# Weathering the storm: Women's experiences of living with HIV / AIDS

by

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# Abstract

The purpose of this ethnographic study was to explore women's experiences of living with HIV / AIDS. Five women diagnosed with HIV / AIDS were interviewed using an unstructured interview format. The interviews were analysed using an ethnographic approach (de Laine, 1997; Spradley, 1980). Three common themes emerged: feeling limited hope, experiencing inconsistent health care, and transforming from victim to advocate.

The research findings encapsulated the narratives of five women confronting the most difficult health challenge of their lives. Living with HIV / AIDS is a complex and powerful experience for these women, one that provided the impetus for them to embark on a journey of creative self-discovery.

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# Dedication

I dedicate this thesis to the five women who participated in this research project. Their stories have provided valuable information that is most useful to those infected and affected by the AIDS epidemic. I further dedicate this thesis to the Cuzzetto family and Dr. Christopher Morrant, whose love and unwavering support have given me the strength to complete this manuscript. You have all taught me a lot about the generosity of the human spirit and provided me with inspiration and patience at a very important time in my life.

# Chapter 1

## *Introduction*

The first publicly recorded cases of what was to become known as acquired immunodeficiency syndrome, or AIDS, were initially reported in the United States in June 1981. Two unusual illnesses, pneumocystis carinii pneumonia and a rare cancer of the blood vessels called kaposi's sarcoma, were reported in young homosexual men living in San Francisco, California. Then by early 1982, 159 cases of AIDS had been identified in the United States, Europe and Africa. However surveillance and prevention campaigns by public health experts focused upon men who had sex with men, despite early reports of women who tested positive for the human immunodeficiency virus (HIV), the virus responsible for AIDS. Later, when epidemiological statistics were available, one of the earliest reports of a woman dying from AIDS occurred in Europe in 1977 when Dr. Grethe Rask, a Danish physician practicing surgery in Zaire, died from pneumocystis carinii pneumonia as a result of AIDS. It is believed she contracted HIV from poor sterile techniques in the operating theatre. By the early 1990s it was clearly evident that the incidence of HIV/AIDS among women was increasing at a rapid rate globally, disproportionately affecting women in the developing world and marginalized and poor women in the global north. In Canada since 1985, women have accounted for 14.7% of cumulative positive HIV test reports and 8.4 % of total cumulative reported AIDS cases among adults (Health Canada, 2003).

I have continually engaged in gathering information about the disease to deepen my understanding and knowledge of my own illness of HIV. This process was augmented by my experiences as a volunteer in the education department of a local AIDS agency. In this role I observed increasing numbers of HIV positive women attending the organization requesting information on HIV / AIDS and using support services available to them. What caught my attention was the passionate desire and unyielding drive of these women to participate as volunteers in the agency. As a volunteer I had the opportunity to informally discuss with them their experiences of living with HIV / AIDS. I took time to sit and listen to their thoughts and feelings about living with the disease.

I became acutely aware of biased inferences about HIV/AIDS based on gender. Once diagnosed with HIV / AIDS, these women found it difficult to get medical information, drug treatment, counseling and support. As I attempted to understand these women's experiences with their disease, I noticed the glaring omission of women from scientific research.

If women were considered at all, they were perceived by researchers as the vectors and carriers of HIV disease passing the virus on to men who then became ill. The hypothesis developed by scientists was that the infected male, would then sexually transmit HIV / AIDS to another woman who would unknowingly pass on the virus to her unborn child. The plight of infected women has not changed dramatically in terms of research in the areas of prevention and treatment, as women continue to remain a low priority in HIV / AIDS research programs, interventions and policy debates. This raises the important question of the lack of knowledge of women living with HIV / AIDS and provided an impetus for my interest in this topic of inquiry.

### *Statement of the Problem*

Current epidemiological surveillance on HIV / AIDS states that women who test positive for HIV are among the fastest growing populations both in the Province of British Columbia as well as internationally (Health Canada, 2003). Until recently the primary focus of research studies, medical textbooks, and media accounts has been on men having sex with men, making the experiences of women with HIV disease seem almost nonexistent. This has led to serious consequences in that women have not been identified as a group at risk by the medical and scientific communities and often are diagnosed in advanced stages of HIV disease at which time their response to medical treatment may be extremely limited. While some research has been conducted on women's experiences of living with HIV / AIDS in the African American and Hispanic communities and communities which inject drugs, research remains limited in addressing the experiences of women more generally. The paucity of research and resultant effect on women's health cannot be overstated. An inquiry that attempts to understand the tribulations and problems that HIV positive women face could provide a deeper understanding of those infected and affected by HIV / AIDS.

### *Purpose of the Study*

The purpose of the research is to explore the experiences of women living with HIV / AIDS. It is hoped that by focusing on this topic a greater understanding of women's experiences of living with HIV / AIDS will be revealed. Such understanding will contribute to the gap in our knowledge of women's experiences of this disease. My research uses an ethnographic methodology, which is suitable for the study of individuals' experiences of health within the social and historical context (Spradley, 1979). A relative and integrative review of relevant literature on such experiences follows in chapter 2.

# Chapter 2

## *Review of the Literature*

### *Current Knowledge: Gender Inequities*

In my review of the current HIV /AIDS literature which focused on the experiences of women living with HIV/ AIDS, it became abundantly clear that only a small body of literature exists which actually deals with the health and related issues of these women. Since the beginning of the AIDS epidemic in the early eighties, the experiences of men living with HIV / AIDS has been the prime focus of those reporting and researching people suffering from the disease. Furthermore, the limited research currently available on women's *experiences* of living with HIV / AIDS, tends to focus on women within oppressed and marginalized groups such as sex trade workers, injection drug users and African-American and Latino populations within the United States of America. The epidemic of HIV has affected *every* demographic group for both men and women, as epidemiological research reveals (Health Canada, 2003). However, gender inequities stand out in the literature in terms of attention given to women living with HIV / AIDS. For example, in terms of accessing quality health care, Bell (1997) states:

> The lack of focus on women in this epidemic in conjunction with the traditional neglect of women's health issues in general and women's inferior social and economic status places women with AIDS at a disadvantage in terms of accessing and receiving quality health care. (p.1519)

Jackson et al.'s (1999) research on Canadian women and HIV prevention concluded that "much of what we know about HIV / AIDS is based on research from cohorts of gay and bisexual men" (p. 308). Weitz (1993) suggested that a gender bias influenced both a deficiency in the literature as well as inadequate health care for women. Weitz also suggested that difficulty in receiving an accurate diagnosis due to limited access to treatment and hospice care can lead to an earlier death for women from AIDS. Similarly Metcalfe, Langstaff, Evans, Patterson and Ried (1998) state: "Treatment protocols for women with HIV have been based on studies and clinical trials where the subjects were male. This is due to under-recognition that HIV is also a female disease, and perceptions that female subjects complicate research" (p. 31).As I indicated in chapter one, the paucity of research and resultant effect on women's health cannot be overstated. Many women *are* diagnosed in the advanced stages of HIV disease as they still continue to be considered at a low risk for contracting the virus. Furthermore, Farazdegan, et al. (1998) discovered that "women with half the viral load of their male counterparts progressed to AIDS in a similar length of time."

### *Socio-economic Factors and Race*

Current research has concluded that socio-economic factors and race may play a role in women's susceptibility to contracting the HIV virus. Sowell, et al. (1997) investigated the quality of life in HIV positive women in the southeastern United States and discovered that many women with HIV / AIDS tend to be poor, non-white, and predominately infected through heterosexual contact. Sowell, et al. (1997) stated further that the interrelationship of factors such as social class, the role of caregiver within the family and the expectations placed upon women in society contribute to a unique context in which HIV infected women live their lives. Demi, Moneyham, Sowell and

Cohen (1997) and Ciambrone (2001) found that HIV positive women tend to be marginalized single mothers who are poor and lack education.

However, it is important to understand that *all* women can be at risk from HIV / AIDS even though a majority of the literature focuses on poor women with identified risks. Grove, Kelly and Liu's (1997) view is that:

> AIDS is a socially constructed condition ... In the evolving social construction of AIDS, certain risk groups became associated with the disease. These groups, because of their social orientation, drug use, race, or class, are perceived at risk. At the same time, anyone who is not, by existing group affiliation, already at risk is excluded from the public discourse surrounding AIDS. (p. 318)

Grove et al. (1997) and Emlet, Tangenberg and Siverson (2002) conclude that white middle class women are at a disadvantage as they are not in a socially recognized risk group, and often physical symptoms are not thought due to HIV infection, resulting in a diagnosis in the later stages of the disease. Nannis, Patterson and Semple (1997) studied participants who were generally well educated, employed women and not suffering from or defined by socio-economic factors associated with inner city living, commercial sex work or drug use. Results from their research revealed that this population had improved styles of coping, which means they had better social support and fewer cases of loneliness and depression. In contrast, Sarna, van-Servellen, Padilla, and Brecht (1999) examined the quality of life in women living with HIV / AIDS and noted that: "women who are poor and living day to day with the implications of their disease and effects of treatment are inherently vulnerable"(p. 604). Their studies revealed that attention to their psychological needs including fear of rejection and stigma was important for these women.

### *Disclosure and Stigma*

#### *Complexity of disclosure.*

For most individuals suffering from HIV / AIDS, receiving the diagnosis can create great turmoil. Issues of disclosure and the dread of subsequent stigma further complicate their lives, especially for women. The repercussions of voluntary and involuntary disclosure can affect women in various ways, both in their personal lives and in the community. Voluntary disclosure for some women can be a strengthening process that allows them to take charge of their lives and seek support and medical care. Involuntary disclosure, on the other hand, has often led to loss of employment and isolation from friends, family and the community.

Semple et al. (1993) describe major stressors in the lives of women who have been infected with HIV. For many women the disclosure of being HIV positive was one of the most difficult decisions they had to make. Hackl, Somlai, Kelly and Kalichman (1997) revealed that women who shared their HIV / AIDS status with family or friends risk various forms of stigmatization such as reactions of fear, shock and blame.

Not surprisingly, disclosure for many women is a calculated conscious effort that they find extremely difficult. For many it remains a decision that occurs on a one to one, “need to know” basis (Semple et al. 1993). Moneyham et al. (1996) found that factors of paramount importance to women at the time of disclosure were the perceived compassion, understanding, trust, and rapport with the intended recipient of the information. Moneyham et al. (1996) discussed that many women would not disclose if the potential risks of disclosure outweighed the potential benefits.

Sowell et al. (1997) discovered that for some socio-economically deprived women, disclosure is made in an effort to improve their lives. Their decision to disclose their HIV status often occurred at a time when they were facing deterioration in their health related to the disease. They concluded that for many disclosure was seen as a way to unlock and access needed resources.

#### *Stigma.*

Illness is naturally a stressful event further compounded when the illness is terminal and associated with social stigma. In the evolving social construction of AIDS, certain groups, whether because of their sexual orientation, drug use, race or class, have become associated with the disease and society has frequently labelled these HIV positive women as deviant, promiscuous individuals who inject drugs. This not only complicates their already difficult lives, but also leads to further isolation and feelings of loss of control.

Leenerts and Magilvy (2000) provide the following analysis of stigma experienced by HIV positive women: "Social stigma associated with HIV diagnosis functions to destroy a positive sense of self and encourages further loss of self through isolation and alienation. Stigma added emotional distress, and perceptions of stigma influenced coping processes" (p. 69).

### *Women and HIV / AIDS Health Care*

Women living with HIV / AIDS have been distressed by health care providers' lack of scientific knowledge of the diagnosis and treatment of HIV / AIDS. The consequences have sometimes led to either a misdiagnosis or a late diagnosis in the course of their disease. This in turn caused a more rapid deterioration in their health because the medications they required, at the later stages of their disease, were often toxic and made more so by a rapidly deteriorating immune system. Bunting, Bevier and Baker (1999) Metcalfe et al. (1998), Gray (1999), Amaro, Raj and Reed (2001) describe the failure by the medical community to identify the association between HIV and gynecological diseases. Moneyham et al. (1998) discovered that women presenting with symptoms of HIV such as vaginal candidiasis, fatigue and weakness often had these symptoms incorrectly attributed to increased stress or depression.

