists in the field are knowledgeable in this domain. This may not extend however, to the majority of individuals who provide direct hands on care to people living with HIV/AIDS.

The findings of this study demonstrate that access to HIV/AIDS resources for women in Manitoba is limited. This may be due in part to the geographical location and to the relatively few number of infected women in Manitoba. Some women in the study did access information from the larger centres in Canada and the United States.

Interestingly enough, the findings did reveal that women felt discriminated against in the health care system. It appears however, that this is not necessarily related to their gender, but rather to the disease. Descriptors such as "abused by the system, treated less than human, rude, uncaring" surfaced in discussions related to care provided by nursing staff and auxiliary personnel. As evidenced in the findings, there was a strong belief that staff continue to be afraid of the disease and they do not want to deal with their fears.

In contrast to previous research on the topic (Hellinger, 1993), the majority of women did not have problems accessing health services. Women were not discouraged from being tested for the virus and once diagnosed for HIV they did not experience difficulties receiving medical attention. Gynecological problems although common, were recognized and promptly treated. In fact the participants were satisfied that specialists in the field were trying their utmost to consider their circumstances as women in the choice of treatments.

Reasons which may contribute to the difference in the findings of this study with previous research in the United States may be related to the differences between the Canadian and the American health care system. In Canada health services are more readily available to the population at large, while in the United States this is not necessarily so. Another important consideration may be that healthcare providers are becoming more informed on the psychobiological impact

of HIV/AIDS in women. Another contributing factor appears to be that physicians and clinical nurse specialists are keeping abreast of the newest research and literature on the topic.

Another important finding congruent with other research (Semple et al., 1993; Gaskins & Brown, 1992), is that an HIV diagnosis was a traumatic event in the lives of these HIV positive women. The response was described as one of anguish and shattered dreams. The shock, disbelief, and devastation that occurred was profound. Women experienced a psychological struggle as they attempted to overcome the reality of their situation. Women began a long journey of reevaluating their lives, that is their past, present, and future.

Another important factor associated with learning of one's seropositivity is the fact that the majority of women did not perceive themselves at risk for contracting the virus. This concept is pervasive in past research and in the literature (Christian & Susser, 1989; Glenn, Nance-Spronson, McCartney, & Yesalis, 1990; Haynes, 1993; Crouse Quinn, 1993; Shayne & Kaplan, 1991; Kinsey, 1994; McNicol, Hadersbeck, Dickens, & Brown, 1991). This attitude has the tendency to intensify the response to the initial diagnosis. The majority of women had difficulty understanding how they could have contracted a "gay man's disease". Women did not have the information to deal effectively with preventative

strategy. It was not apparent in this study as suggested in past research (Glenn et al., 1993) that women chose to deny their risks.

In comparing the findings of this study to observations in the literature on reproductive choices, it is important to note that indeed, women feel a heavy onus of moral responsibility when making reproductive decisions. This study revealed that women were so traumatized at the prospect of infecting their child that they categorically made a decision to forego childbearing altogether. It was with sadness and resignation that these women faced the prospects of a childless future. Once the decision was taken however, these women did not look back. They forged ahead and explored other avenues in their lives to provide a sense of worth and fulfillment.

Marital/partner relationship

Another finding which is congruent with the literature revealed that the majority of HIV positive women were interested in a relationship, but felt discouraged at the prospects of a meaningful intimate relationship. They described the desire or the wish for a relationship as an exercise in futility, for they could not compete for a partner. Women questioned their femininity. They felt dirty, unattractive, and unwanted. They firmly believed that they had lost their sexual appeal. They were confused about the risks involved with sexual activity.

Generally speaking women were resigned to lead celibate lives.

In examining research addressing the issues of HIV positive women involved in monogamous relationships, the findings of this study were consistent with results from other studies. More specifically, one HIV positive woman in this study reported her spouse was more supportive than she expected. She described him as being a caring and loving partner. However, concerns were surfacing related to his desire to remain in the marriage. There were specific aspects of his comportment that she could not understand. Certainly from the investigator's perspective the spouse appeared to be withdrawing from the relationship.

A significant finding not previously reported in the literature relating to relationships, is the loss of anonymity. Even though HIV positive women desire an intimate relationship, there is some reluctance in becoming involved. The fear of disclosure, of being discovered as an HIV positive woman was so great that the majority of women did not wish to risk becoming involved. They were afraid of being subjected to more pain and suffering.

Child and family issues

Previous research and literature acknowledge the importance of child and family issues in the lives of HIV positive women. Findings in this study strongly support findings from past research. Child and family issues are difficult and complex. Disclosing HIV status to children and family members, child rearing

issues, concerns with the future guardianship of children were significant in the lives of HIV positive women. Generally speaking, the women in this study demonstrated remarkable strength of character. Whether it was caring or being concerned for children, spouse, parents, or siblings, it was clearly demonstrated that women strongly valued the need to nurture, protect, and console their significant others.

