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Listening to the voices of women living with HIV/AIDS: A qualitative study of psychosocial impact and quality of life issues

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Listening to the Voices of Women Living with HIV/AIDS
A Qualitative Study of Psychosocial Impact and Quality of Life Issues

By

Edna Aryee

BA (Hons), University of Ghana, Legon, 2000

THESIS
Submitted to the Department of Psychology
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ABSTRACT

In spite of the increasing number of women infected with HIV around the world, little is known about the psychosocial experiences of these women. In the mid-1990s, medical advances dramatically altered the experiences of living with HIV/AIDS. The shifting medical climate raised new social and psychological questions such as coping strategies and the possibility of gaining access to resources and services in the community. In this qualitative study, I examined how 5 women living with HIV/AIDS in Southern Ontario deal with their daily psychosocial needs and challenges. Based on a life history methodology, responses of participants were coded and analyzed in relation to the ecological framework of community psychology. The thematic analysis indicated that despite the existing medical, governmental, and community support provided in a Canadian context for women living with HIV/AIDS participants nevertheless faced numerous daily challenges. Psychosocial challenges that were identified included: stigma and social exclusion fear of death, suicidal ideation, as well as lack of adequate or appropriate support from healthcare professionals and psychologists. In addition participants also noted frequent experiences of loneliness, housing problems, poverty and unemployment as part of their every day challenges. Although the women reported adequate levels of support, it was also noted that there is an urgent need for various directions for enhanced services for HIV/AIDS women. The findings of the study are discussed in relation to the development of holistic, psychosocial strategies to address the daily needs and challenges of women living with HIV/AIDS. Findings have conceptual and methodological implications for future psychosocial research on the quality of life issues on women living with HIV/AIDS.

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Finally I am grateful to the Almighty God for His Grace throughout my studies in Canada.

DEDICATION

I dedicate my work to all women living with HIV/AIDS, affected families, HIV/AIDS orphans and men and children living with HIV/AIDS in the world.

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CHAPTER ONE

INTRODUCTION

1.1 Preface

The Acquired Immune Deficiency Syndrome (AIDS) caused by the Human Immunodeficiency virus (HIV) continues to be among the leading causes of death in our present world (Annan, 2003). According to Penedo et. al., (2003, pp 203-213), "HIV disease is characterized by a progressive depletion of CD4 T-lymphocytes, a subset of white blood cells responsible for coordinating and regulating immune responses. This condition eventually leads to impairment of immunologic function leaving the infected individual susceptible to opportunistic infections such as pneumonia and other diseases normally prevented by the immune system. In addition once infected with the virus, HIV+ individuals must endure a debilitating and unpredictable clinical course that can impact all facets of their lives."

The chronic and debilitating course associated with living with HIV/AIDS (e.g., fear, social stigma, uncertain disease course, unemployment, complex regimens and medical costs) has been associated with increased depression, suicidal ideation, anxiety and poor quality of life (Siegel & Schrimshaw, 2005). Again, these challenges may overwhelm an individual's capacity to effectively cope with the stressful demands associated with HIV/AIDS and compromise not only the psychological well being, but also the physical health (Siegel & Lekas, 2002) of the person. Since the development of the Highly Active Antiretroviral Treatment (HAART) for HIV/AIDS, more individuals are coping with the chronic, complex and unpredictable course of this disease. These medication regimens, although highly effective, must be strictly followed (i.e. > 95% adherence) in order to obtain the therapeutic gains from the medications and prevent viral mutations and drug resistance to HAART regimens (Al-Harthi & Landay, 2002).

1.2 Personal Standpoint

Throughout my work as an HIV/AIDS advocate I have realized that while a lot of research is been conducted on HIV/AIDS; most of these studies to a large extent have focused on prevention, treatment and pharmaceutical intervention (Snyder, et al., 1991). In a similar manner, a great deal of HIV/AIDS research is centered on African cultures (Lamptey et. al., 1997) and North American males. The phenomenon of women living with HIV/AIDS has been relatively understudied (Burgess et al., 2000). Despite women's increasingly high representation among diagnosed cases of HIV/AIDS, few published studies specifically address women's psychological adaptation to the HIV/AIDS disease. This information is increasingly important, especially as combinations of new antiretroviral medications are enabling seropositive patients to delay progression of the disease (Deeks et al., 1997). In addition, it is also known that very little research has examined the psychosocial difficulties affecting persons with HIV/AIDS who are being treated with HAART combination therapy regimens even though these regimens may carry mental health implications (Kelly et al., 1998). It is only in the last few years that researchers such as Lee et al (2002) begun to fully and publicly recognize the relationship between the psychological effects of social exclusion and stigma for women living with HIV/AIDS (Lee et al., 2002).

It is important for us as professionals to note that a long and sustained effort will be required to effectively address and reduce the stigma and challenges associated with HIV/AIDS among infected women. My research is focusing on the relationship between the social context and psychological wellness of women who are living with HIV/AIDS in Southern Ontario (Toronto). My aim is to increase the understanding of the specific experiences, challenges, quality of life and coping and survival strategies for women living with HIV/AIDS in our communities.

I will begin by addressing the question of perspective and identity, "why is a young Ghanaian woman interested in working with women living with HIV/AIDS in Southern Ontario?" I am of the view that my background and subjective position as an African woman, my cultural background, socio-economic and international status influence my interpretation of issues around women's health. Indeed my personal reflection and subjectivity has affected my choices, feelings, thoughts and interpretation of women's issues. Having worked with women living with HIV/AIDS in Ghana has helped me understand the psychosocial experiences, challenges, survival and coping strategies of HIV/AIDS women in developing countries. My thesis study on HIV/AIDS is an opportunity for me to transfer my knowledge and skills into the Canadian community as well as gain specific skills and knowledge in graduate school to transfer back to the Ghanaian community.

I grew up in Ghana; however my family frequently traveled and lived in several African countries. During these periods; I learned to understand the various struggles that people go through to make life a little more comfortable. Growing up in a family of educated individuals is a privilege yet at the same time it is challenging and very competitive. My parents being erudite and devoted Christians expected me to live by certain standards and principles in the society. In addition, my external family also played a significant role in my life. In traditional Ghanaian communities, every child is a treasured element of the society irrespective of how the child was conceived. Behind every Ghanaian, there is the extended family, which is made up of uncles, aunts, cousins, grandparents, and so on and they all serve as sources of strength.

Growing up in such a broad family setting and the unique role played by my parents gave me the opportunity of living with several family members which influenced my life in a significant way. My entire family placed emphasis on culture, social justice, and empowerment in the life of each individual especially the empowerment of women in the family. I have grown to accept the fact that the greater number of women in my family placed the women in a more influential position than the men. This significantly affected the way younger females, such as myself, asserted and presented ourselves. I grew up accepting women as equal individuals in the community and learned to acknowledge everyone in a unique way.

Coming to Canada as a student admitted into the Community Psychology program at Wilfrid Laurier University serves as a turning point in my life not only because I am studying in a developed country but also because I am in a profession/program that reinforces values that are congruent with the values of my country and community in Ghana. Ghana is a developing country on the Western Coast of Africa and is not a country one can describe as wealthy by any economic explanation, yet it is a country that appreciates diversity and multiculturalism. As well, due to our stable peaceful socio-political environment, we are able to attract multinationals into the country.

Traveling to various countries gave me the opportunity of developing my potential and skills in the area of social change, empowerment and social justice. At the age of eight, I joined the Nigerian branch of the United Nations Education and Scientific Organization (UNESCO) and the Red Cross Society. At that early stage I had the passion for empowerment of young girls in my community and always wanted to know why girls took certain programs in school whilst boys were encouraged to take the sciences and mathematics. Later in Ghana, at the age of fourteen I joined the Planned Parenthood Association as a peer educator and an advocate. Working with women affected by sexual and domestic abuse also paved the way for me to connect my psychological values and the real world issues during the writing of my undergraduate thesis.

I sometimes see myself as an individual torn between two worlds, trying to understand the gap between the disadvantaged and the privileged. I deeply value the problems of disadvantaged individuals; especially women as universal, and am convinced about the need to do something to improve women's quality of life. The strong experiential background and knowledge I had during those years came to the fore as I presented my research findings to the United Nations Population Fund office in Ghana. These findings based on a review of literature, grounded facts, personal experiences and systematic quantitative methods, motivated me to look beyond the status quo to what could be done to empower women in my community. These experiences had a strong impact on my life and contributed to my current career path.

Unsurprisingly, choosing a career in psychology appears to me as a mission to help disadvantaged people in our community, especially women. I have always had the passion to effect change in the lives of women and girls on a larger scale in my country yet at the same time I felt very incapable, lacking adequate resources and skills. I realized that passion is an important and vital part of my work to effect change as a young advocate. However, I would need to supplement this zeal with professional and practical skills such as proposal writing for funding, skills in evaluation, needs assessment, logic model development, participatory action research, and lobbying techniques among others.

Here in Canada, my practicum experience with Kitchener-Waterloo Sexual Assault Centre has sharpened my experience in working with women affected by sexual and domestic violence. Again, experiential knowledge has broadened my concepts of violence against women, which cuts across all cultures, race, class and socio-economic status. This cross-cultural experience has made it a perfect fit with my interest and passion to understand the psychosocial impact and quality of life issues of women living with HIV/AIDS in Southern Ontario. My personal encounter with women living with HIV/AIDS in Southern Ontario at various training programs, seminars and conferences has heightened my awareness of the multiple psychosocial challenges that these women are confronted with despite the availability of medical and clinical support and resources. Consequently, even though these women are given available medical and clinical support, I perceived that there was still a critical need to understand the experiences, psychosocial needs and support for women living with HIV/AIDS in southern Ontario.

1.3.1 Understanding HIV/AIDS?

According to Patterson (1997), HIV (Human Immunodeficiency Virus) is a virus which attacks the body's immune system; however for a certain period of time and for several years the body's defense mechanism may mask and keep the HIV infection under control. During this time, a person with HIV may feel completely well and have no symptoms; however, in the majority of cases, the immune system eventually needs help, in the form of anti HIV drugs, to keep the HIV infection under control. After HIV enters the body through unsafe sex (unprotected sex), contaminated needles, and blood transfusions or from mother to child (vertical or perinatal transmission) it comes in contact with a host T-cell. When this happens, HIV will "hijack" the host cell's cellular machinery to reproduce thousands of copies of itself. People infected with the virus can have a wide range of symptoms from no symptoms to severe symptoms. At least a fourth to a half of those infected with HIV will develop AIDS within four to ten years (Canadian AIDS Society, 1995). The term AIDS first appeared in the Morbidity and Mortality Weekly Report (MMWR*)* of the Centers for Disease Control (CDC) in 1982 to describe "a disease, at least moderately predictive of a defect in cell-mediated immunity, occurring with no known cause for diminished resistance to that disease" (CDC, 1982).

Lee, et. al., (2002), recognized that HIV/AIDS is a highly stigmatized disease; however there has been a dearth of research on the internalization of this stigma by people living with HIV/AIDS (PLWHA). The management of HIV/AIDS involves responses to a wide variety of disease-related stressors and it is possible that the emotional disclosure and processing of these stressors impinge on the health and immune status of those living with HIV/AIDS (O'Cleirigh et al., 2003). HIV/AIDS has four characteristics that account for why it is so highly stigmatized (Herek, 1999). First, it is a disease that is perceived as the bearer's responsibility because the primary modes of transmission of the infection are behaviors that are considered voluntary and avoidable. Second, it is perceived as a condition that is unalterable and fatal, although the effectiveness of HIV/AIDS antiretroviral treatment (HAART) has begun to change the perception of HIV to one of a chronic illness (Novick, 1997). Third, conditions that are contagious always have greater stigma attached to them. Fourth, conditions that are visible to others, such as the advanced stages of AIDS, are more stigmatized. In addition, HIV-related stigma is heightened because it is "layered" upon the stigmas associated with homosexuality, drug use, and sexual promiscuity (Crawford, 1996).