Researchers have identified inadequacies and analyzed possible reasons for a medical system being unable to provide a timely and accurate diagnosis for women presenting with HIV / AIDS. Metcalfe et al. (1998) concluded that a delayed diagnosis in women presenting with symptoms of the disease is often caused by a medical system that lacks understanding of HIV illness in women complicated by the fact that HIV symptoms are often masked by normal female reproductive functions.

What is the impact of a medical system that fails to address the health care needs of women living with HIV / AIDS? Gray (1999) concluded that access to care can significantly impact whether women living with HIV / AIDS live or die. As mentioned before, Farazadegan, et al. (1998) discovered in their study that women with half the viral load of HIV compared to men progressed to AIDS in a similar length of time. They emphasized the fact that women should receive a rapid diagnosis and be given the same opportunities as men and be placed on appropriate medical treatment to improve their health and quality of life to the optimum possible.

Meredith, Delaney, Horgan, Fisher and Fraser (1997) discussed the challenges facing women and the medical community. For example, the challenges of providing quality health care to women with HIV sparked fears of increased costs to the medical system. Meredith et al. (1997) concluded that addressing the women's clinical, emotional and situational needs would enhance medical and psychosocial outcomes thereby *reducing* health care costs.

For many individuals the impact of an HIV / AIDS diagnosis creates stresses that at times seem insurmountable, leaving them vulnerable and unable to cope. For women the stresses are often greater as they may be single mothers with a dependent child, suffer financial difficulties and experience health care issues with a medical system that does not fully understand their needs. In recent years researchers have begun to study the psychosocial aspects of HIV positive women and the methods women employ in order to understand and cope with their diagnosis.

### *Coping Strategies Employed by Women Living with HIV / AIDS*

Moneyham et al. (1998) define coping as: "cognitive and behavioural efforts to manage specific external and / or internal demands appraised as taxing or exceeding the resources of individuals" (p.352). In the face of a diagnosis that forever changes their world, many women discover behaviours, which aid their daily functioning and allow them to take command of the situation. Self-care has been identified as one of a number of positive approaches women engage in as they attempt to cope and live with a serious illness. Some women have created a healthier and more proactive approach to their lives, which has helped them to see an aspect of their diagnosis as a thrust towards psychological and spiritual growth. Van-Loon (1996) sought to explore the experiences of disadvantaged women living with HIV / AIDS and discovered that women promoted feelings of personal control through a process whereby they developed beliefs about HIV / AIDS which helped to destigmatize and reframe their experience of HIV infection. The women used a variety of cognitive and behavioral strategies; they focused on spirituality and support from their children and others living with AIDS.

Dunbar, Mueller, Medina and Wolf (1998) sought to understand women's ways of coping by focusing on psychological and spiritual growth in women living with HIV. They concluded that despite serious illness, women in their study strengthened relationships and discovered new values and a sense of purpose through increased self-awareness and self-acceptance. Siegel and Schrimshaw (2000) also described some of the constructive changes that can occur in women's lives as they grapple living with HIV / AIDS. Most women reported that HIV / AIDS had been the incentive required to change long standing destructive behaviors such as drug and alcohol abuse, smoking, and risky sex. Women's experience with illness sometimes improves relationships with their children, family and friends. Those who had support from their families, friends and mental health services, seemed to cope better than those without such support.

Demi et al. (1997) studied the coping strategies of HIV infected women and found that when they used maladaptive coping strategies both their hopefulness and quality of life deteriorated. Common maladaptive coping styles included the avoidance of coping, silence, guilt, the denial and concealment of illness, isolation, substance abuse and even contemplating suicide. Riley (1999) and Florence, Lutzen, and Alexius (1994) describe the effect of stress on individuals living with HIV/AIDS. They found that stress is well documented in HIV positive people and acts as a cofactor in worsening HIV. Florence et al. (1994) found that women deal with sources of stress and anxiety very differently from men and have to tackle burdens such as multiple losses within the family, inability to produce more children, failing health, lack of hope for the future and loss of confidence in their physical desirability. Fear and isolation were common responses that often interfered with the women's ability to self-care which in turn lead to further isolation and thoughts of suicide. Demi et al. (1997) recognized the importance of providing useful coping strategies when planning interventions to help women manage their illness more effectively.

Moneyham et al. (1998) suggested that health care providers should form effective strategies when caring for and supporting HIV positive women, such as interventions that focus on altering cognitive appraisals in order to promote positive emotional states. They suggested relaxation, meditation, and methods of distraction such as mental imagery and recreational activities. Also, support groups were viewed as an effective intervention because they provide a safe environment that gives women the opportunity to discuss their experiences without the fear of negative responses from others. Many women in their study viewed this opportunity as paramount when seeking support.

### *Summary of the Literature Review*

The literature review reveals that present knowledge is incomplete and lacks sufficient depth to provide a full understanding of women's experience with HIV / AIDS. The inequities of research on various components of women's experiences of living with HIV / AIDS has been recognized by researchers. Recent research has concentrated on specific aspects of women's experiences such as their coping strategies, effects on relationships and the impact on their health. The impact of HIV / AIDS is devastating to women. Research is required to improve our understanding of women affected in order to provide high quality care and support. Given the importance of women's experiences of living with HIV / AIDS and the noted gaps in the literature, an ethnographic approach was used to examine the experiences of women living with HIV / AIDS. It is to a description of the methodology used in this study that I now turn.

# Chapter 3

## *Research Methodology and Methods*

I used an ethnographic research methodology to study the experiences of five women living with, and suffering from, HIV / AIDS. de Laine (1977) states that ethnography is particularly well suited to the study of peoples' perceptions of health and illness because of its focus on culture. Indeed, this qualitative approach is being used increasingly in health research to study behaviours in culturally and linguistically diverse groups. As LoBiondo-Wood and Haber (1994) add, "the goal of the ethnographer is to understand the native's view of the world or the emic view" (p.268). An ethnographic research methodology provided me with an approach for understanding participants' culture. In this study, the specific culture is one shared by a small group of women who are living with HIV / AIDS. Spradley (1979) defines culture as the "acquired knowledge people use to interpret experience and generate social behaviour" (p.6).

An ethnography is a study of both explicit and tacit cultural knowledge revealed through speech, both in casual comment and in lengthy interviews (Spradley, 1979). Explicit cultural knowledge can be consciously communicated with relative ease, but tacit cultural knowledge consists of unspoken or implied knowledge: interviewees often know things that cannot talk about or express consciously. Spradley (1979) believes that the role of the ethnographer is to make inferences about what people know by listening carefully to what they say (and) by observing their behaviour.

### *Entering the Field*

The site for accessing the women took place at a health care facility, which also provides care for individuals living with HIV / AIDS. I began by introducing my proposed research project to the staff at one of their regular meetings. The team members decided that a nurse identified as the contact person would approach potential participants about their participation during their medical appointments.

### *Accessing Participants*

The nurse mentioned above approached potential participants, gave them an explanation of the research and asked for their participation. The criteria for women participating in the study included: having a diagnosis of HIV / AIDS, being nineteen years of age or older, and being willing to share their experiences. They were informed that their participation would contribute knowledge of women living with HIV / AIDS. If a participant agreed, the nurse set up a convenient interview date and time for her to meet with me. The nurse acted as a "gatekeeper" whose role was critical in terms of accessing and reaching the research subjects (Berg, 2001). Five women attending the clinic volunteered to participate.

### *Setting the Stage for the Ethnographic Interview*

At the beginning of each interview situation, participants who volunteered for the study were informed that they would take part in one or two interviews of an hour or two at a mutually convenient location. I informed them that the interviews would be tape-recorded so the information could be transcribed and analyzed further. If the participant was not comfortable speaking English, a professional translator from the clinic was used in order to translate for us. This service was required for one participant who spoke a south Asian language. An honorarium of $30 per interview per participant was provided to defray the cost of inconvenience, transportation and childcare expenses. To establish rapport, nutritious snacks were provided throughout the entire interview.

### *Participant Group*

A convenience sample of five women living with HIV / AIDS volunteered for the study. These five women were the first to agree to volunteer for the study from a larger group of women who attended the clinic mentioned above. The participants ranged in age from early twenties to early fifties. Three of the participants were married with children, while the other two were single mothers with children. Two of the women were of south Asian origin, one was south Asian / northern European, two were mixed European heritage. All participants had completed high school education; three had pursued further educational opportunities. Two participants lived with their immediate family and extended family. One participant lived with her husband, one participant lived with a child and one participant lived alone.

### *Data Collection*

When engaging in this research approach, the researcher enters into the everyday lives of individuals. To help me gain an understanding of women's experiences of living with HIV / AIDS I used a variety of data collection strategies: individual interviews and participant observation. Field notes were kept in a journal to record my observations and facilitate the reflexive process I continually engaged in throughout the research process.

### *Individual interviews.*

One face-to-face open-ended individual interview took place with each of the five women living with HIV / AIDS. Opening remarks, prompts and questions for the interviews were created to aid the interview process (see Appendix B, Interview Questions, p. 82).

Each interview lasted between one to two hours. The location for the interview took place in a comfortable private environment in the clinic. The women who participated in the research study were asked to reflect on their past and present experience of having been diagnosed and living with HIV / AIDS. All of the interviews began with descriptive questions (Spradley, 1979) that used open-ended prompts such as “What was it like for you to discover that you were HIV positive?” or “Tell me what an average day is or was like for you?” My purpose in using this kind of question was to encourage participants to give their perspective with as little probing as possible. Opportunity was provided for the women to describe their experiences of living with HIV / AIDS from the time when they discovered they were HIV positive until the present. They were asked to reflect upon and describe how a typical day in their life appeared to them (Spradley, 1979). Occasionally the conversation would get off track so gentle prompts such as “now getting back to your experience” were required to keep the focus on participants’ experiences.

### *Participant observation.*

Participant observation involved entering the social setting (Spradley, 1980), the health care clinic that the women attended, and becoming acquainted with those both attending and employed at the clinic. As a participant observer I entered into the everyday life and activities of five women of living with the HIV / AIDS virus. It was through my visits to the clinic and interactions with staff and the five women that I came to know the shared culture, as I took part in some of their daily activities. Schwartz - Barcott (1999) describes participant observation as: "a process of direct observation of everyday life in study participants' natural settings and participation in their lifestyle and activities to the greatest extent possible" (p. 185). I attended the clinic on numerous occasions, both on patient and non-patient days in the clinic in order to record notes about the environment and activities taking place. I positioned myself in the clinic in a discrete area of the waiting room that provided physical distance between the patients and myself. For example, I observed patients interacting with staff members or waiting quietly for their appointments with their health care providers.

As a participant observer I noted, for example, the physical layout of the clinic to determine whether it provided some comfort for the patients. I also noted whether the environment provided private areas for patients to discuss their health care needs with their health care professional. I observed the layout of the clinic and the flow of patients through their many meetings with health care professionals to determine the impact this might have on their experience of this particular health care venue. Observations about the patients' appearance, manner, their routines, unusual events that might occur within the setting as well as human groupings, such as women of certain cultures within the clinic, were also made (Spradley, 1980).

#### *Field notes.*

Field notes included my observations of participants pertaining to each interview situation and to my observation of the site. I situated myself in the waiting room area and took copious field notes in order to record and recall the patient care activities that took place during each woman's clinic visit. Observations that occurred during each individual interview with the women in the study were also recorded. Emmerson, Fretz and Shaw (1995) provide a description of the process of creating field notes as: "the first hand participation in some initially unfamiliar social world and the production of written accounts of that world by drawing upon such participation" (p.1). I wrote up my field notes the same day I was in the field. My goal in the field notes was to document any observations relevant to women's experiences of living with HIV / AIDS. My observations of the environment, the participants and the interview process were recorded in the field notes (Spradley, 1980). For example, observations such as body language, eye contact, clothing and perceived mood were recorded during and after each interview. The purpose of recording this information was to improve accuracy when I came to recollect the information and circumstances of the setting and participant group (Emmerson et al., 1995).