Other observations worth noting is that HIV positive women report disclosing to family members is a stressful event. They feared abandonment and or rejection from family members. It became apparent that women greatly needed family support and approval to promote their psychological health.

Disclosure to children was a significant issue for the HIV positive mother in this study. This individual desperately wanted to protect her children from suffering and worries about the future and against the social stigma associated with the HIV infection. She feared the negative ramifications this might have on the psychological health and well-being of her children. She dreaded the potential behavioral changes in her children, as well as the potential or eventual change in the mother-children relationship.

This single mother was also encountering many difficulties in making decisions and concrete plans for the future of her children. She was torn with the anxiety of separating from her children and having to face the reality. These

concepts are well supported in the literature (Clark et al., 1993; Pinch, 1993; Semple et al., 1993).

Pinch (1993) states that women must display remarkable strength in caring for and supporting their families even though their own needs for care and support are not being met. Certainly this was the case in the majority of circumstances in this study. The findings demonstrated that as a result of their roles, women dreaded the debilitating outcome of this disease, as they feared becoming dependent on their partner, family, and/or children. Women were genuinely concerned about requiring care from their loved ones. They also chose to ignore the difficulties they were having with these issues. They did not want to deal with the painful realities of what might be.

Occupation

Another important finding congruent with research by Semple et al. (1993) reveals that occupation is an area of concern for HIV positive women. Individuals infected with HIV did not appear to have the physical stamina to maintain full time employment. In fact one of the participants had to terminate her employment for that very reason. Women in this study perceive that they are being discriminated against in the workforce, in that places of employment are not agreeable to part time work particularly, if employers are informed of the reason. The majority of participants felt they would have to lie about their disease to obtain a paid position.

Social network

As reported in the literature, Stuntzer-Gibson (1991) and Summers (1994), describe women as being a diverse group culturally, economically and spiritually, and they have a wide range of sexual gender roles and family configurations. The women in this study represented a broad range of cultural, spiritual, and socio-economic groups. Although there are only thirty-eight women living with HIV/AIDS in the province of Manitoba, none of the five women in this study, who all lived in Winnipeg, knew of one another. Findings revealed that women were isolated, secretive, and preferred not to be visible. It was clear that women felt very alone with their disease. This was particularly evident in relation to a woman from a different ethnocultural community who felt extreme isolation as someone who was not a part of mainstream society. It became apparent that the greater the perception of stigmatization and discrimination, the greater the isolation.

The message was loud and clear from HIV positive women. They have nowhere to go for support other than to their primary care providers. The guilt experienced from the lying, the disclosure, and the lack of community amongst HIV positive women promotes their isolation and vulnerability. This further renders women more susceptible to stigmatization, discrimination, rejection, and abandonment.

The findings showed that the majority of women perceive AIDS support groups as being for gay men and feel that these services are not appropriate for them. Women described themselves as preferring one-on-one conversations rather than meeting in groups. The majority of women had a difficult time relating to groups and they did not appreciate coming together to talk about their illness.

Coping with HIV/AIDS

An important factor not discussed in the literature is how women cope with their disease. In this study the findings revealed that these women appeared to deal with their disease from the perspective that there is a greater power or being that controls life. These women appeared to have the capacity to transcend their disease and move beyond, into a spiritual dimension of being. It should be emphasized that all individuals in this study were able to find a means of expressing that spirituality in unique ways so as to respond to their physical and emotional needs.

Conceptual model

Mandala Model of Health

Keen (1975) states that the investigator must avoid categorizing a phenomenon within the context of a known theory or concept (as cited in Knaak, 1984). Although the Mandala Model of Health (Hancock, 1985) was selected, the

purpose of the model was not to guide the research process in any way, but rather it was used as a measure by which to compare the findings of the study. In addition, it appeared that the model was broad enough so as not to constrain the richness and depth of the lived experiences of women with HIV/AIDS. Furthermore, it seemed to be congruent with the assumptions of phenomenology.

Interestingly enough, the findings of this study demonstrated that indeed to fully understand the lived experiences of women living with HIV/AIDS, they must be viewed within the broader context of the community, the environment, and the culture (biosphere). The five participants in this study came from different social, cultural, and economic backgrounds. This influenced how they interacted with the health care system, the community, and their families. One participant had recently immigrated to Canada, she had lived her life in poverty, isolation, and had seen the devastation of the HIV epidemic. This woman's experiences differed greatly from another participant who had been an intravenous drug user, or a young woman who had been sexually abused as a child, or a Causcasian woman who had led a comfortable affluent lifestyle. All these women were diagnosed with HIV infection, but each one of them experienced their illness within the context of the world around them.

Their culture, socialization process, influences from family and friends, social status, where they lived, whom they socialized with, all influenced how the

women in this study perceived themselves and how they coped and lived with their illness. The Mandala Model of Health provided the framework to obtain a greater understanding of the lived experiences of Winnipeg women living with HIV/AIDS.