The impact of HIV/AIDS stigma affects both HIV-positive and HIV-negative persons. The stigma associated with HIV/AIDS negatively impacts people's decisions regarding whether and when to be tested for the virus (Chesney & Smith, 1994). It also deters many HIV-positive people from seeking medical care and from disclosing their HIV status to others because doing so can lead to rejection, discrimination, hostility, and physical violence (Chesney & Smith, 1999). In turn, the choice to not disclose one's HIV status can lead to an increased sense of isolation and psychological distress among HIV-positive people (Crandall & Coleman, 1992) and/or an increased likelihood of engaging in unsafe sexual practices (Wenger et al., 1994). Stigmatized individuals are also vulnerable to feelings of self-hatred, which can result when they internalize society's negative views of them (Herek, 1990; Lewis, 1998; Novick, 1997). This is likely to negatively affect their HIV status and appropriate disclosure of HIV status (Alonzo, et al., 1995).

1.4 Rationale of Study

The need for better understanding of the psychosocial needs, experiences, challenges, quality of life, survival and coping strategies among women with HIV/AIDS is widely recognized (Center for Disease Control and Prevention, 1997). The present study was designed to explore and document the lived experiences, challenges, coping and survival strategies and quality of life for women with HIV/AIDS as well as address gaps in knowledge and services by increasing understanding of the specific experiences of individuals living with HIV/AIDS at multiple levels: the family, health system, community. This research was a logical step in providing community stakeholders with information that allows for, and can guide in addressing the issue of lack of psychosocial support, resources and services at the individual, family, community and government level for women with HIV/AIDS.

1.5 Paradigm: Constructivist- Feminist-Epistemology

Feminist epistemology attends to the ways in which gender does and ought to influence our understanding and knowledge of women's issues (Larson, 1990). Feminist researchers identify ways in which dominant conceptions and practices of knowledge attribution, acquisition and justification systematically affects disadvantaged women and other subordinated groups (Cochran, et al1989). As a researcher informed by feminist beliefs about knowledge and power, I identify with researchers such as Anderson (1995) who strive to challenge and change the misconceptions and practices surrounding feminist activities.

The stereotypes of the "good woman" and the "bad woman" have heavily influenced public thinking about women and HIV/AIDS (Siegel, 2000). HIV/AIDS is often associated with promiscuity. In my experience, women in Ghana are most often blamed for spreading the disease to male partners, despite the lack of evidence of this claim and given the biological knowledge of transmission common to all populations (Aggrey, 1990). A feminist research lens requires that we examine how the social relations of gender influence our experiences, research and practices. Though feminist methodologies began by focusing on gender, a critical feminist work considers rectifying all the various forms of social inequalities based on race, class, sexual orientation, ability and gender (Frye, 1983). The use of feminist life history methodology in this study with women living with HIV/AIDS provided a critical lens into the discovery of the quality of life issues of these women.

CHAPTER TWO

LITERATURE

As a prerequisite to understanding the purpose, importance and direction of this study, I have provided a review of the literature in diverse areas as well as purpose of the study and the research questions.

2.1 Reviews of Theories and Definitions

The origin of the human immunodeficiency virus (HIV) is controversial. The earliest known case of HIV in a human was from a blood sample collected in 1959 from a man in Kinshasa, the Democratic Republic of Congo (Dickson, 2000). Genetic analysis of this blood sample suggested that HIV may have stemmed from a single virus in the late 1940s or early 1950s and may have existed in the United States since at least the mid- to late 1970s (Hooper, 1999). From 1979-1981 rare types of pneumonia, cancer, and other illnesses were being reported by doctors in Los Angeles and New York among a number of male patients who had sex with other men. These were conditions not usually found in people with healthy immune systems (Berry, 1998). In 1982; public health officials began to use the term "acquired immunodeficiency syndrome," or AIDS, to describe the occurrences of opportunistic infections, Kaposi's sarcoma (a kind of cancer), and *Pneumocystis carinii* pneumonia in previously healthy people (Pybus, 2000).

Formal tracking (surveillance) of AIDS cases began that year in the United States (Robertson, 2000) and in 1983; scientists discovered the virus that causes AIDS. The virus was at first named HTLV-III/LAV (human T-cell lymphotropic virus-type III/lymphadenopathy-associated virus) by an international scientific committee. This name was later changed to HIV (human immunodeficiency virus), (Pybus, 2000). For many years scientists theorized as to the origins of HIV and how it appeared in the human population, most believing that HIV originated in other primates. Then in 1999, an international team of researchers reported that they had discovered the origins of HIV-the predominant strain of HIV in the developed world (Korber, 2000). A subspecies of chimpanzees native to west equatorial Africa had been identified as the original source of the virus. The researchers believe that HIV was introduced into the human population when hunters became exposed to infected blood (Korber, 2000).

2.1.1 The Contaminated Polio Vaccine Theory

According to the oral polio vaccination (OPV) hypothesis, the main (M) group of HIV-1 (the viruses responsible for the majority of global AIDS cases) emerged as a result of the vaccination of about one million people, who were largely living in the Congo from 1957–60, with an oral vaccine against polio virus that had allegedly been cultured in chimpanzee kidneys (Hahn, 2000). This is claimed to have enabled the transfer to humans of chimpanzee simian immunodeficiency virus, the closest relative of HIV-1(Hahn, 2000).

Batches of experimental oral vaccines against poliovirus (OPV CHAT) that were administered in Central Africa in the 1950s have been implicated in the origin of the AIDS pandemic because of possible retroviral contamination during the vaccine's manufacture, which allegedly involved chimpanzee kidney cells. The potential for oral polio vaccines to initiate the AIDS pandemic has been investigated previously. Many species of African non-human primates are naturally infected with simian immunodeficiency viruses (SIV) and the common chimpanzee (*Pan troglodytes*) harbours SIV, the closest relative to modern strains of the human immunodefiency virus HIV-1. The use of chimpanzee cells to prepare CHAT vaccine may therefore have resulted in the inadvertent transmission of SIV to humans (Hahn, 2000).

2.2 Background of the Study

The profile of the HIV/AIDS epidemic in Canada has changed. The profile of a disease that initially affected men who have sex with men and other marginalized groups, such as injection drug users is increasingly changing. Significantly, there is now a growing number of women living with HIV/AIDS in Canada (Health Canada, 2004). In 1993, women represented 7.5% of reported AIDS cases; in 2003, women represented 24.8%. By the end of 2002, there were 7,580 positive HIV test reports among women in Canada; this represents 15.3% of positive HIV test reports among adults (Health Canada, 2004). The proportion varies considerably by age and is highest among young women (15-29 years old). Aboriginal and Black women have also been identified as vulnerable populations. It is estimated that 3.1 of every 10,000 pregnant women in Ontario in 2002 were HIV-positive (AIDS Committee of Toronto, 2004).

Biological and social realities cause different HIV/AIDS risk factors and infection patterns for most women. Access to prevention, care, treatment and support may also vary for men and women. Women are infected with HIV mainly through unprotected sexual acts (such as vaginal and anal sex without a condom) and injection drug use (by sharing used or contaminated needles or equipment for injection drugs). Other methods of transmission include: pregnancy, delivery and breast feeding (from an HIV infected mother to her infant); occupational exposure in health care settings and sharing of unsterilized needles for tattooing, skin piercing or acupuncture (Health Canada, 2004).

Women are at greater risk than men of being infected with HIV during vaginal intercourse because: there is a higher concentration of HIV in semen than in vaginal fluid; the surface area of the vagina and cervix is large; and the membranes in this part of a woman's body are fragile. The use of a condom may require a man's cooperation, while this kind of agreement may be present in cases where a woman enters the sex act willingly; it is compromised by power imbalances between women and men and by sexual violence (AIDS Committee of Toronto, 2004).

Many factors may affect women's HIV survival rates, including: late diagnosis; delayed treatment because of misdiagnosis of early symptoms; limited access to drug trials and antiretroviral treatment; lack of research into women and HIV; social and economic conditions, including higher rates of poverty among women and reduced access to adequate health care and the tendency of many women to make self-care a lower priority than the care of children or other family members (Bassett & Mhloyi, 1991).

Women who share their HIV diagnosis with family members or friends risk stigmatization (including reactions of fear, shock and blame) isolation and potential loss of self-esteem (Kelly, 1998). However, keeping the diagnosis of HIV as a secret may hinder a woman's ability to develop effective coping strategies and leave her vulnerable to suicidal ideation, fear, anger and depression (Gala, 1992; Kalichman, 2000; Kelly, 1998 & Sherr, 1993).

Financial or material dependence on men means that women cannot always control when, with whom and in what circumstances they have sex. Some women have to exchange sex for material favors for daily survival. There is involvement in the sex trade but there are also settings where women are dominated socially, emotionally or financially where sexual activity may be many women's only way of providing for themselves and their children. In these instances women are not expected to discuss or make decisions about sexuality and therefore have limited, if any, means to protect themselves from HIV exposure (Kalichman, 1995).

The many forms of violence against women mean that sex is often coerced which is itself a risk factor for HIV infection. Some women cannot request, let alone insist on using a condom or any form of protection. If they refuse sex or request condom use, they often risk abuse. In the context of my home country, Ghana, a female request for a male partner to use a condom may raise suspicions of infidelity. The double standard however exists where it is culturally acceptable for married and unmarried men to have multiple partners which may openly include sex trade workers. In Southern Africa men seek younger and younger partners in order to avoid infection even though these are forms of risky behaviours (Takyi, 2002).

2.3 HIV and AIDS in Canada- HIV Surveillance Data

A total of 56,523 positive HIV tests have been reported to the Centre for Infectious Disease Prevention and Control (CIDPC) in Canada from November 1985 (when reporting began) up to June 30, 2004. The rising trend in positive test reports outlined in previous reports appears to be continuing. The annual number of reports has increased from 2,112 in 2000 to 2,499 in 2003. In addition, in the first six months of 2004, there were 155 more positive HIV tests reported compared with the first six months of 2003. Females represent a growing proportion of positive HIV test reports, reaching 26.6% in the first half of 2004 (Public Health Agency of Canada, 2005). This increasing trend is being observed particularly among younger women who represented 42.6% of the 15-29-year age group and 23.9% of the 30-39-year age group in the first six months of 2004.

Starting in 1999, the heterosexual category became the second largest exposure category, increasing from 7.5% prior to 1995 and reaching over 30% by 2001(Public Health Agency of Canada, 2005). Within the heterosexual category, positive test reports attributed to persons from HIV endemic countries have increased from 2.9% in 1998 to 8.6% in the first six months of 2004. Men who have sex with men represent the largest exposure category among cumulative AIDS diagnoses, but annual trends demonstrate a decreasing proportion, from 78.0% prior to 1994 to 34.6% in 2003.

White Canadians also represent a decreasing proportion of AIDS diagnoses, from 86.4% prior to 1994 to 53.8% in 2003. This decline has been coupled with increases among both Black and Aboriginal Canadians. Understanding some of the reasons for the increase in positive HIV test reports may be changes in HIV testing patterns, reporting delays, and/or underlying infection rates. However, this increase is at least in part due to changes in immigration policies at Citizenship and Immigration Canada that were implemented in 2002 (Public Health Agency of Canada, 2005).