Issues related to the research were recorded in a reflexive journal to be used later in the analytic process (Banister, 1999). This reflexive process provided a way for me to ruminate upon my feelings, assumptions and biases that I brought to the research. It also allowed me a process in which to reflect on my presence in the research and account for the possible ways that these feelings, assumptions and biases may impact my description and interpretation of the women's experiences of living with HIV / AIDS.

### *Data Analysis*

I came to realize that data analysis is an ongoing activity, enabling the fieldwork to gain momentum towards providing deeper understanding. Throughout the data collection and analysis I was guided by my research question: “What are women’s experiences of living with HIV / AIDS?”

The analytical process involved numerous careful readings of my field notes and interview transcripts to get a sense of the whole (Hammersley and Atkinson, 1995; Sandelowski, 1995). Throughout data analysis I constantly engaged in a process of marking the data as well as taking further notes about any patterns, connections, similarities or contrasting points that occurred in the data. I engaged in a recursive process of data collection and analysis throughout the research process (Lincoln and Guba, 1981). I sought further clarification from some of the participants in extra interviews, asking them to think back and reflect upon some of the emerging categories to see how relevant they were to their experiences of living with HIV / AIDS. The data gathered during my field visits to the clinic provided material for further enquiries on subsequent visits. As the fieldwork progressed I would constantly question myself as to what the data meant, what was happening in these women’s lives and what I had discovered in this learning process. I recorded my deductions, thus giving myself material that I could later compare with data derived from other sources.

As a guide to analyzing my research, I began to look for common categories of meaning in the data. I began to ask myself questions such as “What terms do the women have for things?” (Spradley, 1979). “What can I identify as categories, even if the participants do not?” I kept in mind that the purpose of my study was to elicit “the native points of view” or the point of view of the five women living with HIV / AIDS (Fetterman, 1989, p.12). In this step of the process I was able to ascribe a unique number of categories to each participant. The number of common categories ranged in number from 24 to 36 for each of the participants (see Tables 1 – 5, Categories, p. 73 - 77). Common categories ranged from importance of family, lack of knowledge of HIV / AIDS, importance of God in their life and dealing with their diagnosis.

Through a process of recursive reflection and re-reading of the transcripts, field notes and my journal I was able to reduce the common categories of meaning of each participant into nineteen larger categories of meaning. (see Table 6 – Larger Categories of Meaning, p. 78). Through further immersion in the data, reflection of the transcripts and field notes, the following three themes emerged: feeling limited hope, experiencing inconsistent healthcare, and the transforming from victim to advocate.

### *Issues of Validity and Reliability*

Lincoln and Guba (1985) suggest that, credibility, auditability and fittingness could be used as a measure of scientific rigor. I employed these elements to strengthen the rigor of the study.

#### *Credibility.*

Lincoln and Guba (1985) consider four techniques for testing credibility: prolonged engagement, persistent observation, triangulation and member checks. Each will be discussed in turn.

Lincoln and Guba (1985) refer to prolonged engagement as the investment of sufficient time to achieve certain purposes: for learning the culture, for testing for misinformation introduced by distortions either of the self or of the respondents, and for building trust. The time I spent in the field facilitated an in-depth understanding of the phenomena under inquiry. My fieldwork involved persistent observation through numerous visits designed specifically for this purpose.

Triangulation is viewed as a mode of improving the probability that findings and interpretations will be found credible (Lincoln and Guba, 1985). In the study, triangulation of data included two main data collection techniques: individual interviewing and participant observation.

de Laine (1997) describes member checking as the activity that provides a direct test of the findings and interpretations with the human sources from which the findings have come. In this research study two participants were contacted following analysis of data and asked to confirm the preliminary findings. These participants agreed with the preliminary categories of meaning and themes that emerged in the research.

#### *Auditability.*

Auditability is the criterion proposed by Lincoln and Guba (1985) and Sandelowski (1986) for judging consistency in qualitative research. Auditability is the ability of another researcher to follow the research decision trail. In this study auditability was achieved by describing the research process in detail. In order to facilitate auditability, a standardized interview guide (see Appendix B – Interview Questions, p.84) was developed as well as the establishment of a consistent and well documented format used for keeping analytic notes.

#### *Fittingness.*

Lincoln and Guba (1985) describe fittingness as a measure within qualitative research to determine if the findings are applicable outside the study situation. This criterion pertains to the extent to which study findings fit the data; that is, the findings should be truly grounded in the experiences of the participants under study and they view the findings as meaningful and applicable in terms of their own lived experience

(Lincoln and Guba, 1985). Throughout the research process I reflected on the position of the women in the study living with HIV / AIDS. Their findings fit within the context of experiences of other HIV positive women I had met at the local AIDS service organization, International AIDS conferences and my own experiences of living with HIV.

### *Ethical Considerations*

The research proposal was subject to ethical review according to the guidelines set out by the University of Victoria Human Subjects' Committee and the University of British Columbia Behavioural Sciences Screening Committee. Given the exploratory nature of this research project, I explained to the participants the nature and purpose of the research both verbally and in written form. All participants read the note of request to participate and were asked to read and sign the "letter of informed consent" before the interview began (see Appendix C – Letter of Informed Consent, p. 84).

Another ethical consideration for this research study was the issue of confidentiality. In the study, all material was assigned a code for each participant and the audiotapes used during the interviews were also labeled with codes. All notes, interview materials and audiotapes were kept in a secure place with only myself, as the researcher, having access to them. The only people who listened to the tapes and read the transcripts were my research supervisor, the transcriptionist employed in the process of typing the interviews onto computer discs and myself. Demographic information about the participants has been altered and reconstructed throughout the research report so as to protect the women from any possible identification.

### *Support for the Researcher*

In conducting these interviews, I realized that my own circumstance of being HIV positive could be a potentially intense and emotional experience for me. I incorporated support mechanisms for myself during this study to preserve the "researcher's integrity" (Davies and Oberle, 1990) and to handle the emotional reactions that could result from the research. This process involved support mechanisms such as a short debriefing with a nurse at the clinic after each visit to conduct interviews, and keeping a journal of my personal reflections, thoughts and feelings during the research.

The research question focused on what women's experiences of living with HIV / AIDS are. In the following chapter I will focus on the five women involved in the research study and provide pertinent findings and answers to this important research question.

# Chapter 4

## *Findings*

This chapter will be divided into two sections. The first section will provide a glimpse into the lives of each of the women living with HIV / AIDS who took part in the study. Their short narratives will provide the reader with an image of their world and a glimpse of their journey and their strengths and weaknesses as they attempted to cope with the implications of their diagnosis. An examination of three common themes that emerged from the five women's stories will be presented in the second part of this chapter. Participants' own words will be used as much as possible in an attempt to illustrate their unique and powerful experiences living with HIV / AIDS. The three themes are: 1) feeling limited hope, 2) experiencing inconsistent health care, and 3) transforming from victim to advocate.

### *The Five Women*

#### *Kulwant.*

Kulwant is a young south Asian woman and mother of two young children. She lives with her children, husband, and extended family. As part of routine medical screening, after the birth of her daughter, Kulwant was asked whether she wanted to be tested for the HIV virus. Kulwant agreed to the test thinking she was not at risk for infection with the virus. Upon further testing, it was discovered that not only was Kulwant HIV positive, but so were the immediate members of her family.

Disclosure of Kulwant's HIV status occurred in an open hospital corridor when her physician announced her HIV status to her immediate family members and relatives who were present at the time. Kulwant stated that she felt incriminated by the approach taken by her physician as he questioned her in an accusatory manner as to how she had come into contact with the AIDS virus. At the time of the news neither Kulwant nor her relatives understood what a positive HIV test meant and no attempts were made to assess her understanding. Kulwant was given an information sheet and was left to develop her own understanding of how the AIDS virus would affect her life and that of her family.

Attempts were made by Kulwant's friends and family to provide support. However, after a short time, many of those supporting Kulwant, especially those with young children, became increasingly afraid for their safety and the potential spread of the virus. Friends and family expressed anxiety about allowing their children to play with Kulwant's child from fear of contagion. For Kulwant, numerous issues exist within her community which include false information creating fear and subsequent stigma towards individuals living with HIV / AIDS. She expressed anger about people in her community who do not seek correct information and further perpetuate such fear and ignorance. Kulwant admitted to her own limited knowledge of the disease. Her early understanding of HIV / AIDS was that those who contracted the virus became extremely ill and often died in a relatively short time.

Following her diagnosis, Kulwant became withdrawn and depressed as she began to worry about the impact of HIV / AIDS on herself, her child and her husband. Of further concern to Kulwant was how her child would deal with her illness in the future should she become unable to care for her child from illness or death. However, Kulwant was optimistic about obtaining good health care at a medical clinic providing treatment for HIV / AIDS. She received regular monitoring and the latest treatments provided by a compassionate staff that provided her with the latest information and took time to listen to her concerns. She stated that after her visits, she left with a renewed sense of hope that she would live longer than she initially had expected. Kulwant believed that by engaging in a proactive approach, taking the medications prescribed and by following the information provided at the clinic, she would remain healthy for some time to come.

Kulwant's strong belief in a hope for the future was also built on a foundation that consisted of a strong faith in her God and the belief that if she and her family took the daily medications prescribed and followed the information provided by the clinic, God would protect them by ensuring the good health of the entire family. Kulwant stated that her relationship with her husband had suffered since her family was diagnosed with the AIDS virus. She sensed that her husband felt ashamed of their family being HIV positive although he rarely expressed such feelings to her. Kulwant frequently worried far more about her child's health than her own health and that of her husband.

### *Sarnam.*

Sarnam is a young south Asian woman, married, mother of three children. She lives with her husband, their children and her in-laws. As part of her routine pre natal health care, Sarnam's physician asked whether she would like to be tested for the AIDS virus. Having limited knowledge of HIV / AIDS, Sarnam agreed to have the test done and felt that she was at no risk for contraction of the virus. A few weeks later Sarnam received her HIV test results and to her surprise her physician informed her she was positive for the AIDS virus. Then, when her family was tested for the virus, the tests also revealed that two other members in her family were HIV positive. Sarnam described her experience of HIV testing as distressing in terms of the approaches taken by her health care providers. Her primary care physician, an individual she respected and trusted, ordered the HIV test and provided minimal counselling. A locum physician asked her to attend the clinic a week later and informed her of the positive HIV test result.

Sarnam made a conscious decision not to disclose the family's HIV status to anyone except her immediate family due to fear of reprisal from others in her community. Sarnam stated that ignorance of HIV / AIDS exists in the south Asian community perpetuated by a lack of education and the apathy of those individuals who remain ignorant about what exists beyond their personal circle.

Antiretroviral drug treatment to combat the HIV virus was initiated immediately for all infected family members. Her infected children received antiretroviral treatment at birth and today remain healthy. Sarnam states that she is frequently depressed and plagued with thoughts like "maybe I die soon" with future concerns of what might happen to the children should she die of AIDS.