Study limitation

This descriptive, exploratory study's small sample of five women had a limitation that has affected the nature of the data as well as the interpretation of the findings. In addition, all five women had diverse cultural, economical, and family structures. Although most of the time each category or theme that emerged from the data analysis was strongly supported by the interview data, in other instances the interpretation was based on only one or two participants' stories. The intent of the study however, is not for predictive purposes or for generalizations to all HIV positive women.

Recommendations for nursing practice and education

Findings from this study support the recommendation that nurses who provide bedside care develop a better understanding of the manifestations and impact of HIV/AIDS in women. Nurses hold key positions as women's advocates in the health care system. In order to fulfill that role continuing education must be

pursued. Several measures would allow staff to increase their expertise and knowledge in this field: the provision of workshops and inservices; the inclusion of this topic in course curricula; and keeping current with the latest literature.

Nurses need to be aware that women living with HIV/AIDS are an invisible and vulnerable group. Nurses need to play a role in moving these women out of isolation and integrating them within the AIDS community. Armed with education, skills, and compassion, nurses can be proactive in program development and ensuring that services will be responsive to the needs of this population.

Recommendations for nursing research

A number of research recommendations arise from this study. Within the Manitoba context, further research relating to all aspects of HIV/AIDS in women is necessary. This could encompass research in areas of female-specific manifestations of the disease, participation in screening to detect early signs and symptoms of the illness, participation of women in clinical trials, the impact of the disease on HIV positive women in our society, women's coping mechanisms, and effects on their mental health and well-being. Essentially any research in Manitoba addressing the topic of women and HIV/AIDS is desperately needed.

Summary

This phenomenological study explored and described within the Manitoba context: a) the essence of the lived experience of five Winnipeg women surrounding living with HIV/AIDS, b) the needs of women living with HIV/AIDS, and c) women's perceptions as to whether their needs are being met. The richness of the collected data provided for an in-depth discussion as to the everyday issues and concerns in the lives of these women.

The majority of the findings from this study validated the results from prior research and a few new discoveries emerged. Based upon this study's findings and the investigators personal observations and experience in the field, the investigator concurs with Chung and Magraw's (1992) conclusion that women's experiences of HIV/AIDS is inseparably linked to their experiences as women.

The findings of this study "fit" exceptionally well within the conceptual framework of the Mandala Model of Health. This may be due to the study's methodology creating room for expression of all levels of the human in the context of the community and the world.

Although these research findings cannot be generalized to a larger population of HIV positive women, some valuable information was obtained that may sensitize health professional and the public at large to the trials and tribulations in the lives of women living with this incurable disease. Most

importantly, this study has provided the opportunity for five Winnipeg women's experiences to be heard.

This chapter also described the implications for nursing practice, education, and research. By obtaining the necessary knowledge and expertise, health care providers will be in a better position to provide culturally sensitive care to Manitoba women living with HIV/AIDS.

References

- AIDS Working Group on HIV Infection and Mental Health. (1992, December). HIV disease and mental health. Canada's Mental Health, 26-32.
- Anderson, J. M. (1989). The phenomenological perspective. In J. M. Morse (Eds.), Qualitative Nursing Research: A contemporary dialogue. Rockville, Maryland: Aspen Publishers.
- Arras, J. D. (1990). AIDS and reproductive decisions: Having children in fear and trembling. The Milbank Quarterly, 68(3), 353-382.
- Benner, P. (1984a). From novice to expert: Excellence and power in clinical nursing practice. Don Mills, Ontario: Addison-Wesley.
- Benner, P. (1984b). Stress and satisfaction on the job: Work meanings and coping of mid-career men. New York: Praeger.
- Benner, P. (1985). Quality of life: a phenomenological perspective on explanation, prediction, and understanding in nursing science. Advances in Nursing Science, 8(1), 1-14.
- Benner, P. (1994). Interpretive phenomenology: Embodiment, caring, and ethics in health and illness. Sage Publications: New Delhi.
- Benner, P. & Wrubel, J. (1989). The primacy of caring: Stress and coping in health and illness. Menlo Park, California: Addison-Wesley.

Bradley-Springer, L. A. (1994). Reproductive decision-making in the age of AIDS. Image: Journal of Nursing Scholarship, 26(3), 241-246.

Brody, L. (1992, November). 3 faces of AIDS: Portraits of women infected by their lovers. Shape, 114-119.

Buckingham, S. L., & Rehm, S. J. (1987, Winter). AIDS and women at risk. Health and Social Work, 5-11.

Buehler, J. W., Hanson, D. L., & Chu, S. Y. (1992). The reporting of HIV/AIDS deaths in women. American Journal of Public Health, 82(11).

Carovano, K. (1991). More than mothers and whores: Redefining the AIDS prevention needs of women. International Journal of Health Services, 21(1), 131-142.