These changes include the addition of HIV testing to the routine immigration medical assessment and reduced restrictions on certain groups of immigrants (such as family class and refugees) who would have previously been considered medically inadmissible because of high demands on the Canadian health care system. From January 2002 to June 30, 2004, 772 individuals tested positive for HIV infection during their routine immigration medical assessment in Canada, accounting for 12% of the positive HIV test reports during this period (note that this excludes HIV-positive applicants who apply from outside Canada). Those applicants who test positive in Canada are included in the national surveillance numbers, since they are handled in the same manner as all other positive HIV tests and included in provincial/territorial HIV reporting to CIDPC (Public Health Agency of Canada, 2005). These new policies may also be contributing to some of the changes observed in the distribution of positive test reports in exposure category and ethnic category in both HIV and AIDS surveillance. Another important finding that will have implications for guiding prevention and a treatment program is the continuing rising trend in the proportion of positive HIV test reports among females in each age group. This is especially true among those in the younger age groups, who are soon going to represent half of the positive test reports among all young Canadians, (Canadian AIDS Society, 2005).

2.4 Report on HIV/AIDS in Ontario

To date, 23,523 HIV infections have been diagnosed in Ontario. About 1,000 HIV infections were newly diagnosed annually for the past six years. Overall, 2,898 or 12.9% of diagnoses were among women. However, the proportion of HIV diagnoses comprised by women increased from less than 5% following the introduction of HIV testing to 20% in the late 1990s and, in 2002, to 27%. The number of HIV diagnoses gradually decreased over the 17-year study period from 1985 to 2001 but increased slightly to 46% in 2002 from 42% in 2001(Statistics Canada, 2005).

HIV prevalence in Ontario has continued to increase year over year since the beginning of the epidemic. In the past five years, prevalence has increased 36%, approximately 6% annually. This is in part related to the continued and, in some cases, increased HIV incidence as well as decreased mortality due to the advent of highly active antiretroviral therapy (HAART) in 1996 (Public Health Agency of Canada, 2005). In the last few years, three groups with significant increases in HIV prevalence are particularly concerning: persons from HIV-endemic countries and other persons infected through heterosexual transmission and men having sex with men (MSM). Among persons from HIV-endemic countries, HIV prevalence increased 90% since 1997, for an average annual increase of 14%. Further, the proportion comprised by persons from HIV-endemic countries continues to increase (Public Health Agency of Canada, 2005). The relative increase among persons from HIV-endemic countries has received some attention in recent years; a situation report was updated in 2002. However, the most dramatic relative increase in recent years has been among other persons infected through heterosexual contact. 7,329 AIDS cases have been reported in Ontario since the beginning of the HIV epidemic. HIV prevalence among persons infected by heterosexual contact increased 68% over the past five years (average annual increase 11%). These two groups, both related to heterosexual transmission, now account for 26% of HIV infected-persons in Ontario. In comparison, in 1997, these groups comprised 20% of estimated HIV infections. Finally, for MSM, HIV prevalence increased 27% since 1996, with an average annual increase of 5%. MSM remain the group most affected by the HIV epidemic in Ontario, constituting 62% of HIV-infected persons in Ontario (Health Canada, 2005). The number of reported AIDS cases decreased dramatically in recent years since a peak of 719 cases in 1993, although the low numbers in the last three years are likely underestimated due to delayed reporting.

In fact, it appears that, after adjustment, AIDS incidence has increased since its adjusted low point of 161 in 2000. The lower proportion of women among AIDS cases than among HIV diagnoses is likely related to the time from HIV infection to progress to AIDS (Canadian AIDS Society, 2005). With respect to mother-infant HIV transmission, 430 HIV-infected women who delivered in Canada have been identified to date, to which 114 HIV-infected infants were born.

Overall, the majority of the infected infants were born to mothers who themselves were born in HIV-endemic countries. 48 HIV-infected infants born in Ontario since July 1994 have been identified to date. According to Canadian AIDS Society, an estimated 29,366 persons in Ontario have been infected with HIV to date; 6,770 persons have died, leaving 22,114 persons living with HIV (Canadian AIDS Society, 2005).

2.5 Experiences of Women with HIV/AIDS

The experiences and consequences of marginalization described by Collins (1990) and other feminist theorists such as Anzaldua (1990) are relevant to understanding the lives of women with HIV (Gallego, 1998). Attributions of immorality and blame, often linked to conservative religious beliefs, have further marginalized many individuals with HIV/AIDS, many of whom belong to stigmatized groups. The AIDS crisis has required community psychology and other professions to address many serious physical, emotional, existential and social concerns. Issues involved in work with HIV-affected individuals, including social stigma, discrimination, questions about the meaning of life and death, and adjustment to unpredictable physical and psychological changes, have created unique, difficult challenges for those who are involved in clinical practice and research (Hoffman, 1996 & Sontag, 1989). The belief that AIDS is a punishment for immoral behavior, such as drug use and sexual activity, has also affected both social responses to HIV/AIDS and the self-perceptions of those who are infected (Hoffman, 1996 & Sontag, 1989).

Knowledge of the life experiences of women with HIV has been limited by the social invisibility of this group and the reluctance of many of the women to participate in service and research efforts (Roth, 1998). This reluctance may be attributed to many factors, including the women's historic distrust of medical and social institutions; fear of the consequences of disclosing their HIV status and life style such as drug use; unstable physical, emotional, and mental well-being related to the virus; and often overwhelming life situations and responsibilities (Roth, 1998). Another possible explanation for the paucity of literature on the experiences of these women is related to the different kinds of knowing and the ways in which women understand and frame life events and processes related to the diagnosis. Ways of knowing expressed by women with HIV include personal experiences (involving partners, family members, friends, and social institutions), religious and spiritual beliefs, and physical experiences of illness and such other conditions as addiction and pregnancy, and the mass media's constructions of HIV/AIDS - and the importance of these cannot be underestimated in this study (Roth, 1998).

2.6 Quality of Life

Although the term quality of life is frequently employed in medical literature, there is no universally accepted definition. According to Wu and Rubin (1994), quality of life is defined as "those aspects of a person's life that are affected by health or health care." The definition of quality of life offered by Ferrans and Powers (1992) includes a "person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her." Despite the varied definitions, there is general agreement that health-related quality of life is a multidimensional construct. Most conceptualizations of quality of life include the dimensions of functional status, physical status, psychological status, and social functioning (Burgess & Catalan, 1991). A conceptual model proposed by Wilson and Cleary (1996) identified five dimensions of quality of life, including biological and physical factors, symptom status, functional status, general health perceptions, and overall quality of life. Quality of life has been studied in relation to numerous diseases, and more recently, the concept has been extended to HIV/AIDS (Holzemer & Wilson, 1995).

Wachtel et al., (1992) provide important information on the devastating and significant impact that HIV/AIDS has on the quality of life of persons who contract this disease. Much work has been completed in relation to measuring and defining the varying dimensions of quality of life. Whereas several investigators have adapted general quality of life measures to patients with HIV/AIDS (Lubeck & Fries, 1992; Wachtel et al., 1992; Wilson & Cleary, 1996), others have developed and tested HIV/AIDS-specific quality of life measures (Holzemer, Spicer, Wilson, Kemppainen, & Coleman, 1998). Not only have these measures proven to be reliable and valid indicators of quality of life in HIV/AIDS, they have provided much information about changes in the varying dimensions of quality of life across the stages of illness (Lubeck & Fries, 1992; Ragsdale & Morrow, 1990).

Studies are also beginning to appear that evaluate quality of life in special populations, including women with HIV/AIDS (Rose & Clark-Alexander, 1996). With improvements in treatment options, quality of life has become a central issue in the medical management of HIV-infected individuals who now can expect to live with their disease for many years. Quality of life encompasses multiple aspects of life satisfaction, such as: role functioning; self esteem; spiritual fulfillment; a sense of control over one's environment; a sense of security in the present and future; a sense of social integration, enjoyment, appreciation and pleasure (Andrews & Withey, 1976). Physical functioning, mental health status and social role functioning are also important dimensions of health-related quality of life (Wu & Rubin, 1992).

2.7 Stress Intensity and HIV/AIDS

Stressors are life events or daily interactions that are appraised as a threat, challenge, or potential harm (Lazarus and Folkman, 1984). This negative appraisal is important because it distinguishes stressors from the normal consequences of social life and its various developmental stages (Pearlin, 1981). Certain HIV infected populations have been shown to have a higher stressor load (Blaney, et al, 1990; Nott & Vedhara, 1999). HIV positive homosexual men were shown to experience a greater number of stressful life events than did their HIV negative counterparts (Blaney, 1990; Nott & Vedhara, 1999).

Lazarus and Folkman (1984) are very clear in their theory that the outcome of a stressful event is dependent on the person's appraisal of the event. For some women, the diagnosis has a devastating effect because it is associated with death, fear, and stigma (Jackson & Selby, 1998). Anderson (1995) found that among 127 HIV-infected men and women, perceptions of stress influenced the selection and use of coping strategies. Thus, understanding how HIV-positive women view the reality of HIV infection is important to understanding their ability to achieve mastery over stress.

The physical effects of living with HIV infection may interfere with using resources to overcome stress. These physical effects may interfere with daily activities and decrease the amount of energy available to invest in relationships with others. Derdiarian and Schnobel (1990) in their work noted that intense life changes occurred as the illness progressed. As the number of HIV symptoms increased, depressive mood and emotional distress also increased (Demi, et al., & Seals, 1998; Kelly, 1991). Conversely, when women with HIV infection are asymptomatic, they report high levels of physical and role functioning and better overall adjustment (Bova, 2001).

2.8 Depression and HIV/AIDS

Studies have tried to address the "chicken-or-the-egg" issue of whether depression is a predictor or result of disease progression by measuring depression in the intervals before AIDS or the development of medical symptoms (Goodkin, 1998). This approach helps establish whether the depressive symptoms occurred before changes in disease status. If disease changes are gradual, however, this approach may not address the order of events (Goodkin, 1998). Existing research provides some evidence that psychosocial factors, such as chronic depression and stressful life events, may affect HIV disease progression (Lutgendorf, 1998). It must be noted that the majority of the cited studies on psychological moderators of HIV infection have been conducted on males; however, findings from recent studies among female samples, have been consistent with those conducted among males (Lutgendorf, 1998). Wolcott (1986) observed similarities between the concerns and anxieties experienced by HIV-positive patients and cancer patients, while Frigo (1986) reported severe anxiety, fear and depression in 48% of their HIV-positive sample, and a further 10% were observed as having serious psychological difficulties.

Lackner (1992) also describe the contribution of social ostracism to heighten the distress experienced by homosexual HIV-positive individuals. This distress is not believed to be any less in HIV positive women (Tross & Hirsch, 1988). Similarly, Dew (1990) reported that HIV-positive hemophiliacs experienced significantly more distress than HIV-negative hemophiliacs. Another stressor, which is recognized as a potential source of distress, is the necessary behavioural adjustments that HIV-positive individuals need to make to prevent the spread of infection. They may be limited to a particular sexual partner or sexual role (Siebert & Dorfman, 1995).