### *Jaz.*

Jaz is a Caucasian middle-aged woman of south Asian and northern European ancestry. Jaz is married and has three children. Currently Jaz lives in a comfortable home with her second husband. Her first marriage ended, and after raising three children on her own, Jaz decided to pursue post-secondary education. However, during her studies Jaz frequently became ill with breathing difficulties. Unable to confirm a definite diagnosis, her physician sent her to a specialist who assessed and diagnosed her as having a common respiratory ailment. Over the ensuing months her health continued to deteriorate; all the while she continued to attend her classes. Her specialist continued to follow her closely and finally decided to admit her to hospital and ordered tests to help make a definitive diagnosis and plan an effective course of treatment. Despite these invasive and painful diagnostic tests, her specialist was no closer to providing her with an accurate diagnosis. Jaz continued to suffer for two more years. One day when her breathing became extremely difficult, Jaz went to the emergency department to seek medical attention and receive some relief. While in the emergency department further tests were performed. Finally Jaz received a clear diagnosis and cause for her illness. The specialist came to her hospital room and informed her that she had PCP (pneumocystis carinii pneumonia), "the type of pneumonia which people with HIV / AIDS get". Jaz experienced shock and disbelief. Further blood testing confirmed that she was HIV positive.

When she reflected upon her past experiences with the medical system Jaz felt that her delayed diagnosis was due in part to her physician's not considering her to be at risk HIV. Not surprisingly Jaz has little trust that her health care providers will keep her up to date with the latest information on HIV / AIDS. In her own search for the latest information Jaz has discovered a local AIDS service organization's treatment exchange program, which provides her with an excellent source for information about the disease. She remains concerned that if she does not maintain an active approach she will "fall between the cracks" again.

Presently Jaz engages in self care practices that include meditation, exercise, diet and frequent rest periods. Jaz states that financial freedom and family support have been key elements as she strives to remain healthy. The role of activism to address the basic rights of women living with HIV / AIDS remains a high priority in Jaz's life as she is constantly reminded of the stigma surrounding women living HIV / AIDS. Jaz hopes that one day a cure will be available for people living with HIV / AIDS and that she will be able to surpass her earlier predictions of a limited life expectancy.

### *Barbara.*

Barbara is a young Caucasian woman, single mother to two young children. After graduating from high school, Barbara decided to pursue post secondary education. One evening while returning home from her studies Barbara was raped. The rape went unreported and Barbara was never tested for any sexually transmitted diseases. It was later discovered that the individual who had raped her had tested positive for the AIDS virus and the hepatitis C virus. It was during her prenatal screening that Barbara's physician asked if she wanted to be tested for the AIDS virus. Barbara agreed; two weeks later she received the results that she was positive for the AIDS virus and hepatitis C virus.

At the time of screening for the AIDS virus Barbara's physician informed her of the purpose of the HIV test; no formal pre-test counselling was offered. Barbara felt at ease and unconcerned, believing that the HIV test would return negative. However, two weeks later when Barbara returned to her physician, he presented the grim news to her that she was HIV and hepatitis C positive. She was completely shocked and stunned; feeling that the world was crumbling around her. No post-test counselling was provided. Before her medical appointment Barbara's physician had taken the bold step and decided to book an abortion without previous consultation or approval from Barbara.

When her physician informed her of the plan, Barbara panicked, refused the abortion, and vowed never to return to her physician for medical care.

Barbara sought the services of a health care professional, whom she had sought guidance in the past and together they developed a workable plan to find a non-judgmental and compassionate physician to continue her care. This new physician stated that she was not an expert and that they would work together as a team to develop a suitable plan that Barbara could accept. Her physician immediately contacted a local medical expert in the diagnosis and treatment of HIV / AIDS. A workable plan was developed that provided treatment and allowed Barbara to continue with her pregnancy to full term. Antiretroviral drug therapy was administered to her child after the delivery to prevent transmission of HIV. Today her child remains healthy having tested negative for HIV. Barbara had been plagued with feelings of guilt that she might pass the virus on to her child but believes that God had rewarded her with a healthy child.

Barbara became involved in the local political community as an activist fighting for the rights of women living with HIV / AIDS. Education was an important stepping-stone in advancing her own self-care. The importance of a medical facility providing HIV / AIDS health care for Barbara cannot be overstated. Many therapeutic options were available to her there.

Barbara engages in self-care practices that include medications, a healthy diet, exercise and volunteering within the local AIDS community. Her days are long and tiring and she often returns home exhausted from her volunteer work; but she feels that she has given to her community and believes she is creating a positive difference.

Barbara lives with a renewed sense of hope for her life based on recent scientific advances in the treatment of HIV / AIDS.

*Deb.*

Deb is a middle-aged Caucasian woman and mother of two adult children. Deb has been married twice; divorcing one husband and losing the other husband to AIDS. Deb currently lives alone. Deb found out about the possibility of having HIV / AIDS after receiving a phone call from a woman who informed her that she had contracted HIV from Deb's husband. She advised Deb to seek immediate HIV testing. However both Deb and her husband waited for many months to be tested for HIV, at a time when their health began to deteriorate. Deb could not understand how she could have been married to her first husband for many years with no adverse health consequences and then, shortly after marrying her second husband, contract a virus that could possibly kill her. Her immediate reaction to the news was disbelief, anger and grief.

To maintain her health Deb takes numerous antiretroviral medications each day; medications with unpleasant side effects. Often Deb described feelings of frustration with her health care providers as she felt they did not take the time to listen, frequently interrupted her before she had the opportunity to discuss medication side effects and other health related issues she was experiencing. The thought has crossed her mind to stop taking her medications when the side effects were too difficult for her to handle. Deb remains strongly convinced that if her physician had listened to her concerns and trusted her comments, such unpleasant experiences would not have occurred as frequently.

Upon reflection Deb remains surprised that she had not actually died from AIDS. Her biggest lesson and message throughout this experience was "to get off the couch". For example, seven years ago she became motivated and decided to engage in a proactive approach to her illness and rejoin society. Her drive was to volunteer with one of the AIDS agencies in her community as she often worries about the plight of other women living with HIV / AIDS who feel powerless in their circumstances.

Deb is optimistic about her health and no longer sees HIV and AIDS as the death sentence she once dreaded. Despite her many hardships, Deb hopes that the medications available today for women will maintain her health for years to come.

## *The Themes*

### *Feeling limited hope.*

Feeling Limited Hope was a belief and a self-subscribed philosophy that was embraced by all the participants in this research study. When the women spoke of hope they described a force or motivation that propelled them to "keep on living". Women within the study prefaced such hope as "limited", accepting a shortened life span. Every participant was fully aware of the predicted outcome of her illness and of living with HIV / AIDS. Participants were cautiously optimistic about current media reports describing new discoveries of improved treatments for the AIDS virus that the medical community believed would improve survival rate in individuals living with the disease. Interestingly, participants did not view the date of contraction of HIV / AIDS as affecting their survival time as they believed they would be alive for some time to come. The women described numerous factors that supported the concept of "feeling limited hope": their children, spirituality, relationships and medical advances.

Children played a key role in the lives of the participants. They provided the participants with a renewed sense of hope. However, the women expressed concern about their children's future and their desire to see their children grow up and survive on their own. Having a young child in the women's lives improved the quality of their lives; it allowed them to spend time with their young ones and for that moment to put their illness aside. A sense of guilt encompassed numerous women as they considered their role as a vector in the potential or actual transmission of the virus to their children. Sarnam described the role of children in her life, the hope they provide and the concerns she experiences every day:

> I'm really happy that my kids are not positive. That makes me more happy and healthier, because it's really easy to suffer if you are sick and it's really hard to suffer when your kids are sick … So that's why I was really upset for one year and, I say like, 'if I'm just going to worry about like this, I'm going to die soon. Who's going to take care of my kids?' So I have to have – *live* a happy life, like as much as I can spend time with them, as long as I can live, so I can take care of them. If I really worry about every time, 'oh, my God I'm HIV, I'm crying and I'm gonna die soon'. Probably if I'm gonna live ten years, maybe I'm gonna live – die within five years. So I have to live *for* my kids.

Barbara described the hope that she experienced through her young daughter and the encouragement she feels the relationship has provided: "She gives me hope, yes. I think that's what keeping me alive. It's something to live *for*. I just hope I make it to see her graduation, if I make it that long."

Two other participants have grown children who also provided them with a sense of hope. For example, Deb had forged links with her adult children providing her with a sense of hope for the future both as a mother and future grandmother:

> I was very estranged from my whole family when I moved … and I didn't talk to anybody for years. And then I did I started re-establishing communication with them. My youngest actually moved out of the house first and as soon as he moved out he started contacting me and our relationship has been getting better. He moved into a house with his girlfriend right away and then they got married and now they have a son. So, our relationship is growing better all the time for him and myself.

Participants described their experiences living with HIV / AIDS as an awakening and an awareness of a higher being. The women described an experience of traveling through unchartered territory as they became more acutely aware of the strengths and power they possessed from within. The participants realized that remaining healthy was a self-care program that not only included a reliance on their inner strengths and a higher being but also on embracing current drug therapies in combating HIV / AIDS. They believed that a positive belief system coupled with a program of self-care provided them with hope for the future. Kulwant describes the role of spirituality in the lives of herself and her daughter, who also has HIV:

> A little bit of hope is with God. And then we feel that help is going to happen if we have medication, along with the medication that God will help us. That even when I'm giving the medication to my child, I say, 'God has given and he says to eat this and we'll be better'.

Hope included a multi faceted self-care program in their quest to remain healthy. Jaz speaks to this hope:

> I definitely have more deepening of my spiritual values and my spiritual path. …Well I'm following my sort of religious path more. I have a good practice of meditation and that type of thing … I get up, I take my 'meds', I drink some water, I've got a little meditation room, I go to my meditation room and meditate, do Chi Gong and then I either lift weights or I go for an aerobic walk.

Recent medical advances in the diagnosis and treatments of HIV / AIDS also provided a new sense of hope for the women who were initially skeptical. This is despite the fact that women are one of the fastest growing groups of new AIDS cases (Health Canada, 2003). However, the women had hope due in part to access to the latest antiretroviral drug treatments. This provides hope that some had previously only dreamed of. Deb, a long-term survivor of the AIDS virus, speaks of a shift on her perspective from believing she would die to having hope:

> You know? The doctor told me, after I was diagnosed, that HIV wasn't a death sentence and I thought, 'You are wrong, if you were sitting in this chair you would think that way.' And after ten years I'm actually convinced now it's not really a death sentence anymore. And I used to be a person that didn't even put their hope in the drugs because I thought 'It's a conspiracy they just want to kill us all anyway. The drugs probably don't work. It's getting hope where there is none'. But I have lots of hope now and I actually think that there's still a cure out there when most people think it's impossible.

In order to maintain optimum health when living with HIV / AIDS participants subscribed to a proactive approach of information gathering about the latest reports in the treatment of HIV. This involved making contact with caring and supportive professionals who provided the most up to date knowledge, care and support. Kulwant gives us a synopsis of how she and her family strive to remain healthy:

> We have to listen and follow the instructions given here because at least there's a hope and we tell ourselves, basically trying to make ourselves understand that there is help. When we come [to the clinic], we feel pretty confident that everything is going to be all right and then when we go home … I try to obtain appointments here [the clinic] every month, instead of every two months because I like coming here every month, so there's hope and I find out what is happening.

Limited Hope provided an overwhelming drive for these women to keep on living despite the adversities they faced. The five women described their concept of hope not only as the sole reason for remaining alive but also for living life to the fullest. They were quick to point out that hope just did not end up in their lap but that a concerted effort and a positive belief system were also required.

Positive relationships in the lives of the women also provided a sense of hope and a reason to continue living. The support provided by their children, husbands, and other important people contributed to their desire to remain alive and stay healthy. Most of the women expressed the desire to foster positive relationships and rebuild strained relationships from their past. Difficult relationships with the women's partners took on new meaning as they evaluated the importance of these associations in attempts to rid their lives of toxic relationships and build personal power. For example Barbara's separation from her husband provided a sense of freedom from previous feelings of what she describes as "feeling emotionally dragged down" by constantly providing him with emotional support when her needs were being ignored:

> I felt like he drained me physically and mentally, it was an imbalanced relationship … After my diagnosis, I didn't feel like he was close to me anymore, like I was some horrible freak ... I did understand but the more I tried the worse it got, it was too stressful, I just don't feel like he supported.