Carter, B. J. (1989). A phenomenological study of survivors of adult cancer. Unpublished doctoral thesis. University of California, San Francisco.

Chesla, C. (1988). Parents' caring practices and coping with schizophrenic offspring, an interpretive study. Unpublished doctoral dissertation, University of California, San Francisco.

Chung, Y. J., & Magraw, M. M. (1992). A group approach to psychosocial issues faced by HIV positive women. Hospital and Community Psychiatry, 43(9), 891-894.

Christiano, A., & Susser, I. (1989). Knowledge and perceptions of HIV infection among homeless pregnant women. Journal of Nurse-Midwifery, 34(6), 318-322.

Clark, R., Hankins, C. A., Hein, K., Mitchell, J. L., & Williams, A. B. (1993). HIV: What's different for women? Patient Care, 119-149.

Cohen, M. Z. (1987). A historical overview of the phenomenological movement. IMAGE: Journal of Nursing Scholarship, 19(1), 31-33.

Crouse Quinn, S. (1993). Perspective AIDS and the African woman: The triple burden of race, class, and gender. Health Education Quarterly, 20(3), 305-320.

deBruyn, M. (1992). Women and AIDS in developing countries. Soc. Science, Medicine, 34(3), 249-262.

Denenberg, R. (1990). Women and HIV illness: What should we be looking for? PWA Coalition Newslines, 59, 20-26.

Dorfman, L. E., Derish, P. A., & Cohen, J. B. (1992, Spring). Hey Girlfriend: An evaluation of AIDS prevention among women in the sex industry. Health Education Quarterly, 19(1), 25-40.

Easton, B. (1992). Women and AIDS. Healthsharing, 12-18.

Faulstich, M. E. (1987). Psychiatric Aspects of AIDS. American Journal of Psychiatry, 144(5), 551-556.

Fineberg, H. V. (1988, October). The social dimensions of AIDS. Scientific American, 128-134.

Flaskerud, H. J. (1987). Psychosocial aspects of AIDS. Journal of Psychosocial Nursing and Mental Health Services, 25(12), 9-16.

Flaskerud, H. J., & Thompson, J. (1991). Beliefs about AIDS, health, and illness in low-income white women. Nursing Research, 40(5), 266-271.

Flaskerud, H. J., & Ungvarski, J. P. (1992). HIV/AIDS: A guide to nursing care (2nd ed.). Philadelphia, Pennsylvania: W. B. Saunders Company.

Gaskins, S., & Brown, K. (1992). Psychosocial responses among individuals with human immunodeficiency virus infection. Applied Nursing Research, 5(3), 111-121.

Gilligan, C. (1982). In a different voice. Cambridge, Massachusetts: Harvard University Press

Glenn, P. S. F., Nance-Spronson, L. E., McCartney, M., & Yesalis, C. E. (1990). Attitudes toward AIDS among a low-risk group of women. JOGNN, 20(5), 398-405.

Haines, J. (1991, February). Women and AIDS. The Canadian Nurse, 15-17.

Hancock, T. (1985). The mandala of health: A model of the human ecosystem. Family and Community Health, 1-10.

Hankins, C. A., & Lapointe, N. (1990, June). Pregnancy, AIDS and the newborn. Medicine North America, 966-971.

Hankins, C. (1995, July). AIDS: What is happening with women? The Canadian Journal of CME, 37-42.

Haynes, L. Y. (1993). A women's issue: HIV/AIDS. Perspectives in Psychiatric Care, 29(1), 23-25.

Health and Welfare Canada. (1990). Women and AIDS: A challenge for Canada in the nineties. Ottawa: Minister of Supply and Services.

Health Canada. (1995). Quarterly surveillance update: AIDS in Canada. Ottawa: Minister of Supply and Services.

Heidegger, M. (1962). Being and time. New York: Harper and Row.

Hellinger, F. J. (1993). The use of health services by women with HIV infection. Health Services Research, 28(5), 544-561.

Houde-Quimby, C. (1994). Women and the family of the future. JOGNN, 23(2), 113-123.

Holloway, M. (1994). Trends in women's health: A global view. Scientific American, 271 (2), 76-83.

Hutchison, M., & Kurth, A. (1991). "I need to know that I have a choice... ": A study of women, HIV, and reproductive decision-making. AIDS Patient Care, 17-25.

Hutchison, M., & Kurth, A. (1990). Reproductive health policy and HIV: Where do women fit in? Pediatric AIDS and HIV Infection, 1(6), 121-133.

Johnston, C. (1994). Many Canadians unaware of AIDS' impact on women. Canadian Medical Association Journal, 150(2), 247-249.

Jones, A. D. (1991). HIV-seropositive childbearing women: Nursing management Journal of Obstetric, Gynecology, and Neonatal Nursing, 20(6), 446-452.

Kinsey, K. K. (1994). "But I know my man!" HIV/AIDS risk appraisals and heuristical reasoning patterns among childbearing women. Holistic Nurse Practitioner, 8(2), 79-88.