HIV-infected women can experience significant difficulty adjusting to their illness. One recent epidemiological study of HIV-infected women identified 77% with chronic or intermittent symptoms of clinical depression (Ickovics et al., 2001). Other research has also identified similarly high rates of probable clinical depression among women living with HIV/AIDS, (Simoni & Cooperman, 2000). The high rates of depressive symptoms among women living with HIV/AIDS suggest an urgent need to identify factors associated with their adjustment, so that effective interventions can be designed and implemented.

2.9 Stigma and HIV/AIDS

Learning that one is HIV positive sets a new life course that will involve decisions from disclosing serostatus to partners, family, friends, and health care professionals to entering and participating in care. The stigma associated with HIV infection casts a definite negative shadow on these already difficult tasks. Discovery of a person's HIV serostatus has been shown to lead to loss of family ties, friendship, employment, and housing; dismissal from school; and denial of health and life insurance as well as health care (Folkman, et al., 1994; Herek, 1990; Lyter, et al., 1987; Tross & Hirsch, 1988). At the time of diagnosis with HIV/AIDS, women already are aware of the stigma associated with the disease. They immediately see themselves differently and believe others do also (Carr, et. al, 2004).

Learning of one's HIV positive status could make an individual face a host of psychological and social stresses. HIV-related stigma is associated with psychological distress and can interfere with coping, adjustment, and management of HIV disease. Effective management of HIV disease requires timely testing for HIV infection so that persons who are infected can learn of their serostatus and gain access to care, therefore benefiting from available treatment options. Persons living with HIV disease encounter intense and often unrelenting psychological and social stresses over the course of their illness. Among these stresses is HIV-related stigma that occurs at all phases of the disease and can interfere with coping and adjustment (Crandall & Coleman, 1992). By interfering with this important sequence of events, stigmatization has an adverse effect on persons who are living with HIV and on the further spread of the disease.

HIV stigmatization has also been shown to influence the type of testing used to detect the virus and persons at risk for HIV are more likely to seek testing when it is offered anonymously (i.e., no names are recorded) rather than confidentially (i.e., names are kept in confidential records) (Fehrs et al., 1988; Johnson, Sy, & Jackson, 1988). Apart from direct fears of discrimination, the well-publicized concept that HIV is spread among certain risk groups that are themselves stigmatized by society affects the extent to which persons who may be at risk due to their behavior are likely to perceive themselves to be "at-risk." Thus, persons who are HIV infected may fail to seek help or expose their status because the stigmatization of HIV implies that only people who are "promiscuous and choose partners unwisely" are infected (Weitz, 1989).

An in-depth study in America of disclosure among a small sample of HIV-positive persons provides insight into the problem of stigmatization (Laryea & Gian, 1993). Among 24 HIV positive persons who had disclosed their serostatus to their immediate families and relatives, 50% received positive reactions. The remaining half experienced rejection including dissolution of marriages. Female family members, including sisters and aunts, were reported as being more tolerant and accepting than male family members. One third who told friends experienced negative outcomes and rejection from friends was subtler than that of family, characterized by fewer interactions over time. These results are similar to those reported in a study of over 100 HIV-positive gay men, in which 31% had been rejected by at least one family member, 38% were abandoned by friends, and 11% lost their housing (Crystal & Jackson, 1989). A study by Pergami (1993), indicated that 27% of HIV-positive women in the study reported changes in their social networks and almost two thirds experienced severe disruption of their personal relationships following their notification of HIV-positive results (Pergami, 1993). Similar stories pervade the HIV-positive community, reinforcing a reluctance to disclose one's status.

During the periods of early post-diagnosis or during the onset of physical symptoms there is a high-risk period for suicidal ideation and suicidality (Kelly, et al, 1998; & Rundell, 1992). The prevalence of suicidality among HIV positive psychiatric and drug-dependent individuals ranges from 4 percent to 26 percent, depending on stage of illness. Psychiatric disorders including depression, substance abuse, and personality disorders (Maj, et al, 1994; Marzuk, 1988; O'Dowd, 1993; Rosenberger, 1993) and psychological symptoms such as depression, anxiety, somatization, hostility, and interpersonal sensitivity have been associated with suicidal ideation among individuals with HIV infection (Kalichman, 1995).

2.10 Feminist approach to understanding the Experiences of HIV positive Women

Feminist standpoint provides a way of viewing the subjective and objective aspects of women's daily lives. It is also the site where women can be viewed as being closest to defining their personal epistemologies. Collins (1991) presented a valuable model for conceptualizing the roles of power and oppression in the production of knowledge that emphasized the relationship between knowledge and power, the interlocking systems of oppression that women face, and the ways in which society colludes to render the women's experience less "truthful" than the experience of the dominant culture.

The marginalization of certain forms of knowledge has been described throughout the evolution of feminist epistemology (Harding, 1991) and has significant implications for community psychology assessment and practice. Because the community psychology profession is dedicated mainly to social justice and the empowerment of disenfranchised individuals and groups, the relationship between power and knowledge is a crucial issue for theory, practice and research. To gain a better understanding of the experiences of marginalized populations, it is important to recognize the relationship between social marginalization and ways of knowing that are often neglected in traditional research. The model of marginalized epistemologies, drawn from several feminist perspectives, is helpful in expanding current models of research in community psychology. Using the principles and values of community psychology_will enable the voiceless in our community to become empowered

Women with HIV/AIDS can experience multiple psychosocial stressors and stigmas, including racism, poverty, current or previous drug use, relationships with violent or coercive partners, and various health risks associated with poor nutrition, exhaustion, physical and sexual abuse, and marginal living conditions (Gallego, 1998). Their social power is often extremely limited, and most HIV positive women lack adequate education and resources.

2.11 Community Psychology and HIV/AIDS Prevention

Community Psychologists were decidedly late in their involvement in the prevention of HIV infection and AIDS. At the Society for Community Research and Action's Biennial

Conference in 1989 there was little programmatic discussion of the topic (Peterson, 1990). Given the issues that were discussed at that conference, it appeared that some ingredients relevant to AIDS prevention were in evidence. Though CP covers wider issues and principles, it can be said that in North America the focus include empowerment, social justice, inclusion, social support, a prevention orientation, sensitivity to multicultural and gay-lesbian issues, and recognition of the prerogative of power in relations between men and women and between majority and ethnic minority groups (Tefft, 1982). It is possible that public health was too involved with health, and community psychology had distinguished itself from health promotion and disease prevention as evidenced by the earlier split off of the division of health psychology and the creation of separate journals for health versus community. Since that time community psychologists appear to have a rising interest in AIDS-related research (Schwarzer & Leppin, 1989). Community psychology has much to learn from the advances that have already been made on the topic of HIV prevention and the social ramifications of the disease, and has much to contribute to future advances that are still very much required (Peterson, 1997).

2.12 HIV/AIDS Women and Community Intervention

As community psychologists there are several approaches that can be employed to determine appropriate strategies of interventions for women living with HIV/AIDS that will improve the lives for the affected women. It may be suitable to use Seideman's (1988) theory of social intervention to problematize social regularities of HIV, such as stigma, lack of psychological support and discrimination. From a community perspective, HIV positive women should be provided with all necessary psychosocial resources and services.

Given the increasing rates of HIV among women, more research is needed on women's experiences of living with the disease. With increasing prevalence of HIV/AIDS among women there is an increasing need to expand the health rights mandate from a focus on choice in reproductive rights to a general concern for women's health. While there are several advocates in the community fighting for these rights there is still an overwhelming need for the voices of women living with HIV to be heard (Gonzalez, 2004). Clearly, there is a need to reach all women with educational messages that promote informed choices in health care, including HIV and to educate health professionals and the community at large about women's experiences and needs (Gonzalez, 2004).

2.13 Risk & Protective Factors

$$\textbf{Incidence} = \frac{\textbf{Risk Factors}}{\textbf{Protective Factors}} = \frac{\textbf{organic causes + stress + exploitation}}{\textbf{coping skills + self-esteem + support systems}}$$

Albee's theory concerning the incidence of mental health problems (1982), may also be used as a model to promote psychological health among the HIV/AIDS women. Coping strategies, skills, strengths and existing social support for HIV/AIDS women may be identified through needs assessments as potential issues to build upon. Risk factors that psychologically affect the psychosocial well-being of these women such as stigma and discrimination need to be prevented. Promoting a positive sense of community for HIV/AIDS women could also contribute to a successful community intervention.

Dohrenwend (1978) introduced social stress theory to CP as a framework for understanding both how social environments can have negative impacts on individuals and how social interventions can be designed to prevent social stressors or reduce the negative consequences of social stressors. A central thesis of social stress theory is that stressful life events and changes, particularly negative life events, create stress reactions in individuals and that the long-term consequences of these reactions can be negative, neutral or positive. That is, stress presents an opportunity for growth as well as the potential for negative outcomes. Moreover, Dohrenwend (1978) asserted that there are a variety of psychological and situational factors that can moderate the impacts of stressful life events. For example, a person with a good social support network or good coping skills may adjust well to a stressful life event such as marital separation, whereas a person without such resources may fare worse. Such moderating factors are also called "protective factors" or "stress-meeting resources" (Nelson &Prilleltensky, 2005).

2.14 Empowerment

Arguably, Empowerment has been the central concept of community psychology during the past two decades (Rappaport, 1981). Marin and colleagues (1998) spoke of the relevancy of empowerment in the prevention of HIV/AIDS and on a number of different levels. They related the perception of empowerment, actual empowerment of the individual, and empowerment in a political sense. Marin, Tschann, Gomez, and Gregorich (1998) in their study focused on individuals' sense of their empowerment over their bodies and social interactions. They found out that those who had lower self efficacy for condom use found it more difficult to discuss condoms, and felt less able to control their own sexual impulses and passions.

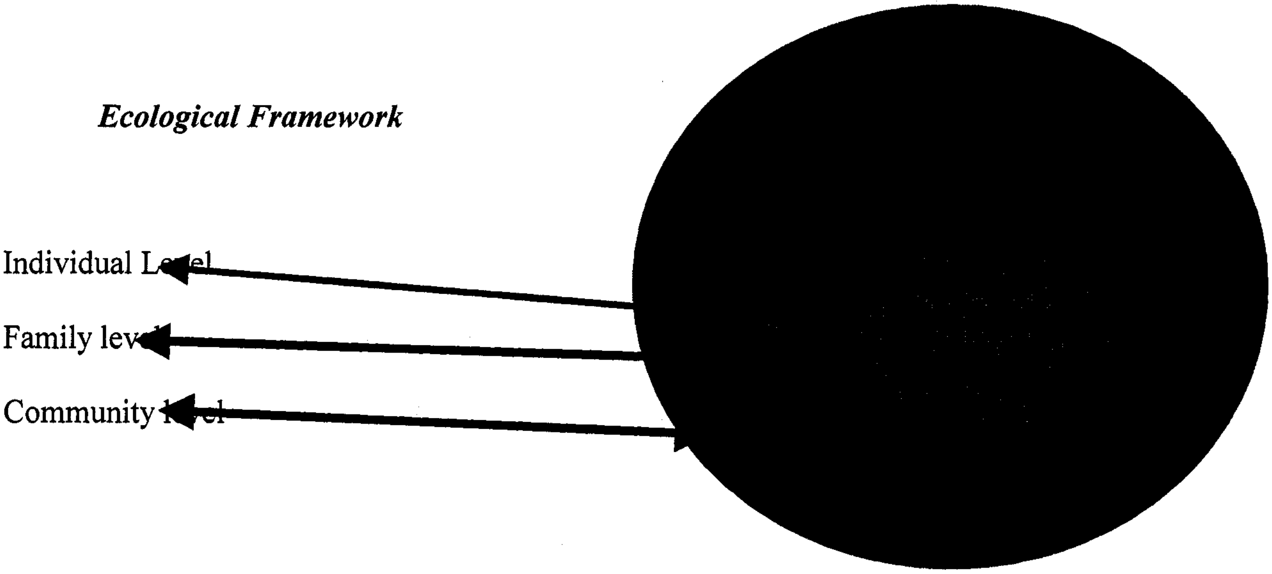
The AIDS literature has generally incorporated Bandura's (1986, 1997) dual model of self-efficacy, which includes the belief of efficacy based on the fact of efficacy. Historically, community psychology has been more interested in actual efficacy than perceptions, but the two concepts merge and are easily confused. Empowerment is also an interpersonal concept within relationships. According to Wingood and DiClemente (1998) empowerment could also be tied to the interaction between sexual partners as individuals, as men and women, and as members of an empowered or disempowered ethnic group. In a similar manner, the cultural and gender meaning of empowerment may also differ across cultures and by gender as well (Riger, 1993). This can be said to be very important for the advancement of both the understanding of the empowerment and in the success of multicultural HIV prevention.