HIV / AIDS provided an impetus for the women to re-evaluate their relationships and to focus on areas that provide a sense of support and a hope for a future. All five women described the experience of limited hope as a source of motivation and a time to re-evaluate their lives. These five women provide living examples of the power of hope and the impact of hope when faced with a life threatening illness.

### *Experiencing inconsistent health care.*

When discussing their experiences of living with HIV / AIDS the women provided innumerable examples of an insensitive health care system unable to identify their needs and provide support. Inconsistent health care experiences were described throughout their interactions with a medical system designed to provide quality care. These experiences not only occurred while screening for the AIDS virus but at times when they sought a diagnosis, treatment and support. These inconsistent health care experiences not only prevented them from receiving the care they desperately needed but shattered their trust in the medical system designed to serve them.

All five women provided accounts of traumatizing experiences surrounding their discovery that they were HIV positive. Before this, they had felt at ease, unconcerned and confident that the test results would return negative, only to have their world shattered by the news that they were positive for the AIDS virus. None of the women were assessed about their knowledge and understanding of HIV / AIDS at the time of testing. For each participant, at the time of diagnosis, minimal counselling was provided despite current standards that recommend that all individuals testing for the HIV virus should be given pre and post-test counselling when testing for the HIV virus (Canadian Association of Social Workers, 1997). These negative experiences of deficiencies in empathy, advice and support jarred their fragile world at a time when such help was critically needed. Kulwant vividly remembers the trauma of receiving her diagnosis from her physician shortly after her husband's test results returned HIV positive: "And when I went to the doctor and my doctor told me I am positive as well. I didn't know what positive was, so I kept asking him, 'what is positive, what is negative?'"

Sarnam describes her dismay when tested for the virus, as her primary care physician requested the HIV test but a locum physician told her the test was positive. As mentioned earlier, during routine prenatal screening, Barbara was asked if she would like to be tested for the AIDS virus. She agreed to the screening test and was given minimal information and counselling, and received the news a week later that both she and potentially her baby were positive for the AIDS virus. To further complicate her shattered world of shock and disbelief, Barbara's physician informed her that she had booked an abortion to take place immediately.

Jaz gave further examples of jarring experiences when, as a full time student, she experienced many episodes of breathing difficulties during a two-year period. Frustrated by the care she was receiving from her GP, Jaz sought for what she thought was the best care possible, by visiting a respiratory specialist. She describes the following inconsistent health care experiences during attempts to establish a diagnosis and receive treatment from a specialist to end her suffering:

> I was going to the [Clinic] and I really like my doctor a lot and he really liked me, we had really good rapport and I think that if he hadn't liked me I might have had a better chance of getting a diagnosis. But because I had rapport with him - I don't know if it really makes sense but it does to me - because I had good rapport with him and I think people think that no one that I know or like could have AIDS, right? I think it's the stereotype around the type of women or the type of men or whoever who get HIV and I think that put blinders on my health care professionals to not get me a diagnosis, to not give me a test.

The impact of these participants' initial meetings with their health care providers ultimately shaped their future expectations and perceptions as they attempted to cope with and understand the implications of their illness at this crucial time in their lives. Women in the study were psychologically affected by the attitudes and relationships they had forged with their healthcare providers. These attitudes remained engrained in the minds of the women at a time when they were actively seeking beneficial coping strategies. Barbara provides a gripping description of the events that unfolded and her analysis of how her relationship between herself and her physician rapidly deteriorated in her attempts to seek quality healthcare for herself and her unborn child:

> The doctor that diagnosed me set up for to have an abortion three days after my diagnosis and I refused to have an abortion. So it was – she made that appointment without my permission for an abortion, and that was difficult. She went against my own personal … I hadn't given her the permission.

Barbara's healthcare experiences have dramatically improved since that time and now she looks forward to her regularly scheduled appointments. She was able to find a new physician who believed Barbara would be able to continue her pregnancy and through consulting with the local HIV / AIDS clinic, a workable plan was initiated that allowed Barbara to continue the pregnancy to full term.

Active listening by male health care providers was a concern expressed by Deb as she attempted to receive quality health care. As a long-term survivor of HIV / AIDS, and self-proclaimed expert in her own health, periods of frustration regularly occurred when she attempted to receive a diagnosis of HIV related symptoms and treatment from her physicians. Deb found that inconsistent health care experiences often occurred in her physician's office when dealing with her health care needs as he did not listen attentively to what she had told him. She candidly admits that she does not always have the answers to her issues, however most often all she wants is for her physician to listen to her opinions and take them into consideration:

> I thought when I changed GP's, I went to this new person and I said, 'I need somebody that can fish out what I'm telling you and do something about it or suggest to me to do something about it or arrange for something to be done about it. But I don't want to come back in here, three or four or five different

> times, saying the same thing and nothing gets done. I need somebody I can work with, that's on the same playing field as me.'

For the women in this study HIV / AIDS related stigma occurred in the medical setting while interacting with their health care providers. The source of the stigma experienced is often based on an individual's values and belief system and manifests itself in discriminatory behaviour (Herdt, 2001). Participants such as Kulwant describe inconsistent health care experiences of a discriminatory nature within the health care environment:

> I was in the hospital and the doctor was there. He was asking questions and my relatives were there at that time. They were standing there. He didn't care that all these people were there, standing. He started asking me direct questions, like 'what is HIV, how did you get it, how long have you been married for?'

Barbara encountered inconsistent health care experiences and further episodes of stigma and discrimination during the birth of her child:

> Yeah, it was because I felt, even from the hospital I felt discriminated … at delivery, yes. Because after those nurses had left, after delivery, nobody would help me clean up … I had to do it all myself. I felt no nurse would touch me. You know how they clean up after delivery, help you take a shower? Nobody would help me ... you could tell by the nurses that, *whoa* they were really careful like, 'Oh, she's HIV.' Like I heard them talking at the station, they were really mean.

All participants described examples of inconsistent health care, which affected them negatively both physically and psychologically and continue to haunt them today.

The inconsistencies occurred in the area of counselling despite the medical community's own recommendations and standards encompassing all individual's testing for HIV / AIDS. Further exacerbating their situation was the discrimination and stigma these women encountered based on their health care providers' values and beliefs. Participants described the importance of healthcare providers who took the time to listen and validate their feelings and provide the support they required but this generally tended to be the exception rather than the rule for most of the women.

*Transforming from victim to advocate.*

Despite their challenges, the experiences of living with HIV / AIDS provided each participant with a renewed sense of strength. The women described a power from within which gave them strength to create positive changes within their lives and their community. Even given their illness and personal difficulties, this is a story about five women with a drive to assist others less fortunate than themselves. These participants were shining examples of advocates not only in their lives but also in the larger community as they attempted to improve conditions for other women and men living with HIV / AIDS. Today some of these women have acquired skills from their volunteer activities that have enabled them to become activists fighting for the rights of women living with HIV / AIDS. The five women were all leaders in their own right, often exhausting themselves and compromising their own health in their endless battle to create a positive difference in the world. The theme "transforming from victim to advocate" describes the personal transformation in the lives of the women in the study.

The women in the study described the need to speak out and be listened to. Their frustrations were aimed at the local medical community, the scientific community and the individuals who specifically shape and guide policies affecting women living with HIV / AIDS. The disease continues to be seen through a lens inscribed with "gender" in which male health is seen as a priority and health care is provided by men who decide the policies and practices to be adopted. For women living with HIV / AIDS to be able to have their health care issues addressed has required them to become activists in the political arena often forcing them to disclose their HIV status and face discrimination and stigma. Jaz's encounters as a political activist were a revelation to her: she discovered she had a voice, the power to speak out and be heard:

> I was never really much of a fighter before. I mean I wouldn't really say I'm a fighter *now* but at least I'll stand up and say 'these are the issues' ... you know – at [name] it's a room full of men and a few women. At the [meeting of HIV / AIDS activists] there's probably eighteen men and two women and the other woman never talks. So, you don't have a lot of support. It's really challenging.

Barbara describes how she feels today and her personal transformation in speaking out and the frustrations she has encountered:

> How I feel today about being a woman with HIV today compared with when I got diagnosed? Well, I feel like I'm totally empowered. I'm an activist. I feel like I want to fight the world. I want to fight the government. I want them to hear what it's like, what we've suffered, why our voices aren't being heard. Where's the compensation for the families and children of HIV? We're the silent voice and I'm tired of it. I want to scream in front of that government to say, 'we're here.' which I will be doing in the coming year.

Sarnam describes her personal transformation as a south-Asian woman living with HIV / AIDS and the approach she takes when talking to others within her cultural milieu and the larger community about her experiences of living with HIV / AIDS:

> I'm talkative. I don't scare. I don't feel like any difference between white colour and black colour. It doesn't make any difference, me with Chinese peoples and another culture peoples …I want to talk to everyone if someone is really comfortable with me. Like, but more so the people, they don't want to. They always make colour difference ... A religion difference. A castism, it doesn't make any difference for me.

The transformation to feeling confident and able to speak out about one's experiences and provide support was seen as vital in the lives of the women as they gained control and power in their lives. Having their voice *listened* to was just as important for the participants as speaking out.

Deb, a long term survivor of HIV / AIDS, describes her struggle to have her health care providers listen to her health issues: "I don't want to come back in here three or four or five different times saying the same thing and nothing gets done. I need somebody I can work with that's on the same playing field as me".

Several participants described how previous to their diagnosis, they did not see themselves as individual beings with women's rights. Some did not believe they had an intrinsic right to negotiate in the bedroom at all. In fact, all the women in the study described being unaware they had run risks in their sexual lives. Jaz describes her thoughts and feelings of the situation many women face in their attempts to protect themselves both physically and sexually:

> Women are subjected to physical abuse or emotional abuse really. You are really in a demeaned position when it comes to negotiating safe sexual, or *safer* sex practices, right? So it seems like it should have been a no-brainer that the female condom should be – it's been around. Actually it was patented like back in the '30's or something so where the hell was it all those years when men were in control of sexuality?

For Jaz, knowledge is power and the beginning of her transformation from victim to advocate.

Moving from a place of being a victim to advocate also required a supportive environment, which included friends, family, and a stable financial situation. Medical knowledge and an understanding of the drug treatment regimens in the battle against HIV / AIDS were deemed paramount as the women strove to maintain their health and remain effective advocates for themselves and others living with the HIV / AIDS. This process included searching out the latest information on present and future treatments for the AIDS virus. Most of the women felt that the local clinic was an excellent source for information. However, they felt that analytical skills were required to discern whether the information they were reading was credible or just hyperbole. Sarnam felt compelled to read and analyze a wide variety of information sources in her hunger to develop a deeper understanding of the treatments available: "I want to know about everything, most of the things I want – I can find out … I always read the titles. If I feel it's really important to read it, I'd read it".

Participants recognized that a deluge of information constantly flooded them with potential and actual treatments of HIV / AIDS, some of which may not have crossed the desks of their physicians or caregivers. Jaz in her role as advocate for herself and others felt compelled to obtain most of her information from the local AIDS service organization treatment exchange:

> The people at the treatment exchange are positive, are HIV positive, that there's a more intensive there's a greater *intensity* in finding out what's going on … They know what's new. They know what's coming. We have been talking about Interleukin 2 [Potential HIV / AIDS treatment] for a good long time, six months or more before I talked to my doctor about it and he didn't know anything about it, which surprised me.

Jaz describes the efforts required and her concerns of poorly informed health care providers as she struggles in the role of self-advocacy in order to maintain her health:

> My doctor will agree to anything but I really feel like I have to be highly informed and an advocate for my own health. I don't know if he is overwhelmed, or if he doesn't read as much, or if he doesn't read the same stuff that I read … I find that a little bit worrisome actually and I don't want to say anything negative.

Deb described similar sentiments in her role as an effective self advocate:

> I used to wait for them to tell *me* what to do and now I don't. I know way more what's going on in me and I can research what I need for it too at the same time. I'm way out ahead of them, way out.