Kline, A., Kline, E., & Oken, E. (1992). Minority women and sexual choice in the age of AIDS. Soc. Sci. Med., 34(4), 447-457.

Knaak, P. (1984). Phenomenological research. Western Journal of Nursing Research, 6(1), 106-114.

Krieger, N., & Margo, G. (1991). Women and AIDS: Introduction. International Journal of Health Services, 21(1), 127-130.

Leonard, V. W. (1989). A Heideggerian phenomenologic perspective on the concept of the person. Advanced Nursing Science, 11(4), 40-55.

Levine, C., & Neveloff Dubler, N. (1990). Uncertain risks and bitter realities: The reproductive choices of HIV-infected women. The Milbank Quarterly, 68(3), 321-350.

Lincoln, Y. S. & Guba, E. G. (1985). Naturalistic inquiry. London: Sage Publications.

Linn, J. G., Anema, M. G., Estrada, J. J., Cain, V. A., & Usuh, D. M. (October, 1994). HIV illness and mental distress in female clients of AIDS care and referral centers. AIDS Patient Care, 254-259.

LoBiondo-Wood, G., & Haber, J. (1990). Nursing research: Methods, critical appraisal, and utilization (2nd ed.). St. Louis: The C. V. Mosby Company.

Mackie, D. I. (1993). AIDS, the female patient, and the family physician. Canadian Family Physician, 39, 1600-1607.

Manitoba Health Report. (1995). HIV/AIDS in Manitoba. Winnipeg: Communicable Disease Control, Manitoba Public Health Branch.

Marte, C., & Allen, M. (1991). HIV-related gynecologic conditions: overlooked complications. Focus: A Guide to AIDS Research and Counselling, 7(1), 1-4.

McCoy, H. V., & Inciardi, A. J. (1993). Women and AIDS: Social determinants of sex-related activities. Women & Health, 20(1), 69-84.

McNicol, L. B., Hadersbeck, R. E., Dickens, D. R., & Brown, J. E. (1991). AIDS and pregnancy: Survey of knowledge, attitudes, beliefs, and self-identification of risk. JOGNN, 20(1), 65-72.

Norr, K. F., McElmurry, B. J., Moeti, M., Tlou, S. D. (1992). AIDS prevention for women: A community-based approach. Nursing Outlook, 40(6), 250-256.

Novello, A. (1991). Women and HIV infection. JAMA, 265(14), 1805.

Nyamathi, A., Bennett, C., Leake, B., Lewis, C., & Flaskerud, J. (1993). AIDS-related knowledge, perceptions, and behaviors among impoverished minority women. American Journal of Public Health, 83,(1), 65-71.

Nyamathi, A., Leake, B., Flaskerud, J., Lewis, C., & Bennett, C. (1993). Outcomes of specialized and traditional AIDS counseling programs for impoverished women of color. Research in Nursing & Health, 16, 11-21.

Oiler, C. (1986). Phenomenology: The method. In P. Munhall and C. Oiler (Eds.), Nursing research: A qualitative perspective. Norwalk, Ct: Appleton-Century Crofts.

Oiler, C. (1981). The phenomenological approach in nursing research. Nursing Research, 31(3), 178-181.

Omery, A. (1983). Phenomenology: a method for nursing research. Advances in Nursing Science, 5, 49-63.

Pinch, W. J. (1993). Vertical transmission in HIV infection/AIDS: A feminist perspective. Journal of Advanced Nursing, 19, 36-44.

Polit, F. D., & Hungler, P. B. (1991). Nursing research: Principles and methods (4th ed.). Philadelphia: J. B. Lippincott Company.

Schoenbaum, E. E., Mayris, P., & Weber, M. P. (1993). The under recognition of HIV infection in women in an inner-city emergency room. American Journal of Public Health, 83(3), 363-368.

Shayne, V. T., & Kaplan, B. J. (1991). Double victims: Poor women and AIDS. Women & Health, 17(1), 21-37.

Shroff, F. M. (1991). The social construction of AIDS, heterosexism, racism and misogyny: And the challenges facing women of colour. RFR/DRE, 20(3/4), 115-121.

Semple, J. S., Patterson, L.T., Temoshok, R. L., McCutchan, J. A., Straits-Tröster, A. K., Chandler, L. J., & Grant, I. (1993). Identification of psychobiological stressors among HIV positive women. Women & Health, 20(4), 15-36.

Smeltzer, C. S. (1992). Women and AIDS: Sociopolitical issues. Nursing Outlook, 20(4), 152-156.

Stuntzer-Gibson, D. (1991). Women and HIV disease: An emerging social crisis. Social Work, 36(1), 22-28.

Summers, M. (1994). Women and HIV/AIDS: An overview. A seminar on Women in Transition, Women's Programs:AIDS Vancouver, 1-18.