Empowering interventions have been directed to AIDS educators as well as to persons with AIDS, young gay men, prostitutes, women and numerous others at risk populations. Empowerment principles have a long history in public health and community psychology and according to Strawn (1994), the popularity and seeming durability of empowerment have not, however, produced a broad consensus on its meaning, measurement, or implementation. Since empowerment rhetoric can serve many different agendas, the need is urgent to examine empowerment, its core assumptions and its implications for how we respond to the challenges of HIV/AIDS.

2.15 Ecological Models and HIV/AIDS prevention

The ecological aspect of AIDS prevention is another area where community psychologists can make a contribution. Gradually more researchers are turning to an ecological framework (Bronfenbrenner 1979) to understand and describe the interplay of the personal, situational, and psychosocial factors that combine to create challenges and difficulties on HIV positive women. Often, the ecological framework is represented, as a series of concentric circles locating the individual within a larger social system comprised of interrelated and dynamic parts. Consistent with Bronfenbrenner's theory of development-in-context (1979), it is important to consider the broader milieu of the women living with HIV/AIDS by relating women's experience in individual (micro), personal (meso), relational (exo) and collective (macro) settings and the ways in which the various levels interact.

Ecological Framework



The innermost circle represents the individual and personal level experiences, challenges, needs, strengths and coping strategies that each woman brings to her behaviour in her daily relationships. The second circle represents the relational and immediate context in which interaction occurs. Frequently it is the intimate relationships within the family level and other HIV positive women in the same network groups. The third circle represents the community, which includes, institutions and social structures in which relationships are entrenched (church, clubs, school, the work place, peer groups, social networks among others) as well as the wider economic and social environment. The crossing point between these levels is fluid, and factors at one level may influence - and in turn be influenced by - those at other levels.

An ecological framework thus shifts the focus of analysis and intervention from concepts of individual risk to the creation of an enabling environment. Even though in the current study I am looking at the experiences of women living with HIV/AIDS and how these experiences are influenced at the individual level, family and community, it must be noted that the experiences of living with HIV/AIDS and its related psychosocial need/support are sometimes difficult to understand, complex and dynamic.

2.16 Summary and what needs to change?

As described in this literature review, HIV/AIDS among women is a very pervasive and prevalent problem in today's society. The literature also reveals that the phase of HIV/AIDS has changed and in today's society more than 20 years into the epidemic, women account for nearly half of the 40 million people living with HIV worldwide. Despite this alarming trend and the numerous research conducted on HIV/AIDS; most of these studies to a large extent have focused on prevention, treatment and pharmaceutical intervention (Snyder, et al., 1991). In North America the emphasis was on MSM because they were the most infected population and any available research findings focused on them. The number of women living with HIV/AIDS is growing in North America and research is growing looking at some of their needs and psychosocial challenges though this is not enough. In addition, Roth (1998) claims that the knowledge of the life experiences of women with HIV has been limited by the social invisibility of this group and the reluctance of many of the women to participate in service and research efforts. In addition, women know less than men about how HIV/AIDS is transmitted and how to prevent infection, and what little they do know is often rendered useless by the discrimination and violence they face (UNIFEM Report, 2004).

Some of the existing gaps in my literature review include the scarcity of literature on women living with HIV/AIDS compared to men or people living with HIV/AIDS in general. The experiences of women with HIV/AIDS are different from the experiences of men with HIV/AIDS. For example the lives of women with HIV/AIDS could be more stressful then men because of their social and family roles. They are expected to work and take care of the family and in some case left alone to take care of their children. Women are often required to work harder than men, even if they are infected with HIV. Being stigmatized by family members, friends and the whole society could be devastating to women living with HIV/AIDS. In the literature it was clearly noted that the level of stress has an impact of the physical and psychological wellbeing of women with HIV/AIDS. Disease progression also has an impact on the level of depression as well as the quality of life. The literature again suggests that the quality of life of women living with HIV/AIDS varies across the stages of the disease development. I am interested in exploring these because women with HIV/AIDS have different experiences, quality of life and coping mechanisms. In some cases women with HIV/AIDS had to be compared with women living with cancer in exploring their psychosocial needs and challenges because of inadequate literature of data on the issue. It is in this vein that I chose to conduct this study because I want to add to the emerging knowledge on women with HIV/AIDS. I chose to look at the quality of life, psychosocial needs, challenges, survival and support because these are the most neglected areas. In conclusion, I believe that women must not be regarded as victims; they are, in many places, leading the way forward and we need to listen to their experiences, to their voices by conducting qualitative research with women living with HIV/AIDS.

2.17 Purpose of the Research

The purpose of this study was to explore and document the voices of HIV/AIDS women and to describe and inform the community about the psychosocial impact of HIV/AIDS, experiences, needs, challenges, coping and survival strategies of women living with HIV/AIDS. The purpose of the study was to gain deep understanding of the participants' experiences as women living with HIV/AIDS. Guided by the life history of these women I strived to provide a vehicle for otherwise neglected voices in our community. The study was aimed at exploring and documenting the nature and impact of social stigma and depression on HIV/AIDS affected women.

2.18 Specific Research Objectives

The aim of this research was to:

1. Explore the psychosocial impact of social stigma on women's lived experiences of being HIV positive and increase understanding of coping of HIV/AIDS women.
2. Explore the quality of life issues on multiple dimensions (individual, family, community, health sector and society) of women living with HIV/AIDS.
3. Explore proactive strategies for improving quality of life, at multiple levels, for women living with HIVAIDS.

2.19 Research Question

1. What are the various levels of influence on women's experiences, needs, challenges, coping and survival strategies of HIV/AIDS?
2. How can women's voices and experiences contribute to policies and proactive strategies for advancing the quality of life of women living with HIV/AIDS?

CHAPTER THREE

METHODOLOGY

This chapter discusses the methodology used to develop the understanding of the psychosocial challenges and needs of women living with HIV/AIDS in Toronto. First is a brief overview of life history/narrative approach, community based research, the research design and the rationale behind the approach, which is followed by the methods section on data collection and analysis.

3.1 Life History/Narrative Approach

Life threatening illness, such as HIV/AIDS, also threatens people's sense of identity and taken-for-granted assumptions about the temporal framing of their lives. In response, people often experience transformations in values, spirituality and life priorities. Life history methodology has been increasingly utilized to study the subjective experience of illness (Kleinman, 1988). As Polkinghorne (1988, p. 11) points out, the core argument of narrative theory is that narratives are "the primary scheme by means of which human existence is rendered meaningful." Life history methodology has numerous advantages, not the least of which is that it provides a sophisticated response to some of the philosophical and methodological problems raised by postmodernists (Ezzy, 1998). Life history methodology provides an innovative and useful way of approaching the subjective aspects of human experience in general and the illness experience in particular: "We make as well as tell stories of our lives and this is of fundamental importance in the clinical world" (Mattingly, 1994, p. 811).

Life history is a qualitative research methodology of particular value to record the less dominant voices in the world, such as women and minority members. Life history is complementary for research studies, which focus on identifying and documenting health patterns of individuals and groups (Smith, 1994, Fontana & Frey, 1994). A life history methodology allowed me to explore the individual experiences within a history of the time framework of the women living with HIV/IADS who participated in this study. Importantly, life history researchers recognize research participants as collaborative partners involved in the research process (Smith, 1994).

The life history approach is well suited for inquiry in a wide variety of psychosocial phenomena. The approach incorporates core values shared by health care professionals, including recognition of the agency of each individual and the essential role of context in the living of a life. It is a holistic, dynamic process incorporating the participants' retrospective life experiences and the researcher's interpretations (Admi, 1995). Many psychosocial phenomena do not occur spontaneously; rather, they develop over time in response to a wide variety of influences.

The life history methodology facilitates study of such phenomena because the researcher obtains lifelong data, allowing him or her to explore a variety of experiences and relationships and to examine changes over time. Participants actively remember and construct their lives through the telling of their stories as the researcher guides them through their life stories. The researcher guides the participants through their life history, prompting memories and encouraging the participants' reflections, interpretations and insights. This approach yields data that helps researchers gain insights into how past events and relationships might influence current phenomena and how human beings understand their lives (Haglund, 2003; Sandelwski, 1991).

Life history information again challenges the researcher to understand an individual's current attitude and behaviour and how they may have been influenced by initial decisions made at another time and in another place. The women in this study had the opportunity of narrating their experiences, past life before HIV, psychosocial needs and challenges with HIV/AIDS, in addition to their survival and coping strategies. The data were rich and copious, allowing elements that were not immediately apparent to the participant and were surprising to me to be included and eventually identified.

3.2 Community Based Participatory Research

Community-based participatory research involves a high degree of cooperation between researchers and stakeholders with constant feedback loops and a commitment to using the findings and to raising all participants' consciousness about problems in their social contexts (Barnsley & Ellis, 1992: Chesler, 1991; Gaventa, 1993). Organizing a stakeholder group and clarifying roles was one of the first planning processes in my study. The stakeholders included HIV positive women, as well as community agencies such as Voices of Positive Women and the AIDS Committee of Toronto (ACT).

All stakeholders agreed upon the goal of this study, problem definition, as well as what the participants might be expecting in this study. The conceptualization of the issues made sense to all stakeholders. The early stages of partnership were organized around specific tasks, with a well-defined work plan and schedule of meetings. Although we wanted to meet regularly as a committee we were not able to achieve it because of financial constraints and time. Some members of the committee were full time workers and it was so difficult for them to be committed to a regular meeting and it was also financially challenging for me because I had to pay for the transportation cost of the women living with HIV/AIDS every time we met. Due to all these challenges I had to meet these committee members individually throughout the whole interview process. The expertise of the multiple stakeholders was recognized and the sense of "equity of voice" flowed throughout the process. Although the committee comprised of HIV/AIDS professionals, experts and support worker, the women living with HIV/AIDS on the committee were allowed to express their views and opinions without intimation or reservation. I was told women living with HIV/AIDS in the Toronto region feel researchers take advantage of them. They feel their views are not well presented and most of the research questions are not well structured. The other members on the committee wanted the women to articulate their own thoughts, likes and dislikes about the research. This was allowed because committee members did not want to impose their views on the women or they did not want to appear exploitative. We respected each other's views despite our backgrounds and diversity.