Volunteering and the role of political activism were viewed as important tools that provided opportunities for these women to improve their environment and specific situations in their lives and at the same time assist other women.

To volunteer provided an opportunity that many of the women labeled as "giving back to the community"; one that they felt provided the motivation to become involved and re-engage in life's activities. Involvement through volunteering with an AIDS service organization and working with others less fortunate than themselves provided these women with a sense of purpose and satisfaction. Initial volunteer efforts evolved into full working days, proving to themselves and those they assisted how fortunate they were to be alive. These women described an immense satisfaction at being able to share their stories with other women and to provide advice based on personal experiences. Barbara describes her satisfaction at volunteering and assisting others living with HIV / AIDS and the impact this positive experience has had on her health:

> I feel good about it; it is physical sometimes depending on what's come. Like, if I'm doing peer support it's draining but I find when give back to the community I feel good. It's taught me a lot about being compassionate. It's a good thing, it's positive for me. I don't feel useless: I feel like I'm doing something, I'm giving back. Cause if I'm not doing something I'll be getting depressed. I need an outlet, something else to focus on other than dealing with my illness all the time.

Deb described a novel experience for her. She had never felt appreciated in her marriage and her life has seemed to be without purpose. Indeed, she had passively resigned herself for death. Volunteering gave Deb a sense of purpose and deep, personal satisfaction. She remarked, poignantly: "When I started volunteering, people were very thankful to have me volunteering and I'd never really felt like that in my marriage. I'd never felt like I'd been appreciated for anything I did".

For some of the participants, volunteering allowed them to share their personal experience with others, take part in health promotion projects, and develop leadership skills. Volunteering also provided a sense of appreciation and personal satisfaction for the innumerable hours of hard work they donated. The passionate work of these women was not without its own costs. Often many of the women would spend countless hours trying to improve the situation of others in order to make a positive difference, only to return home at night exhausted from overwork. Barb describes these exhausting, yet fulfilling, days of volunteering with the local AIDS agency:

> Doing the kitchen at the AIDS agency, so I do the kitchen program where we make lunch for thirty people a day. If I do then I get [my child] ready to go to her dad's. Then I go volunteer. Then I come pick my child up.

Their involvement in volunteering and political activism provided further strength that allowed them to recognize their inherent leadership skills and the difference they could make in their community. Jaz realized such inherent skills as she engaged in various forms of political activism: "I was never really much of a fighter before. I mean I wouldn't really say I'm a fighter *now* but at least I'll stand up and say 'these are the issues'".

In their personal lives or in the larger community, all participants described the experience of a personal transformation in their lives that enabled them to shift from victim to an advocate for themselves and others. However, the process of transformation required a considerable amount of energy to tackle tough issues such as stigma and women's health care while dealing with their own illness at the same time. For some of these women, this meant public disclosure of their HIV status. Disclosure for some of the participants meant a potential backlash within their own culture. However, the participants saw HIV/AIDS education as vital to helping themselves and others afflicted with the same illness. These women felt self-fulfilled by staying involved and keeping active through their volunteer work.

These are the stories of five women who became HIV positive by circumstances outside their control. Despite their initial dreadful prognosis, they were able to come to terms with their illness and today have a limited hope for the future. The condition of these women was further exacerbated by the lack of a quality and consistent health care system; the current system is male dominated and often appears to prioritise men's health care issues. Despite the stigma and resultant discrimination these women face, they were able to use complementary and alternative medicines to take control of their personal health and enhance their overall sense of well-being. As a result of improved physical and psychological health, these women felt able and duty bound to assist both male and female sufferers of HIV/AIDS by becoming involved in peer support groups and AIDS activism. This is truly a group of women who has weathered a storm! The following chapter will discuss the findings of my research and the implications for health care providers.

# Chapter 5

## *Discussion*

The purpose of this research study was to develop a deeper understanding of the experiences of five women suffering from HIV / AIDS. The research findings from this study provide us with insight into the women's personal battles and strengths required to maintain normality within their shaken world. These are the thoughts and feelings of five women formerly unaware of the risks they faced every day, being relatively powerless in their struggle to remain HIV negative and to the danger of passing the virus on to their children. This is also the story of five women with few socio-economic factors predisposing them to the AIDS virus who nevertheless must awaken daily to the stark realities of living with this disease.

This research also provides descriptions of unforeseen risks that occur because gender frequently determines a woman's ability to protect herself in her sexual life. These are five heterosexual women whom the medical and scientific community considered at a low risk for contraction of the AIDS virus yet who tested positive for the disease. To add insult to injury, these women were also discriminated against and mistreated by the medical community whose purpose it is to provide quality health care.

This research provided me with a deeper awareness of how five women lived with HIV / AIDS and the difficulties they encountered. It also highlighted issues these women believed they needed to discuss, not only for themselves but also for other women living with HIV / AIDS. This research focused on daily struggles within these women's lives, such as accessing health care, their relationship with their spouse and family, and coping with fear and stigma. Despite their difficult experiences, these women discovered an internal power, which provided strength and resilience to survive despite their tragic diagnosis.

These are the stories of a group of women whom the world today does not consider at risk for HIV / AIDS and yet each was diagnosed with the life threatening virus. These women, however, may be the lucky ones as they *received* a diagnosis and are now able to take control in attempts to maintain their health. This research makes the important point that HIV /AIDS exists in every community and the needs of those infected and affected must be considered. We, as a society, can no longer be complacent and ignore the risks of contracting HIV / AIDS that now exist. Treatment and support initiatives have recently focused on women living within marginalized communities such as sex trade workers and those injecting drugs, but HIV / AIDS leaves no population unscathed as it affects all communities and socio-economic levels (Buzy and Gayle, 1996). Who would ever think that their mother would be at risk for HIV / AIDS? We need to ask ourselves these questions.

Women are often labeled as dirty and promiscuous when disclosing their HIV status -unlike other diseases such as breast cancer– because of the way the virus is acquired. Therefore, society takes on a completely different attitude towards women with HIV, one that is devoid of compassion and filled with blame (Taylor, 2001). For this group of women, in my study, many issues surrounding disclosure and stigma surfaced that alienated them from society and for some prevented them from seeking support at least initially.

Today a gender biased approach to HIV / AIDS exists. Women are often excluded from drug treatment trials available to men living with the disease. HIV /

AIDS is still frequently referred to as a gay male disease with supports and services designed by men for men (Hackl et al., 1997; Russell and Smith, 1998). It is difficult for women suffering from the disease to have a voice in the AIDS political arena. From my own personal experience in attending meetings organized by the local AIDS activist community, when it comes to women speaking up, middle class men who have campaigned for the rights of positive men for years, often drown out HIV positive women's voices. Jaz speaks to this bias:

> At the meeting, the [AIDS activist meeting], there's probably eighteen men and two women and the other woman never talks. So you don't have a lot of support. It's really challenging but I really feel strongly that somebody has to do it … I don't know if it's a room full of men that don't think its important or just the politics.

Health care providers view women, such as these five participants, as low risk and the potential diagnosis of HIV / AIDS is often overlooked. Women's health care is further compromised as such women may have symptoms of HIV, such as vaginitis (Sowell, et al., 1997), that are often considered to be common female complaints and any possible link to AIDS is overlooked by their health care providers. A woman today is taught to be aware of the signs and symptoms of such diseases as breast cancer yet no similar formal teaching exists for HIV / AIDS (Taylor, 2001).

Women in monogamous relationships rarely consider any potential risk for HIV for themselves and unsurprisingly, only use protection to avoid pregnancy (Amaro, Raj and Reed, 2001; Pinch, 1994; Taylor, 2001). When these five women became pregnant, testing was encouraged during routine prenatal care. Testing was not encouraged at other times (Amaro, Raj and Reed, 2001; Pinch, 1994; Giffin, 1998; Taylor, 2001).

This research demonstrates how women may have a false sense of confidence and security when it comes to their health and feel they are immune to contagious diseases. If a woman became infected she would probably infect her unborn child and be vilified for it. Women today continue to be seen as vectors of disease although the spreading of HIV is totally out of their control (Amaro, Raj and Reed, 2001).

The research provided further insight that some treatment issues for woman living with HIV / AIDS are not being addressed. For example, when they approached their health care providers to discuss issues such as side effects for medications, they were not listened to, which left these women to make their own decisions about whether or not to stop such medications. Few research studies exist that take into account medications, medication dosing and side effects specific to women (Durante et al., 2003).

Results of this study point to the need for support strategies for women. From recent observations as a volunteer in a local AIDS agency I have noticed that certain women may have access to available services within the community and feel comfortable using them. However, for most other women, accessing support services may be difficult and uncomfortable, preventing them from taking an active role in their health care. Such women are often unaware that support services even exist.

Women described the importance of knowledge and education as a stepping-stone from a being a victim to becoming an advocate. However not all women are well informed and therefore may feel helpless as they seek support in their lives. Speaking out and fighting for the rights of women living with HIV / AIDS has proven to be difficult and today only a few women have taken on this task.

Women described the importance of support in their personal lives, whether from their children, partners, extended family or the medical community. For participants, some relationships improved and flourished between them and their children. Results from this research also stressed the importance of reducing toxic relationships in the lives of the women.

The role of gender and its impact on the health of these women was clearly demonstrated. Gender based power relations between men and women often result in a heightened vulnerability to HIV transmission in women (Pinch, 1994; Taylor, 2001). It remains difficult for women in general to negotiate safer sex with their partners due to this power imbalance and these factors are further influenced by cultural values and economic dependence (Emlet, Siverson and Tangenberg, 2002). Many factors can restrict women's ability to demand safer sex, (such as having her partner wear a condom) leaving some women at a real risk for contracting HIV and other diseases (Giffin, 1998).

### *Implications for Health Care Providers*

This study revealed the importance of receiving positive medical information these women could trust as an encouragement to live fully and creatively. Hope for the future can be experienced by the reception of honest information given in a compassionate and encouraging manner. This points to the necessity that health care providers sum up what women need to know by listening to the them attentively and providing women with information in an open and candid manner: women living with HIV / AIDS need to be given the opportunity to speak and be listened to.

As health care providers we need to develop an understanding of women potentially at risk for HIV / AIDS. Questions we need to address are: "How do we become more vigilant in detection of HIV beyond prenatal screening?" Adequate prevention efforts and strategies need to be planned that can offer screening for all women.

Support for women living with HIV / AIDS must take into account *all* women's needs. Maintaining confidentiality must be ensured throughout the entire health care experience in order to gain women's trust so that they will seek support and feel comfortable to speak out. Women also need to know what supports and options are available should their marriage disintegrate or if they are become psychologically and / or physically abused in their relationship.

The five women in this study experienced difficulties with their health care from the onset. The health care system that was supposedly designed to provide quality health care failed them miserably, not only at determining they were at risk for HIV / AIDS, but once it was determined they were at risk, treated them in a inconsistent and uncaring manner. All women were diagnosed later in the infection cycle, thereby putting them at a further risk for developing AIDS. It was either through contact notification, illness, or routine prenatal care and testing that any suspicion was raised about their risk for contracting HIV. Health care providers must diagnose HIV infection in women very early on.

When the diagnosis of HIV / AIDS was made, little emphasis was placed on providing adequate counselling for these women. Some medical personnel discriminated against these women, broke their right to confidentiality and made choices for them without their prior consent. Furthermore, these women were made to feel judged and blamed for causing their own illness. Today, concrete policies exist that guide health care professionals on how to provide counselling, when to provide it and to whom it must be provided. Some support agencies already exist in the community for women with HIV / AIDS. These agencies however, should be better recognized as they are under utilized even though they are available for *all* women in need. It remains important that consistent caring medical personnel, individuals whom women can trust, be involved in their care. Their health care should include high quality counselling provided in a confidential setting. In addition, women living with HIV / AIDS can be encouraged to access support groups within AIDS service organizations which provide the opportunity for such women to speak to other women who have gone through similar circumstances.