Taylor, C. (1985). Human agency and language: Philosophical papers I. New York: Cambridge University Press;

Taylor, D. (1990). Women and AIDS. Healthsharing, 1-6.

The AIDS Report (1993). Women living with AIDS. Cambridge: Harvard AIDS Institute.

Van Manen, M. (1990). Researching lived experience: Human science for an action sensitive pedagogy. London, Ontario: The Althouse Press.

Wagner, J. (1979). Images of information. London: Sage Publications.

Wiener, S. L. (1991). Women and human immunodeficiency virus: A historical and personal psychosocial perspective. Social Work, 36(5), 375-378.

Whipple, B. (1992). Issues concerning women and AIDS: Sexuality. Nursing Outlook, 40(5), 203-206.

Williams, B. A. (1992). The epidemiology, clinical manifestations and health maintenance needs of women infected with HIV. Nurse Practitioner, 17(5), 27-41.

Williams, B. A. (1991). Women at risk: An AIDS educational needs assessment. Image: Journal of Nursing Scholarship, 23(4), 208-213.

Wofsy, C. B. (1988). Women and the acquired immunodeficiency syndrome: An interview. Western Journal of Medicine, 149, 687-690.

APPENDIX A

**1993 Revised CDC Case definition for HIV infection and AIDS
(Adolescents and Adults)**

CD4 T-cell categories	A Asymptomatic, acute (primary) HIV or PGL	B Symptomatic not (A) or (C) conditions	C AIDS-indicator conditions
1. $\geq 500/\mu\text{l}$	A1	B1	C1
2. 200-499/ μl	A2	B2	C2
3. $< 200/\mu\text{l}$	A3	B3	C3

Category A:

- Asymptomatic HIV Infection
- Persistent generalized lymphadenopathy
- Acute (primary) HIV infection with accompanying illness or history of acute HIV infection.

Category B:

- Bacillary angiomatosis
- Candidiasis, oropharyngeal
- Candidiasis, vulvovaginal; persistent or poorly responsive to therapy
- Cervical dysplasia (moderate or severe)/cervical carcinoma in situ
- Constitutional symptoms (eg: fever $\geq 38.5^\circ\text{C}$, or diarrhea lasting > 1 month)
- Oral Hairy Leukoplakia
- Herpes Zoster (shingles), involving at least two distinct episodes or more than one dermatome.
- Idiopathic thrombocytopenic purpura
- Listeriosis
- Pelvic inflammatory disease, particularly if complicated by tubo-ovarian abscess
- peripheral neuropathy
- other (specify) _____

(For classification purposes category B conditions take precedence over category A. Therefore a person who is no asymptomatic after receiving treatment for oral thrush would still be classified in clinical category B)

Category C: (AIDS defining conditions)

- Candidiasis of bronchi, trachea, or lungs
- Candidiasis, esophageal
- Cervical cancer, invasive
- Coccidioidomycosis, disseminated or extrapulmonary
- Cryptococcosis, extrapulmonary
- Cryptosporidiosis, chronic intestinal (> 1 month's duration)
- Cytomegalovirus disease (other than liver, spleen, or nodes)
- Cytomegalovirus retinitis (with loss of vision)
- Encephalopathy, HIV related
- Herpes simplex: chronic ulcer(s) (> 1 month's duration) or bronchitis, pneumonitis or esophagitis.
- Histoplasmosis, disseminated or extrapulmonary
- Isosporiasis, chronic intestinal (> 1 month's duration)
- Kaposi's sarcoma
- Lymphoma, Burkitt's (or equivalent term)
- Lymphoma, immunoblastic (or equivalent term)
- Lymphoma, primary, of brain
- *Mycobacterium avium* complex or *Mycobacterium kansasii*, disseminated or extrapulmonary.
- *Mycobacterium tuberculosis*, any site
- *Mycobacterium*, other species or unidentified species, disseminated or extrapulmonary
- *Pneumocystis carinii* pneumonia
- Pneumonia, recurrent
- Progressive multifocal leukoencephalopathy
- *Salmonella* septicemia, recurrent
- Toxoplasmosis of brain
- Wasting syndrome due to HIV

APPENDIX B

LETTER OF INVITATION

A study is being conducted by Suzanne Nicolas, Masters of Nursing student at the University of Manitoba. The study has been approved by the Ethical Review Committee of the Faculty of Nursing.

The purpose of the study is to obtain an understanding of the unique issues faced by Manitoba women living with HIV/AIDS. You are invited to be in this study to share your experiences of what it is like for you to be living with HIV/AIDS. Your story is valuable in trying to understand what women go through when they have this disease. There may be no direct benefits for you by participating in this study, but the results of the study may help health care providers and the public to better understand what women go through. It may also help to develop better services to Manitoba women in the future.

This letter of invitation is being given to you by your doctor or your nurse where you are being treated so that your identity is confidential and not known to the investigator. Your participation in this study is entirely voluntary and will in no way affect the care you are presently receiving, or the care you will receive in the future. The first five people who volunteer will be included in the study.