3.3 Description of the Organizations

Voices of Positive Women (VOP) was established in response to the lack of adequate services and support for women living with HIV/AIDS. It is the only agency in Ontario that focuses entirely on the needs of women living with HIV/AIDS. It is a provincial organization run by and for women living with HIV and AIDS. Their goals include empowerment of women living with HIV/AIDS through support, information and education. The organization also advocates and represents the issues of women living with HIV/AIDS to government and non-governmental organizations and finally, they carry out educational activities, which include educating the public by promoting accurate, affirming images of women living with HIV/AIDS.

Referrals are also made to HIV aware doctors, dentists, health care providers and other organizations. Collective concerns are addressed by representatives of VOP sitting on boards and advisory committees of other organizations and government bodies. VOP also provides treatment funds supported entirely by private donations which contribute to the cost of treatments not covered by provincial health insurance as well as complementary and alternative medicine.

The AIDS Committee of Toronto (ACT) is a community-based, charitable organization that provides support, HIV prevention, and education services for people living with and at risk for HIV/AIDS. ACT provides confidential support and practical services to men, women, youth and people living with HIV/AIDS (PLWHA) and can provide information and support to their partners, friends, and families, all free of charge. In partnership with other agencies, ACT offers a monthly community kitchen where Caribbean and African women living with HIV/AIDS get together to share a meal, a laugh, and their stories. The kitchen is also an opportunity for women to learn about strategies to stay well.

ACT also organizes a weekend retreat that enables women with HIV/AIDS to get out of the city, meet their peers, and learn strategies for improving their health.

3.4 Steering Committee/Gate Keepers

To ensure relevance and effectiveness in this research, and the privacy and comfort of participants, I employed a collaborative participatory approach in this study. I connected with and collaborated with various stakeholders who functioned as steering committee members and gatekeepers. They were informed and participated at every level of the research and their inputs were integrated into how I conducted the research.

The development of the steering committee and selection of a gatekeeper comprised of 5 people from ACT, Voices and myself. Rob Travers who is an HIV/AIDS expert and advocate in Ontario acted as the gatekeeper in this study. He introduced me to Voices made sure I got all the needed support during my data collection. He was part of the steering committee. Other members included Kadu of Voices, Winston Husband of ACT and a woman living with HIV/AIDS from Voices. Kadu is a community program officer and a personal support worker at Voices. She helped in the recruitment of participants as well as reviewed the participation of the women. Winston Husband is a senior researcher and program director at ACT. He reviewed all the research documents, which included the consent form, poster and questionnaire. Another member was a woman living with HIV/AIDS who suggested the rephrase some of the questions in a manner that will be accepted by the other women living with HIV/AIDS. I was the fifth person and my role as the researcher on the committee was to guide the process systematically.

We were supposed to meet as a group throughout this process; however due to the different time schedules of members I had to meet with them separately on all issues related to the research. I met with them twice a month for two-months after the initial stages of the research and at the initial stages they were consulted on all the various objectives and overview of the research. The interview guides were reviewed to assess the understanding and clarity of the research instrument as I worked with the steering committee. They were also asked to review the meaningfulness of the questions as a way of making sure that the questions were void of any ambiguity and that the questionnaire could be clear, respectful and relevant to participants.

3.5 Design

Due to the highly sensitive nature of this evolving and understudied topic, I used a qualitative methodology to investigate the aforementioned questions, which is also described as flexible method research (Anastas & MacDonald, 1994). In choosing qualitative research methods I was able to provide richer information with more relevant insights than would be possible with quantitative methods alone (Darlington & Scott, 2002; Lincoln & Guba, 1985; Nelson & Prilleltensky, 2004). Nelson and Prilleltensky (2004) have stated that through a shared emphasis on diversity, understanding people in context and collaborative research relationships, qualitative research offers much to community psychology. Once more as indicated by Anastas and MacDonald (1994), flexible method research is best used when an emergent and complex topic of inquiry is in need of mapping, clearer definition, and exploration. The general purpose of flexible method research is to discover new phenomena that by definition cannot be directly observed. In this study the phenomena researched are the experiences of HIV/AIDS women who are facing various psychosocial challenges.

Through the use of a flexible method approach, the participants' subjective and objective knowledge about the daily challenges of living with HIV/AIDS was investigated with related contextual factors. Since people's experiences are not often predictable and since the experiences of women living with HIV/AIDS are understudied, it was useful to have the flexibility inherent in qualitative research in order to adapt to and incorporate the information that the participants provided throughout the process. This approach allowed for the presentation of the voices and stories of the participants and provided for an in-depth understanding of their triumphs, struggles, supports and needs. The use of this research design is also inline with the paradigm of critical feminism that guides my research; which emphasized the importance of testimonial evidence when studying women living with HIV/AIDS.

3.6 Procedure

A multiphase research process was used in this community-based study. Official letters of introduction approved by the Ethical Review Committee of Wilfrid Laurier University were sent to the various research settings introducing the researcher and the purpose of the research. I went to these organizations personally and introduced myself to them as a graduate student and I described at my research. After a series of five meetings I began working closely with the steering committee and gatekeeper in the recruitment of participants. I placed posters advertising the research project in areas where HIVAIDS women would have access to the information. Some of these identified areas were the offices of ACT and VOP. I also liaised with associations in Toronto and also spoke to members at various HIV/AIDS meetings and workshops I attended. I also asked HIV/AIDS caseworkers to forward information about the research to any woman that they felt would be appropriate and interested in participating in this study.

3. 7 The Interview Process

All the five women were interviewed at the Voices of Positive premises as a location where the participants were comfortable as they were familiar with the setting. Each interview began by reviewing a consent form (Appendix 4), confidentiality and the participants' rights. Once all the appropriate documentation was signed the interviews began with various background information questions such as the participant's age, education, and ethnicity, how she was diagnosed with HIV as well as how long she has been living with the disease. The purpose of starting the interview in this manner-in addition to the provision of important information was to relieve some of the anxiety involved in participating in an interview and to allow participants to relax (See appendix 5)

The interview was in three parts and the first set of questions which followed were open-ended in nature and permitted women to discuss experiences that were most relevant to them about the life experiences before HIV (Appendix 5) They were also invited to talk about the special issues that they could remember and their perspectives on any significant experience in their individual lives before HIV. The second part of the interview focused on needs, challenges and psychosocial support for women living with HIV/AIDS. The third and final part of the interview invited participants to talk about their coping strategies and strengths of these women. As mentioned earlier I also used planned prompts to elicit more specific information and to provide guidance to the interviews.

The interviews ranged from two hours to three and half hours in length. After each interview, I journaled my thoughts about how the interview went, took notes about interesting responses the participants made as well as noted where improvements could be made for the interviews. The caseworker at Voices who is also an HIV/AIDS counselor was present to assist me the event of a crisis, or extreme emotional reaction, during the interview. I although some of them cried at a point during the interview, the case worker was not invited in because I was able to encouraged the women by giving them a pat on the shoulder and also because of my HIV/AIDS counseling skills. However, I also debriefed with the caseworker at the end of each session. The tapes were transcribed, with the average document consisting of approximately forty pages of text.

Each participant was given a pseudonym name that was used during the interview and on all documents containing their names to ensure confidentially. These pseudonyms in a form of codes were used during the write up of the findings of the research. In addition, I took special care in choosing quotes for the findings section of this study that do not reveal the identity of the participants. During my ethics review I had requested permission for the participants' and the consent form asked participants' permission to use quotations from their intervention quotes.

3.8 Participant Recruitment

Purposive and snowball sampling procedures were used to identify the sample for this study. Five women were recruited, all of whom were living with HIV/AIDS and were residing in Toronto. It must be noted that I had to wait for several weeks before I could get in touch with the participants. For several weeks nobody responded to my adverts and posters. The purpose of the study was to gain deep understanding of the participants' experiences as women living with HIV/AIDS. Consequently, recruitment was aimed at the exploration of the needs, challenges and coping strategies of women living with HIV/AIDS:

The following were the selection criteria for participants:

Women living with HIV/AIDS in Southern Ontario.
Late or early stages of HIV/AIDS
Speak English
Between 16-65 years of age
Varied ethnic background (Canadian, African, South American and Jamaican)

3.9 Participants

All of the recruited participants are women living with HIV/AIDS that are currently residing in Toronto. The participants were from the following places Africa, South America, North America and the Caribbean. They represent a broad range of ethnicity and representation for this study.

The participants were identified through the caseworker at the Voices of Positive Women and also through poster advertising the research project (Appendix 8) placed at the Voices of Positive Women Lounge. Following the completion of the telephone interviews, which outlined the goals of the research and participants' eligibility, women who then declared their interest in participating in the study were selected. I later met with them and conducted the individual interviews for three days. We met for the initial interview on a mutually agreed upon date, time and place. During our first meeting we discussed the purpose of the research and the ethical procedures involved. They all consented and two of the women began the first phase of the interview on day one. On Day Two these two women completed Phase Two and Three of the interview process. The other three participants began phase one of the interview guide on Day Two. All five participants completed the entire interview process on Day Three.

Further, I familiarized myself with the lives of these women explaining the research questions, methods and the ethical guidelines of the research. (See appendix 4).

3.10 Description of Research Participants-

The participants in the study ranged in age from twenty-nine to fifty indicating that they fall with my selection criteria. The participants came from five different countries including Canada, even though they are all Canadian citizens. They all live in South-western Ontario specifically in Toronto. They were all women living with HIV/AIDS for at least seven years to twenty years.

Table1: Description of Participants

Questions	**O1-Agnes**	**O2-Mary**	**03-Ethe**	**04-Christine**	**05-Sue**
Age	39	40	50	29	46
Country of Origin	Caribbean	East Africa	South America	Canada	West Africa
Religious affiliation	Pentecostal	Christian	None	None	Protestan
Year of diagnosis	1996	2002	1990	1997	1987
Diagnosed with Depression	Yes (after HIV)	No	No	Yes(after HIV	No
Diagnosed with suicidal thoughts	No	No	No	Yes (after HIV)	Yes (afte HIV)
Current Relationship Status	Divorced	AIDS Widow	Divorced	AIDS Widow and Remarrie	Single
Living Arrangement	Supportive Housing	Live with dependants	Live alone	Live with a partner/signif ant others	Live alone
Current Work Status	Paid Leave/ community Volunteer	Seeking employmen	Commun ty voluntee	Homemaker	Student
Employment/Profess on	Machine Operator	Secretary	General worker	Day care/chil supporter	Day care/chil supporte
Education	Completed High Schoo	Completed University/ ollege	Element ry Schoo	Some high school	Complet d college

3. 11 Sources of Data

The two main sources of data for this study: questionnaire and journal notes. The interview guideline was the main source of my data and was divided in three parts. The first part was made up of nine open-ended questions, which permitted the women to discuss the experiences that were most relevant to them before HIV. There were 13 questions listed in the second part of the questionnaire and they focused on the needs, challenges and psychosocial support for women living with HIV/AIDS. The third and final part of the questions also consisted of nine questions looked at the coping strategies and strengths of women living with HIV/AIDS (See Appendix 5).

3.12 In-depth Interviews

Choosing qualitative research methods helped me in getting more relevant insights on the issues raised in this study (Darlington & Scott; Lincoln & Guba; 1985; Nelson & Prillenltensky' 2004). Although it was important for me to gather information regarding my specific research questions, I realized that the participants would have their own ideas about what was important to share. As a result, the interview guide (Appendix 5) was developed using open-ended questions across a wide range of issues or topics related to HIV/AIDS and its challenges related to the daily living with the disease. I also asked questions about the participants' recommendations for improved practice with women living with HIV/AIDS. The use of open-ended questions allowed for the participants to tell their stories without feeling constrained by the questions. Additionally planned prompts (McCracken, 1988) were used to elicit more specific responses and to help maintain focus. The interview guide was developed through a combination of information derived from the literature review, my personal experiences as a woman who works with women living with HIV/AIDS and guidance and input from academics such as my advisor and those on my thesis committee. I also received input from my steering committee as well as other women who work with women living with HIV/AIDS about the flow and wording of the interview guide. Achieving a good level of flexibility was a central goal when creating the interview guide, as it was important that the questions allowed for a variety of responses. Designing the interview guide was also based on the ecological framework and life history approach.