The AIDS service organizations and the medical community need to take a more proactive approach in offering women information, especially when they face the often difficult task of requesting safe sex with their partner (Chillag et al., 2002). They need to consider potential difficulties that arise for women when negotiating safer sex due to the inherent power imbalances in such relationships. Also, such information needs to take into account a variety of cultural practices. In certain circumstances, introducing professionals from similar cultural groups and the same gender may improve the effectiveness of teaching women and their partners about safer sex practices. Women need to have easy and affordable access to all available choices such as the female condom and other forms of protection.

As this research demonstrated, health care providers often have their own prejudices and fears about HIV / AIDS that may influence the care they provide. Fear is usually born from ignorance. Education services need to be in place to provide training to professionals to help dispel fears about HIV / AIDS and to eliminate the stigma surrounding this disease (Few, 1997).

It is important that health care providers take an all-encompassing approach with women living with HIV / AIDS that addresses their emotional, psychological, physical and socio-economic needs (Gielen, McDonnell, Wu, Campo and Faden, 2003; Russell and Smith 1998). Standish et al. (2001) studied 1,675 HIV positive individuals who had used complimentary and alternative medicine to maintain their health both emotionally and physically. The women in the study affirmed that a self-care plan with holistic approaches was very important in their health regimen, which often included alternative medical therapies such as meditation, massage, acupuncture and naturopathy. Participants in their study believed that complimentary and alternative medicine improved the quality of their lives, reduced their stress and created a physical / spiritual balance. De Visser and Grierson (2002) suggest that complementary medicine and alternative therapies not be used as an alternative to antiretroviral medications but, rather, to complement these drugs.

### *Methodological Implications and Limitations*

#### *Implications.*

Leslie and McAllister (2002) posit that quality research requires strong interpersonal skills, which many nurses bring with them to the research setting. They refer to the cultural construction of "*nursedness*" in the research setting:

> Because people believe nurses to be trustworthy, caring, practical, and worldly, accustomed to dealing with matters that can be private, delicate, intimate, frightening, or even unspeakable, people tend to relate to nurses, openly, faithfully, and expectantly (p.701).

Nurses are habitually required to interview patients and to obtain very personal health information. In order to achieve these working goals, nurses must be able to build trust, probing for information in a non-threatening and non-judgemental manner. Based on my experience as a nurse researcher, I suggest that nurses and other health care providers should value and utilize their interview skills that they often "take for granted". These include their trustworthy, caring and practical approach to sensitive matters that are often private, delicate and intimate (Leslie and McAllister, 2002).

Corbin and Morse (2003) stress that the skill level of the researcher when dealing with sensitive topics may decrease the amount of emotional distress experienced by the participants. A good interview adapted to the needs of the participants such as taking appropriate breaks and postponing painful discussions builds trust and rapport. In addition to being a nurse, I believe that my experience as a researcher with a non-profit HIV / AIDS service organization contributed to the establishment of trust and rapport in the research setting. I suggest that researchers be trained in interviewing or have previous experience in interviewing prior to entering an interview setting in which participants are discussing a sensitive topic. This can contribute to a positive interview experience for both the researcher and the participant and thus contribute to high quality data.

Furthermore, de Freitas (2002) investigated a clinic in London, England providing HIV / AIDS care for south Asian women. She discovered that due to the stigma of HIV / AIDS, south Asian woman in the clinic setting would not talk to each other about HIV. de Freitas (2002) could find no south Asian woman who would talk on the record or even anonymously about living with HIV. In my research project, three woman of south Asian heritage provided insights into their personal experiences of living with the disease. I fully acknowledge and appreciate the difficulty de Freitas had in obtaining participants of south Asian descent. The women in my study were cautious about participating given the harsh repercussions they could potentially face should any other member of their tight-knit community learn of their HIV status. However from my experience, the importance of building trust and rapport with "gatekeepers" (Spradley, 1979) as a first step in accessing such participants was paramount. I suggest that researchers take the time to make themselves known to community members who may assist them in accessing participants for highly sensitive topics. Moreover, when accessing participants on a highly sensitive topic such as this, I found having the "gatekeeper" introduce me to the women who agreed to participate helped them feel more at ease. For example, in this study, the "gatekeeper" remained with the women for a few minutes to help them settle and feel comfortable prior to the start of the interview. I suggest that researchers engaged in studying sensitive topics use some of these strategies to help build trust and rapport with participants.

An important issue that arose early on in the research project was the methodological implications of my standpoint as a male researcher engaged in female ethnography. Horn (1995) discussed issues associated with female researchers interviewing women; she expected that a freer flow of information would then occur. However Horn discovered that a male interviewer is similarly effective: the success of an interviewer of either gender depends upon the establishment of a trusting relationship. I discovered that I was raising important questions and contributing important findings to the knowledge of women's experiences of living with this illness.

*Limitations.*

The results of this ethnographic study reveals the experiences of a specific participant group which may not necessarily reflect the realities of other groups of women living with HIV / AIDS. The women in this study were all proactively engaged in self care health practices aimed at improving their health. This particular group of women was educated and received support from their children, partners and family. In some cases, children provided participants with a strong incentive to remain proactive about their health so that as mothers, they could "be there" for their children. In addition this group of women did not suffer from the stresses and complications associated with poverty and drug addiction. Because this study focused on a specific participant group, findings can not be generalized to the larger population of women living with HIV / AIDS.

### *Implications for Future Research*

Current research on women and their experiences living with HIV / AIDS has clearly shown the impact of gender on women's vulnerability to contracting HIV infection (Giffin, 1998). My intended goal was not to investigate the interaction between gender and HIV contraction; however, this study emphasized the vulnerability women face as a direct result of their partner's behaviour concerning safer sex practices. Future research needs to answer questions such as the number of women who are infected, their demographic profiles and why they are becoming infected. We must ask whether supports are in place to address infected women's needs. Are the services we are providing working for all women and if not what types of services are required? For example, what services are in place for women with families? Furthermore, women need to be included in drug treatment trials specific to women and in research focused on related side effects of such drugs specific to the female body.

Using the ethnographic methodology, future research should focus on a broader sample of women in the culture at large. This could contribute to additional insights into women's experience of living with HIV / AIDS and into women's experiences of health more generally. Future research about women's health may reveal that a gender bias exists for women living with other chronic diseases. For example, in the area of cardiac disease, which is often perceived to be mainly a male illness, it would be important to learn whether a gender bias exists as well. We need to learn whether women presenting with a broad range of health issues are diagnosed with the same effectiveness as men and whether women have equal access to treatment and support.

This research is not a conclusion but a new platform for addressing the issues concerning women's experiences of living with HIV / AIDS. I have highlighted the three themes of feeling limited hope, experiencing inconsistent health care and transforming from victim to advocate. We need to head towards a place of greater life expectancy for those living with HIV / AIDS. This will be accomplished with research on drug treatments and vaccines for all living with HIV / AIDS. For women living with HIV / AIDS, the struggle to be heard and acknowledged continues. To change attitudes of health care providers and the larger public, further education is required in the warning signs of HIV / AIDS. In order to achieve this we must set aside the stereotypes and stigma so that we are not blinded from seeing all potential victims by half-truths. If women do become positive we must be able to recognize their condition and treat them with the dignity and respect they deserve. We must seek to provide for not only their physical and mental needs but also their spiritual and family needs.

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Table 1 – Categories

| | PARTICIPANT 1 |
|---|---|
| 1. | Family – big family |
| 2. | Relatives – Knowing, relatives who found out |
| 3. | Not knowing what HIV was (Knowing HIV) |
| 4. | Dealing with diagnosis (what's going to happen) |
| 5. | Husband dealing with infection of wife (being ashamed) |
| 6. | Participant dealing with diagnosis and pregnancy |
| 7. | Daughter being positive – her future, how's she going to deal with it |
| 8. | Family, friends: how are we going to visit |
| 9. | How did this happen, shame |
| 10. | Education, lack of knowledge of HIV / AIDS (transmission) |
| 11. | Acceptance - what life is like |
| 12. | Working, keeping mind off things, coping |
| 13. | Facing future, living with diagnosis, remembering before diagnosis |
| 14. | Clinic, family feels supported, hope |
| 15. | Community. Fear, contagion dangerous disease |
| 16. | Diagnosis, doctor's, accusing participant, disclosing by doctor |
| 17. | Feeling sick, weathering illness |
| 18. | Baby, worries of baby's health and taking meds and care |
| 19. | God, hope, God and meds will help |
| 20. | Hope, potential cure, obtaining knowledge |
| 21. | Relatives, try to support, they know reality, drags them down |
| 22. | Community, lack of knowledge, know about HIV / AIDS, poor education |
| 23. | Living with HIV, difficult, thinking of future, what will happen, why me |
| 24. | Diet, food will help health |

Table 2 - Categories

| | PARTICIPANT 2 |
|---|---|
| 1. | Diagnosis and treatment with participant and husband, shock |
| 2. | Living with diagnosis, coping, being unsure about future |
| 3. | Latest information, accessing information, knowing is dealing with it |
| 4. | Life in south Asia versus Canada, early marriage, early work, early HIV |
| 5. | Pregnancies, miscarriages, giving birth with HIV, worried about child |
| 6. | Need to be tested and on treatment, to live longer |
| 7. | Wanting to be part of the world, the unknown, curiosity |
| 8. | Personal desires and how HIV has affected those, more independence |
| 9. | Work – long days, 8 hours & working at home |
| 10. | Living with HIV, illness, Hope, shortened life, reality all the time |
| 11. | Community, ignorance of HIV / AIDS, people don't want to know |
| 12. | i) Diet: poor adherence, knowing impact of good diet |
| 13. | ii) Diet: western versus Indian food |
| 14. | Women, education, south Asia (sexism) |
| 15. | Family, sister, concern, support |
| 16. | Non disclosure in south Asian community, (religion, castism) |
| 17. | Belief in diet & medications, improving health, with side effects |
| 18. | Making excuses for health to those who don't know (tougher for husband) |
| 19. | Longing for children to be looked after and have best – should participant die |
| 20. | Husband has improved behavior since diagnosis (cultural) |
| 21. | Difficulty in taking medications around friends and family |
| 22. | South Asian people not educated, don't want to know |
| 23. | i) Husband different now, different relationship |
| 24. | ii) Participant more aggressive, uses disclosure for bargaining, husband lazy |
| 25. | i) Clinic good, health promotion, very important for health |
| 26. | ii) Takes all day, good treatments, staying healthy |
| 27. | The unknown, worrying about future, trying to normalize |
| 28. | Talking to others of same and other cultures to promote health |
| 29. | Problems with medications & disclosure, especially around those close to them |
| 30. | South Asian culture, children, how will daughter respond to diagnosis |
| 31. | Transmission, issues and confusion for participant & community |
| 32. | Community: if it doesn't affect them – happy not knowing |
| 33. | South Asian community – siding with male no matter what |
| 34. | Dealing with diagnosis, death as inevitable, upset crying |
| 35. | Hard working, happy, keeps mind off illness |
| 36. | Normalizing with others, tiring sometimes |