Participating in this study would mean agreeing to two tape-recorded face to face interviews with Suzanne. The interviews would last about one to two hours at your home or in another quiet place of your choice. You may choose to end the interviews sooner, or the tape recorder can also be switched off at your request. If you would like to be more involved in the study, a camera with film will be given to you and you will be asked to photograph anything that is meaningful to you in your life. During a second interview with Suzanne you will talk about what these pictures mean to you. In the event that you have not taken any photos the second interview will consist of reviewing with Suzanne the notes from the first interview and you may add other things that might have come to mind.

There will be no financial costs to you for the camera, film, or film development. At the end of the study you will be able to keep the photographs if you wish to have them, otherwise, Suzanne will keep them in a locked file

All of the information that you provide to Suzanne during the interview(s) will be entirely confidential and anonymous. Your name will not appear anywhere; a code number will be assigned to your name and this information will be kept separately in a locked filing cabinet. Suzanne's supervisor from the University of Manitoba, Faculty of Nursing, will have access to the information, but she will not have

access to the list of names of participants and corresponding codes. Your name will not appear on any reports about the study or in future publications. The data will be kept in a locked file for seven to ten years and then destroyed.

Please feel free to call Suzanne Nicolas at _____ or her supervisor Dr. Erna Schilder at the Faculty of Nursing, University of Manitoba at _____ if you have any questions. If you would be willing to participate in this project, please return the attached form by November X in the self-addressed stamped envelope attached to this letter. If you indicate an interest in participating and have been randomly selected for the study, you will receive a telephone call from Suzanne by November X to further explain the project and set up an interview.

Thank you for your consideration.

Suzanne Nicolas RN/BN

--
I would be interested in participating in the study which looks at the experiences of Manitoba women living with HIV/AIDS.

Name _____

Address _____

Telephone number _____

The best time to reach me is _____

Please return in the self-addressed envelope enclosed with this letter.

APPENDIX C
LETTER OF ACCESS PERMISSION
TO HEALTH CARE PROVIDERS/CLINICS

October X, 1995

XXXXXXXXXXXXXXXXXX
Winnipeg, Manitoba
XXXXXXXXXXXXXXXXXX

Dear _____:

I am a Masters of Nursing student at the University of Manitoba and plan to conduct my thesis research: The lived experiences of Manitoba women with HIV/AIDS, with clients in your practice/clinic. The study has been approved by the Ethical Review Committee of the Faculty of Nursing.

The purpose of the study is to obtain an understanding of the unique issues faced by Manitoba women living with HIV/AIDS. More specifically, the objectives of the study are to explore a) women's experiences surrounding living with HIV/AIDS, b) the needs of Manitoba women living with HIV/AIDS, c) women's perceptions as to whether their needs are being met, and/or how their needs could be met.

The sample will consist of five Manitoba women living with HIV/AIDS. The inclusion criteria are quite broad, related to the inaccessibility of that population and the small number of women living with the disease. Criteria for eligibility will be women having a confirmed diagnoses of HIV or AIDS; they may or may not be symptomatic. The participants must have the ability to speak English or French and must be able to articulate their experiences.

I would greatly appreciate your cooperation in distributing the letter of invitation to clients who meet the above mentioned criteria. Enclosed you will find a copy of the letter of invitation with a self-addressed stamped envelope.

Thank you for your attention and participation.

Sincerely,

Suzanne Nicolas

**APPENDIX D
ETHICAL REVIEW COMMITTEE APPROVAL FORM**

The University of Manitoba

FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N#95/48

Proposal Title: "THE LIVED EXPERIENCES OF MANITOBA WOMEN WITH HIV/AIDS."

Name and Title of
Researcher(s):

SUZANNE J. M. NICOLAS RN, BN
MASTER OF NURSING GRADUATE STUDENT
FACULTY OF NURSING, UNIVERSITY OF MANITOBA

Date of Review: OCTOBER 2, 1995

APPROVED BY THE COMMITTEE: OCTOBER 2, 1995.

Comments: APPROVED WITH CHANGES AND CLARIFICATIONS SUBMITTED TO THE
CHAIR.

Date: OCTOBER 6, 1995.

Linda J. Kristjanson, PhD, RN
Associate Professor
University of Manitoba Faculty of Nursing

Chairperson

Position

NOTE:

Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

APPENDIX E

CONSENT TO PARTICIPATE

Purpose and objectives

A study is being conducted by Suzanne Nicolas, Masters of Nursing student at the University of Manitoba. The study has been approved by the Ethical Review Committee of the University of Manitoba, Faculty of Nursing. The purpose of the study is to obtain an understanding of the unique issues faced by Manitoba women living with HIV/AIDS. I have been invited to be in the study to share my experiences of what it is like for me to be living with HIV/AIDS. My story is valuable to the interviewer in understanding what women go through when they have this disease.