Table 2: Categories of participants and duration of interviews.

Sample	Voices Positive women	Interview Part 1 (Before HIV)	Interview– Part 2 (With HIV/AIDS	Interview part 3 (Coping Strategies)	Total time
WLWHA	5	90mins (1.30hrs)	90mins (1.30hrs)	120mins (2hr	5hrs (5hrs x women= 2 hrs)

Table 3: Days and Duration of interview for participants

Day	Day 1	Day 2	Day 3
WLWHA	Interviews Part 1 & 2	2 Interviews Part 3 Interviews part 1 & 2	Interviews Part 3

3.13 Journal Notes

My journal notes were my second source of data and this allowed me to reflect on my personal opinions, observations and reactions during the research. The journal notes could be divided into three categories: *physical, psychological and behavioral.* Physically I observed that most of the women appeared healthy and strong. I looked out for sores and rash on their skin because these are some of the physical changes that occur among PLWHA. Though I could not see any of these, some of the women talked about change in complexion and body weight. During the interview some of them coughed several times, while others also sneezed and breathed with difficulty. Though they visually looked healthy, I realized they were preoccupied with food intake and ate frequently during the interview process due to their medication. They had to eat more frequently for sustained energy throughout the interview process.

As part of my journal notes I also recorded their psychological and emotional behaviour during the research. I noticed that most of the women appeared happy during the earlier part of the study; however, they cried and stopped talking to me for some minutes. I saw sadness in their eyes though they appeared emotionally strong. This may appear difficult to handle but I knew these were all associated to the stress in their lives due to the disease. I also observed moodiness, low speech, irritability and depressive looks. Though, they told me they were coping adequately with their challenges, I felt they were going through some emotional problems and these reflected in their eyes, voice and behaviour during the study. Some of them cried over the fact that, they have not been able to accomplish their career goals. They felt afraid of death and the future. They cried and felt sad because of societal stigma.

Observing their behaviour was very revealing and interesting. Most of them remained calm though one of them appeared a little aggressive. They also felt guilty for allowing themselves to be infected. They were frank, open and articulated their views and thoughts logically. They trusted me and showed appreciation although one of them did not allow me to record her voice because she did not trust the system. Due to my age and cultural background one of the participants from West Africa wanted to control the study because she felt she was older and saw me as a daughter. I had to redefine the aims and objectives of the study to her again which she accepted and therefore cooperated. I tried not to impose my views on the participants although I tried to follow the basic scientific procedures in any research work. I would not this describe this a conflict between culture and academia because we all came to a compromise despite our background, which I would say led to the success of the study. All the women appeared supportive and gentle during the study.

3.14 Analysis

In addition to the journaling I did after each interview and the impressions that I recorded, I read each transcript several times. My analysis was ongoing: following each interview I wrote and reflected on my thoughts about the interview process and what I considered the main story shared by the participants. Later these reflective notes proved valuable as I delved more deeply into the analysis. I transcribed each interview, verbatim within days, sometimes hours of its completion. Allowing for only a short passing of time ensured that I could better rely on my memory for the meaning of certain pauses or difficult-

[*] *In my culture it is expected that younger people would respect all older people. Older women are called aunts and thee participant from my culture expected this from me, which I willingly did because it was part of my culture. This is also a formal way to respecting addressing older women.*

to-understand words. I enjoyed the experience of transcribing as it allowed me to "relive" the interview and pick up on subtleties that I missed while conducting the interview. Following transcription I added to my reflective notes further thoughts on the main points of the interview.

I analyzed my data by using a modified type of narrative analysis (Polanyi, 1989). I divided transcripts into narratives, and then condensed them into themes. Later I transported the document into the NVIVO software programme (Qualitative software). What I did next was pick out relevant text i.e. information from the texts that bear relevance to my research concerns and as such requires further analysis. At a later stage of analysis, I examined the way in which certain nodes often shared the same quotes and this better enabled me to see the links between categories. As I progressed in the analysis and continued to read through transcripts, I added or renamed categories when appropriate. Overarching themes seemed to emerge from the links between nodes or categories. Although some of themes were based on questions found in the interview guide, I remained open to emerging themes, which captured unanticipated insights. As themes emerged, I returned to the original data to verify my analysis. To further verify the extent to which the research findings are consistent and dependable, I established an audit trail whereby I documented my analysis steps. This audit trail included my reflective notes on changes that occurred during the research, thoughts and reflections following interviews and information on how I developed my nodes and themes. Recording this information enabled me to demonstrate the rationale and process underlying my findings and link them to the original quotes.

Although I initially focused on understanding the uniqueness of the participants' experiences and perceptions, I later sought out commonalities between the participants. I interpreted the data in relation to the literature that helped orient my research, thus ensuring the correspondence between it and my results. Patton (1990) outlines two ways to represent the patterns that emerge from data: through the use of "indigenous concepts" and "sensitizing concepts" and my themes were presented in both ways. I used indigenous concepts or the categories developed and articulated by the participants to organize the themes related to the psychosocial challenges of living with HIV/AIDS. I used sensitizing concepts or those concepts that I brought to the data myself, to represent the inflexibility of the health care system and inequitable resources and services. These themes emerged as I became aware of and developed terms to describe, inductively generated categories for which the participants did not have labels or terms.

Throughout the study I found my personal experiences of being a woman coming from a continent that is consumed by HIV/AIDS and having worked as an advocate for women living with HIV/AIDS to be useful in terms of understanding and connecting with the participants and developing the interview guide. On the other hand, due to my personal experiences my counter transference could potentially influence the reporting of findings. As a result, as I began to analyze the data I knew it was very important that I keep my personal experiences and views separate, in order to present the true voices of the participants. I therefore read all transcripts several times so that I could get a very clear idea of what the participants had said. Again I journaled all of my personal reactions and opinions; this activity was helpful in getting these ideas and responses into my awareness by writing these ideas so they did not infringe on the data analysis. I followed the methodological approaches of qualitative research, recognizing that I can be rigorous while still being aware of my subjectivity as I analysized and interpreted my data. These activities ensured that my views were incorporated into the interpretation rather than unconsciously entering into and biasing the data analysis process. This also enabled me to reflect over the whole interview process and especially what their experiences were and what I gathered from theses experiences. The journaling process also enabled me to remember parts of the interview process that I identified to be important during my analysis although the research questions did not address those issues directly. The journaling process was also a reflective way of reviewing my personal experiences during the interview as well as interpretation and analysis.

While organizing and analyzing my data in this way was a time-consuming process, it allowed me to immerse myself in the data as I listened to the interview tapes, transcribed, read the transcripts multiple times, integrated related information from my reflective notes. In presenting my findings I made extensive use of the participants' own words. Highlighting the participant voice allowed me to provide a description "broad" enough to allow others to understand the results and draw their own conclusions (Patton, 1990). I believe that since "readers of the report make the final interpretation" (Crist & Tanner, 2003, p. 204), the extensive use of direct quotes were important. In providing a broad description, readers will not be limited by my analysis but can make their own interpretation.

CHAPTER FOUR

FINDINGS

In this chapter I will present the findings of my study. Several themes emerged and I grouped them into categories that I deemed outstanding in the study. In all five women living with HIV/AIDS in Southern Ontario participated in this study and the following is a short profile on them.

4.1 Profile of Participants

To stay true to the background of the participants I have chosen to give a brief profile of each of the participants. I used pseudonym for each women as indicated earlier. Five women participated in this study and each of them shared with me a unique story of their lives through the three phases of their lives. Even though they share their experience of living with HIV/AIDS it is important for us to note that these women possess different individual strength and have different life experiences.

4.1.1 Participant One

Agnes is a 39-year-old single mother originally from the Caribbean even though she is now a Canadian resident. She has been divorced for several years and has been living with HIV for the past 10years. She lives with her children in supportive housing on a paid leave. She has a loving family of three sisters and a brother. She has completed high school and worked as a machine operator before she was diagnosed with the disease. Talking about her goals; she can be described as a woman of vision and great ideas. For instance before her diagnosis she planned to become an accountant for her to be able to give her children the best in life. As part of her daily challenges she tries not to remember who she was before HIV because "it's so difficult to accept what you are today". Currently, she works as a community volunteer in Downtown Toronto.

4.1.2 Participant Two

The second participant is Mary who was a former secretary and a university graduate from East Africa. She looks strong and healthy despite the fact that she was diagnosed with HIV in Canada after the death of her husband several years ago. She never knew her husband was HIV positive and about the possibility of her becoming infected. She is 40years old and has been living with the disease for the past 4years. Before HIV she was living a happy life and was never worried about her health. She is burdened with health and socio-economic problems. She is a Christian and a single mother seeking employment. She appreciates Canada because she gets all the medical and governmental support, however she finds life boring here and remains preoccupied with thoughts about poverty, food and money which she states makes life so unbearable.

4.1.3 Participant Three

Ethel is a woman who came to Canada from South America at age 20. She became pregnant and was abandoned by the child's father. Because life was so difficult at that point she decided to become a prostitute as a source of making some money. She got a job as a general worker in a factory but when her daughter's needs began increasing at the age of ten; she went back into prostitution and that was how she became infected. She blames the family doctor she had before contracting HIV/AIDS for not educating her about the uses and importance of condoms. She used to help people in her community but after her diagnosis, she also expressed the feeling of isolation, nobody wants her around. She is now 50 years old and was diagnosed with HIV in 1990. She has been living alone for all these years since her daughter got married. She has no friends or support apart from the people and services provided by Voices of Positive Women.

4.1.4 Participant Four

Christine, a 29-year-old Canadian born woman living with HIV for the past 9 years, was the fourth participant. After the diagnosis, she had experienced depression and suicidal ideation. Her deceased husband infected her; however, at present she is married, pregnant and lives with her children. She worked as a daycare worker. Her friends have not treated her different since being diagnosed with HIV. Her relationship with the health system is okay and she appreciates all the support from the government. She states "living with HIV is difficult but you just have to deal with it."

4.1.5 Participant Five

Sue the last and fifth participant was a West- African woman who was diagnosed with HIV when living in the United States of America. She is a 46 years old Protestant woman who believes in the spirituality of her health condition. She was diagnosed in 1987 with the disease yet her T-cells count is high enough for her to experience good health. When she was initially diagnosed she had suicidal ideations and felt depressed because knowing about her status was very difficult for her to handle. She believes that if women living with HIV eat well, exercises and pray they will live healthy and longer life. She is a single woman and lives alone. She is currently attending school to add more value to her life. She calls herself an "encourager and community volunteer." Due to her in-depth personal experience she finds that she is capable of advising women and girls about HIV/AIDS.

The voices of a highly diverse group of women living with HIV/AIDS are presented. These women are from places as varied as South America, Ivory Coast to the icy streets of Canada. Their educational background ranged from high school to college-educated professionals. Although they are from different countries they are all presently Canadian citizens. One of them was diagnosed with the HIV/AIDS in United States of America while the rest were diagnosed in Canada. Interestingly one of them has been living with the disease for the past 20 years and the youngest among them has also been living with the disease for the past 3years.