Table 3 - Categories

| | PARTICIPANT #3 |
|---|---|
| 1. | Activism, sexuality, women's issues, politics, condom |
| 2. | i) Medical system, unable to get diagnosis, lung disease |
| 3. | ii) Unable to figure out PCP, sick but no diagnosis |
| 4. | Participant + but husband not, he wanted to blame, husband wanted to marry |
| 5. | Living with diagnosis, friends, family devastated, everybody knows |
| 6. | Lung disease, tests done, treating for other ailments but not PCP |
| 7. | Physician finally finds diagnosis, doing thesis, trying to cope, knowing HIV+ |
| 8. | Challenges in south Asian Canadian community, women's issues, violence, |
| 9. | Sewing, factory work, urge to do more, use intelligence |
| 10. | Family background, culture mixed, living on farm |
| 11. | Exercise, fatigue, need for rest, limited reserve |
| 12. | Husband's need to be close and to provide |
| 13. | Stress and its impact on health, stress as negative |
| 14. | Challenges young and single parent |
| 15. | University, sick during most of that time |
| 16. | Activism, few women, difficult, toxic, need for women's issues to be heard |
| 17. | Coping strategies during acute illness, not realizing severity of HIV / AIDS |
| 18. | Illness during school, respiratory problems coupled with cognitive problems |
| 19. | Impact with HIV / AIDS, immediate grief, shock |
| 20. | Stigma, misbehaving, safety around disclosure, physical, emotional abuse |
| 21. | Realization of living with HIV / AIDS, connecting respiratory problems with HIV / AIDS |
| 22. | i)Literature, sources of information, Info newsletter better than Dr's info & clinic |
| 23. | ii)Clinic: need to be your own advocate, being more informed than Dr. |
| 24. | Holistic approach, meditation, not working, staying stimulated and balanced |
| 25. | Daily routine, healthy food, exercise, body image, walking |
| 26. | Stable lifestyle, no worry about material, not marginalized, good friends |
| 27. | Hope, being spiritually grounded, setting ones own course |
| 28. | HIV / Lipodystrophy, waiting for vaccine, knowing what will stimulate T-Cells |
| 29. | Diagnosis loss of weight, things not much different today |
| 30. | Getting over HIV / AIDS, moving on, stereotype of HIV / AIDS |

Table 4 - Categories

| | PARTICIPANT #4 |
|---|---|
| 1. | Exercise, program and meds to improve health |
| 2. | Females, addiction, bleak outlook, |
| 3. | Women, HIV. Pregnant, ASO's had little information, (being good example) |
| 4. | Post – delivery, recovery, difficulties, little support, |
| 5. | Lack of family support, as well as support from husband |
| 6. | Daughter healthy, understanding mom's illness, Hope |
| 7. | Experience of finding out HIV, didn't know much about HIV / AIDS |
| 8. | Long days, difficult, mom & daughter |
| 9. | Dealing with diagnosis, psychological therapy, religion, doctor who give 2 years life span |
| 10 | Alienation, stigma, lack of compassion form health care providers, discrimination |
| 11 | Relationship, dysfunctional, , controlling, abusive, no support, draining |
| 12 | Complicated delivery, no bonding, no touching, too scientific |
| 13 | Growing up, background, separated, radical |
| 14 | Drug holidays, taking control, fear of progression of disease |
| 15 | Disclosure and consequences thereof, stigmatism, activism, government's role |
| 16 | Connecting with good doctors, pregnancy, helpful nutritionist, support from doctors |
| 17 | Drug treatment throughout pregnancy, feeling ill due to AZT, losing weight |
| 18 | Start of the day, eating, exercise, meditation, meds |
| 19 | Becoming voice for women with HIV / AIDS, activism, working in govt. to improve for women |
| 20 | Clinic team listens, follows up, supports, receives meds at clinic |
| 21 | Volunteering, AIDS Service Organization's kitchen, peer support, feeling good, giving back to community |
| 22 | Separation, independence, quality of life, outgoing, compassionate |
| 23 | School, education, feeling empowered, |
| 24 | Difficult physician, required therapist, slow recovery from event |
| 25 | Faced with abortion: refuses, discrimination, physician didn't ask for approval of abortion, refusal |
| 26 | Few women with HIV empowered, difficult backgrounds, speaks, connecting with other good women |
| 27 | Discovery of contraction: discovered HIV during prenatal check |
| 28 | Delivery, baby: AZT, immediate test positive, 6, 12, 18 months negative, difficult waiting for result |

Table 5 – Categories

| | PARTICPANT #5 |
|---|---|
| 1. | Doctors difficulty getting a health diagnosis |
| 2. | Had idea might be +, waited 6 months to test, husband tested, major shock |
| 3. | Work hard, push envelope, volunteer, lack sleep |
| 4. | Medical community, women & drugs, little known on impact or harm |
| 5. | Dealing with diagnosis, from victim to engaging and participating |
| 6. | Volunteering with AIDS Service Organizations, purpose in life, appreciation |
| 7. | Volunteering in AIDS community, appreciated, learning lots |
| 8. | With husband trying to get ahead, |
| 9. | Participant had little hope in spite of doctors comments, now more Hope with drugs |
| 10 | Relax, do yoga, no great energy |
| 11 | 10 years later, not a death sentence, immediate reaction was grief and thoughts of death |
| 12 | Healthy eating, difficulty with digestion, yeast infections, few foods healthy |
| 13 | Pre – diagnosis, exhaustion, night sweats, later grieving, overwhelmed |
| 14 | Receiving support form men & women, helping others walk the walk |
| 15 | On disability, self pity |
| 16 | Difficulty with trial meds, stomach problems, not allowing patient input into choice |
| 17 | Bloating, on drug holiday, drug resistance, |
| 18 | Doctors treating without proper diagnosis, tired of being judged |
| 19 | Drug holidays short, drop in T-Cells, |
| 20 | Different drug regimens, last 8 months, T-Cells low, little rest from drugs, on front lines of trt. |
| 21 | Typical day up at 7, office at 11, chair of different committees, busy, surprises |
| 22 | Cough, rash, no diagnosis, given anti-fungal after requesting: improvement |
| 23 | Lack of diagnosis from GP, became pissed off, found new GP |
| 24 | Contagion concerns from family, non disclosure to others |
| 25 | New physician – unaware of meds, needs, and procedures |
| 26 | Seizing opportunities, moving ahead |
| 27 | Life with first & second husband, family life, life with kids, relationships, grandchild |
| 28 | i) Improving relationships with family, children, mom worried |
| 29 | ii) No energy to visit, told children HIV+ through husband: realized bad move |

Table 6 – Larger Categories of Meaning

| | |
|---|---|
| 1 | Diet |
| 2 | Education / Knowledge |
| 3 | Clinic |
| 4 | Hope |
| 5 | God |
| 6 | Obtaining a diagnosis / dealing with the diagnosis |
| 7 | Family |
| 8 | Husband – response and coping with a diagnosis |
| 9 | Daughter – issues, concerns, health |
| 10 | Challenges within the south Asian community |
| 11 | Relatives and associated issues |
| 12 | Work, Volunteering, Projects |
| 13 | Relaxing, holistic approaches to health |
| 14 | Activism |
| 15 | Drugs, treatments and associated issues |
| 16 | Illness |
| 17 | Living with HIV |
| 18 | Stigma, racialization, socio-economic issues |
| 19 | Issues within healthcare and the medical system |

# Appendix A – Demographic Survey

## Demographic Data Collection Sheet

Code Number: _______________

1. Age: 19-24 _____
25-30 _____
31-35 _____
36-40 _____
41-45 _____
51-55 _____
60+ _____

2. Religion: Muslim: _____
Hindu: _____
Christian: _____
Sikh: _____
Budhist: _____
Jain: _____
Other: _____

3. Cultural Origin: Pakistan: _____
India: _____
Sri Lanka: _____
Bagledash _____
Nepal: _____
European: _____
Canadian: _____
Other: _____

4. Country of Origin: Pakistan: _____
India: _____
Sri Lanka: _____
Bagledash _____
Nepal: _____
Europe: _____
Canada: _____
Other: _____

5. Marital Status: Single: _____
Married: _____
Children: Yes: _____ No: _____
Arranged Marriage: _____

6. Employment Status: Unemployed: _____
Employed full-time: _____
Employed part-time: _____
Professional: _____
Labourer: _____
Social Assistance: _____ Self: _____ Family: ____

7. Level of Education: Less than high school:_____
High school diploma: _____
College diploma: _____
University degree: _____
Other: _____

8. Citizenship: Born in Canada: _____
Recent Immigrant: _____ Year: _____
Awaiting Immigrant Status: _____

9. Family Situation: Living alone: _____
Living with husband: _____
Living with husband and children: _____
Living with husband and children and extended family: _____
Living with husband and extended family: _____
Other: _____

10. Health Husband HIV+: _____
Children HIV+: _____ If yes, more than one: _____
Are you currently on treatment: _____
Has your husband been on or is he currently on treatment: _____
Have your children been or are they currently on treatment: _____

# Appendix B

## Interview Questions

## What are Women's Experiences of Living with HIV / AIDS?

Interview Questions

CODE: ___________

Explanation of research ______________
Consent ______________
Demographic Sheet ______________

Interview Questions

The following descriptive questions are designed to encourage the participants in the project to talk about their particular "cultural scene" (Spradley, 1979). Through a process of asking open-ended questions, the participants will be given the opportunity to discuss their experiences and the meaning associated with them.

1. Can you tell me about yourself / family?
2. I would like to give you the opportunity to provide me insight and to teach me what it is like for you as a women, an expert of your own experience to be living with HIV / AIDS.
3. I am interested in what it was like for you to discover that you were HIV+ and how you have dealt with this diagnosis as well as your experiences since that time.
4. What is different about your life since your diagnosis of HIV / AIDS?
5. What in your life is the same, it at all?
6. If I were to observe you in your home life as a woman living with HIV / AIDS, what would I notice in a typical day?

Opening Remarks

As you know, I am interested in learning about your experiences living with HIV / AIDS as a women living with this disease. I think it is important to ask the questions so that health care providers as well as professional and lay people understand your experience. I think it might be helpful in preparing us to assist you and support people like you facing your experience of living with HIV / AIDS.

Prompts

tell me about your experiences when you first found you were HIV positive and what it is like now to be living with HIV / AIDS?

your feelings are ………….

the experiences are ……….

how is your life different / the same, now and before you diagnosed with HIV / AIDS?

what helps?

what makes it difficult?……

# Appendix C

## INFORMED CONSENT

## Title: WHAT ARE WOMEN'S EXPERIENCES OF LIVING WITH HIV / AIDS?

You have been asked to participate in a Master's thesis research study. It is hoped that by sharing my experiences of living with HIV / AIDS, health care providers will develop a deeper understanding of those experiences and be able to provide culturally sensitive health care strategies. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time without affecting my care at the clinic.

### Purpose

The purpose of the study is to better understand the unique experiences of women around treatment and care living with a diagnosis of HIV / AIDS. You are being asked to participate because you are living with HIV / AIDS.

### Procedures

If you agree to take part in this study, you will be interviewed on one to two occasions for approximately 1 - 2 hours, at a time mutually convenient to you and the researcher. The location will be at the Clinic in a quiet, private place of your choosing. The interviews will be tape - recorded and at a later time what is on the tape will be typed in order to allow the researcher to analyze the information from the interviews.

### Risk and Potential Benefits

If as a result of the interview, you feel overwhelmed, the researcher will help provide supportive counseling, to help you work through your feelings. Should you require further supportive counseling, the social worker at the clinic will also be available to provide such counseling.

### Confidentiality

Any information resulting from this research study will be kept strictly confidential. Any identifying information will have a code number. All notes, interview materials and audio tapes will be kept in a locked filing cabinet with only the researcher having access and will be used for purposes of the Master's research. The only people who will listen to the tapes and see the transcriptions will be members of the thesis committee and possibly a transcriber. All interview tapes will be stored in a locked cupboard and all interview tapes will be destroyed when all written reports are complete.

## Remuneration / Compensation

In order to defray the costs of inconvenience/ transportation and childcare expenses, each participant receive an honorarium in the amount of $ 30.

## Subject Consent

I understand that my participation in the study is entirely voluntary and that I am free at any time to withdraw from the study, free to refuse to answer any questions and can at any time ask for the information to be erased or sensitive information not to be revealed anytime without affecting my care and treatment at the clinic.

I have read the above information and I have had the opportunity to ask questions to help me understand what my participation would involve. I freely consent to participate in the study and acknowledge receipt of a copy of the consent form.

_______________________________________
Signature of Participant Date

_______________________________________
Signature of Investigator Date

_______________________________________
Signature of Witness Date

# VITA

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| | |
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