Procedures

If I agree to participate, I will be interviewed twice for 1-2 hours in my home or any other quiet place I may choose. I will be asked to tell my story about living with HIV/AIDS. If I agree to participate, I will have the opportunity to be provided with a camera if I so choose, and I will photograph things that are meaningful to me in my life. During a second interview, I will share with Suzanne why these pictures are important to me. I understand that the photos are mine to keep when the study is finished. In the event that I have not taken any photos the second interview will consist of reviewing with Suzanne the notes from the first interview and I may add other things that might have come to mind. I also understand that the interviews will be tape recorded and then further transcribed.

Confidentiality and Anonymity

I understand that all of the information that I provide to Suzanne during the interview(s) will be entirely confidential. My name will not appear on written notes, on the cassette tapes, in any reports or in publications of this study. A code number (e.g. 101) will be assigned to my name to maintain my confidentiality and anonymity. Only Suzanne and her supervisor, Dr. E. Schilder will have access to the information. The notes, cassette tapes, and transcripts of interviews will be kept in a locked file for seven to ten years and then destroyed.

Participation

My participation in this study is entirely voluntary and will in no way affect the care I am presently receiving or the care that I will receive in the future. If I decide to participate and then later want to withdraw, I am free to do that without any harmful effect.

Risks and Benefits

There may be no direct benefits to participating in this study, but the study results may help to increase the health care providers and the public's understanding of the unique issues faced by Manitoba women living with HIV/AIDS. This may promote the development of more appropriate and sensitive services to Manitoba women in the future.

I may experience some loss of privacy or feelings of being uncomfortable through participation in this study as a result of being interviewed. However, I understand that I do not have to share any information I do not feel comfortable with. Also I am free to request that the tape recorder be turned off, to end the interview or to withdraw from the study at any time.

In the event that the interview should cause uncomfortable feelings, I can ask to be referred to an appropriate resource such as a counselor.

Questions

I have had an opportunity to have all my questions answered to my satisfaction. Any additional questions I may have can be asked at any time by calling Suzanne Nicolas at telephone number _____. If I wish to speak to Suzanne's supervisor, Dr. Erna Schilder, I may call her at the Faculty of Nursing, University of Manitoba at _____.

Date _____

Participant's signature _____

Investigator's signature _____

I wish to receive a final report of this study: Yes _____ No _____

Mail to: Name _____

Address _____

APPENDIX F**POEM****GENNIE IN A BOTTLE**

There's a little girl, who doesn't live here anymore.
She was very happy to play outside, climb the trees.
Spin till she was dizzy and fell.
Dandelions were roses then.
Life was great, carefree, the way it should be!

Then the shadows came and darkness fell
on all her days and nights, and there was pain.
The tears they came every night and wouldn't go away
till the sandman came and swept her away.
No one heard her cry for help, no one cared, it seemed.

So she ran away, as far as she could go, until there was no more,
and there she hid in a dark corner, alone.
There was nothing, no light...no love...no life, and she wept.
Still no one heard her, no one came to help,
she was lost and confused.

Until one day, someone or something came, it wasn't man or woman,
it just was...Death draped in a cloak of dis-ease, it came to take
her away now, only death cared about the lost and forgotten.
She stood up and faced death, and all that meant,
she wasn't afraid anymore.

Then from within her heart shot a beam of brilliant light,
it formed into a woman, she watched in amazement
as she changed and grew, and became real.
The little girl now knew all life for before stood herself,
but older, grown up, a woman.

The older self reached out to the hurt little girl and said...
 "It is not your time for death! Where have you been little Gennie,
 I have looked everywhere, far and beyond,
 I couldn't find you till dis-ease showed me the way,
 we are together now, and I will protect you.
 I will wipe the tears from your eyes and kiss your booboo's better.

All I ask of you is to be yourself, to show what is real. You see truth and awe in
 all, and when you ran away, I had to grow up.
 Life didn't seem the same anymore.
 The sunshine in my heart was shadowed by shame.
 The tears became so great, I was swept away
 in a rushing current of pain and bitterness.

Now that we are whole again we can face anything together, and our
 love will illuminate even the darkest corners of the world."
 And Death stood there in agreement, Death turned and walked
 away taking with it all the pain and dis-ease

Once and for always the little girl and the woman were one,
 bound by love and honor.
 On the wings of the **GODDESS** the whole woman was taken back to life.
 Where the child within could once again feel the sunshine on her
 face, and life was great, as it should be.

And there in front of her, as in all her childhood dreams she was
 standing in a meadow of wildflowers, and a beam light shot forth
 from her heart and before the whole woman with pride and glee
 stood the child within ready to be free.

The whole woman took the child's hand and said "This meadow is just
 for thee, it flows as far as the eyes can see. You have not need
 to worry, you are protected and free. I will watch over and no one will enter but
 me. So be free my child in perfect love of life
 for you are whole and blessed. So mote it be.