Speaking with these women about their experiences, it became clear that when considering the issues around HIV/AIDS each woman had a unique story to share. The women shared with me stories of their struggles, challenges, needs, coping strategies, and survival and quality of life as individuals who live within the family and the community. They mentioned some family members, friends and community members lowered expectations, stereotyped beliefs and discriminating behaviours. Rather than experiencing an integrative and supportive system within the community and the family, multiple barriers often converged to create inequitable or inaccessible opportunities for women with HIV/AIDS. In the face of these challenges, the participants nonetheless demonstrated strength and resilience in their attempt to resist a stigmatized identity.

It is clear that the women's experiences in the family, community and as individuals are affected by multiple factors. The three life phases explored in their life history interviews are (a) life before HIV/AIDS, (b) life after HIV/AIDS and (c) survival and coping strategies.

4.2 Life before HIV-Phase One

Almost without exception, the participants recognized and highlighted the importance of life experiences before HIV/AIDS. Many of the participants gave very detailed stories of their lives and experiences before HIV. They also gave a description of themselves, the activities they were involved in, and discussed their relationships with themselves as individuals, within their families and community as before HIV. The value the women placed on their experiences before HIV was demonstrated in the time and energy devoted to this phase of their life history.

4.2.1 Individual Level:

Description of self

These women reflected on their lives before HIV/AIDS and they talked about their family, employment and children. Most of them saw life to be interesting and more comfortable, although they had some challenges. One of them saw life to be very hard and difficult. Most of them were fully employed and had most of their friends around them. They described HIV/AIDS as a "rip-off" of their lives.

"Before HIV I was interested in a lot of things, for example I wanted to continue with school and to go to university and become an accountant. Life was fun, not that I have too much physical fun but life was interesting. I look ahead for a lot and had a lot of expectations. I saw myself as physically able to do whatever I put my thought to and work hard to complete. I have been a mother of five and that was rewarding for me. I had full time employment. Life was generally interesting. I wake up strong and able." (01-Agnes)

"It was a very hard life. It was hard, I had to take care of my daughter, and money wasn't enough so I had to do prostitution." (0-3 Ethel)

"Exciting, working and studying. I go out with my friends to the clubs and have fun. It was very exciting." (04-Christine)

Average day before HIV

Recognition of the value of an average day before HIV was expressed in their words and voice. Some of the participants expressed excitement and gladness about their lives before HIV while some felt very sad about their whole life. A participant for instance had to become a commercial sex worker because of financial difficulties in her life even before HIV. They appeared to appreciate the opportunity to discuss their lives before HIV with me. Almost all the participants shared some tears as they looked back at the dreams they had and presently at their lives with HIV/AIDS. Each of these individual women again expressed how they spent a day, weekday or weekend before HIV/AIDS. In their words they revealed how they led their lives as mothers, wives, workers, volunteers and community members before HIV/AIDS.

"Before HIV, my average day was taking care of my kids before I leave for work. Taking them to the baby sitter, preparing lunch and getting breakfast ready and leaving for work which I sometimes leave home at 8.30. I had a full time job. I get back home usually around 5.30 pick my kids form day care, prepare dinner, prepare their bath do some house work. At times I work overtime 2 or 3 hrs overtime and would organize for some one to pick

them up. We get home and would have to prepare food for them and they were young kids at that time. After that we wake up and it continues again." (01-Agnes)

"When my daughter was younger I will leave her to stay with a family and they take care of my daughter as I go to work. When I come back from work I will take her home. I did this until my daughter was 10 years old. When my daughter was 10 yrs old I realized we need more money because she wanted all the nice things she was seeing at school. So I started doing things like prostitution and stuff like that after work and that is how I led my life. My life was tough and I had to learn fast on the job and learning to be okay because I want my daughter to go to university." (03-Ethel)

"Oh come on! When I wake up I look at my kids, prepare meal for them, take care of my husband and do my business. I was happy around my children but I don't talk a lot about my children because you know African men they cheat and lie a lot. But my children I was very happy they are my life and I love them a lot" (05-Sue)

4.2.2 Family Level:

Relationship with family

Family members and relatives seemed to play important roles in the lives of the participants. Most mentioned their parents', siblings' and relatives' encouragement as source of inspiration and support in life. They linked this support and inspiration to future success in life. Most of the participants spoke of the wonderful and beautiful personal relationship and experiences they had with the family members and relatives. On the other hand one woman spoke of the negative relationship she experienced within her family even before HIV.

"I have a very loving family. I have five sisters and one brother... well... my relationship with my brother was never very good from the beginning since I was a young child but with my sisters we were really close and....we love each other very much and live in the same community so we can be close to each other see my mum. We live in a little house for a long time even as adults. Until we started having a lot of things everybody separated and started renting but before then everybody remained in the same community and we live in a little house." (01-Agnes)

"I never had any support from any body it was me and my daughter. My family is at home and I didn't have that close life with my family back at home especially my parents because they never lived with me, they only send me to school and leave me in school. We were not close so it was easy for me to stay here in Canada without them. My parents were outgoing and having me as a child was kind of unfit so I never had any relationship with them." (03-Ethel)

4.2.3 Community Level:

Experience with health system

Some of the women described their relationship with the health system before HIV as supportive and particularly helpful. Some also commended medical professionals, especially the family doctors, for their support and care. In most cases they were not really bothered about their health; they believed their health condition was in a good shape until they were diagnosed with the disease. Virtually almost all the women perceived their doctors and the health care system to have better understanding of their needs when they did not yet have HIV. One woman however who worked in the sex trade profession blamed her doctor for not educating and informing her on the danger of unprotected sex or HIV transmission. Some also had good experience with the doctors but not with the health system.

"Actually I do not have to pay regular visit to the family doctor before HIV, I was very pretty healthy and I only went to the family doctor honestly when I was pregnant and that was my only time I visit the doctor so I did not have regular visit to the doctor. Other than that it was just okay and I know how to take care of myself. So I was very healthy." (04-Christie)

"I was healthy and strong. I had a good doctor and gynaecologists in Africa before I came here. He was very good to me. However I didn't like the health system." (02-Mary)

"I had one and I used to go there with my daughter. He a silent person and not a good communicator. He didn't tell me anything about condoms or unprotected sex and as a young girl then I thought he should have guided me." (03-Ethel)

Interaction with community

No individual is an island as the saying goes and this was evident in the lives of these women. They interacted with the community actively before HIV/AIDS as volunteers, workers, and Sunday school teachers among others. They had the physical and emotional strength to do all that they wanted to do with the community and the family.

"My country is a beautiful African country and I did a lot of things to help my people. I was a Sunday school supporter and I also help people who needed some help" (02-Mary).

"I use to help the people in the community" (03-Ethel)

4.3 Living with HIV/AIDS-Phase Two

The women spoke of their diagnosis and some of the psychosocial challenges such as internalized stigma and quality of life. From my own personal experience and from the findings of this study in addition to available literature, I believe that "contracting" HIV, is no more a death sentence; unless an individual fails to take the medications, attend doctors visits or lack access to the right medications. In spite of these achievements there is the lack of psychosocial support for these women. These include internalized stigma, social stigma, loneliness and helplessness.

4.3.1 Individual level:

Diagnosis and sharing of information

The women highlighted the stories surrounding their diagnosis. Almost all of them indicated in their testimonies how faithful they were in their marriages. They also commented that HIV is not discriminatory; everyone is at risk, especially those who do not practice safe sex. Participants also expressed the feelings and experiences associated with the person with whom they shared the diagnosis. To all of them confidentiality was very important so they shared it with the most significant person in their lives.

"Actually my sister had a baby and she was calling for insurance. The insurance guy came to our home, at that time we were living together. He did the test with her so I was sitting there and asked the guy if I could apply, can I do a test and if I could also get insurance. He said when they come in they have to do a quick test and its swabbing in the mouth and if it changes colour that means you have a problem and they don't know what the problem is so they have to find out. He took the swap from my mouth and when he put the stick in the bottle

it turned blue and I looked at it and said oh boy! Something is wrong with me. He said whatever the problem is he would write to me and I will know whatever it is. They sent me a letter and said the test I made was positive so I should check with my doctor and I checked with my doctor and did a test and it was positive again." (01-Agnes)

"I was pregnant then so as part of my antenatal care, they found out that I was HIV positive. I didn't know I was HIV positive and the kids' father at that time did not tell me he was HIV positive. Well he is dead now." (04-Christine)

"I was feeling that I was sick and when, my daughter said you have to go for a medical test. We also found out that the guy I was dating also died so my daughter said you have to get a test because you might be sick too so I went to the health center and found out that I was sick." (03-Ethel).

"I did not immediately share this information with anybody, but for about 6 months later I shared it with my mum and my elder sister."(01-Agnes)

Average day with HIV/AIDS

The women talked about the same issues as they lived daily with HIV/AIDS. They talked about loneliness, sadness, boredom and isolation. They were not sure of what the future has for them; however, some of them spend quality time with their children. They want to be there for their children and also give them the best in life.

"My days are lonely, tired ...oh boy. It's very hard. Not so much fear of death (She shared some tears at this point). There is fear of not being able to accomplish what I have to. The loneliness is the biggest thing. Not so much that I have to be lonely but I am afraid of

leaving my children behind. My days are spent at home and taking care of my home and my kids but I find things to do around the house since I am not currently employed anymore and I fill my days with these. I also get tired very quickly and my mornings I wake up late especially when the kids are not in school, but when they are I get up a bit early" (01-Agnes).

"You see poverty and HIV is terrible. Government assistance is not much for myself and my family let alone being a sick single mother. Its very terrible." (02-Mary)

"Boring and always at home. Watching television and always thinking. It's terrible, I think and think. HIV makes you think."(05-Sue)

Emotional Challenges

All the women expressed concern regarding the difficulties, challenges, needs, coping strategies, survival and the quality of life as women living with HIV/AIDS. They felt that the lack of services and resources has resulted in undue hardship in their lives. The daily psychological challenges revealed in their transcripts appeared to be equally influential or even more traumatic than the lack of other socio-economic resources such as childcare. Most of the women felt lonely, depressed and suicidal. They also commented on the physiological challenges associated with medication.

"Wishful thinking and building castles in the air. Thoughts about poverty, food and always looking for money. I have fears and sadness when I feel sick and think about my status. (02-Mary).

"I have fears of dying, not being able to take care of my kids and am always sad. I feel sad for not being able to take them on vacation. I am hoping to give my kids the best in life." (01-Agnes)

"I feel depressed, sad and I think a lot about my life. First I wanted to kill my self but now I am better." (05-Sue)

Physical Challenges

Aside from the psychosocial challenges that the women shared with me they also commented about some of the physical changes they are going through. They talked about their body changes and some physiological changes. Among some women there were no obvious HIV/AIDS physical or body changes and nobody could even notice any change in them. I must say that physically they look healthy and strong: they had no rash or sores on their bodies as expected among populations with HIV, however during the interview they shared with me some of the physical challenges that they had to endure daily and these includes bodily pain and weakness. It is also important for us to note that the women had access to modern antiretroviral drugs and also participate in various medical trials. Some of these drugs make them eat more often which in effect makes them to become overweight. During the interview I had to buy them food because I was told they had to eat regularly in order to maintain their energy level. It is important for us to note that this group of women with HIV/AIDS is different and unique because they have access to most of the newly developed antiretroviral drugs and could be prevented from most of these opportunistic infections such as coughing and body sores.

"If I don't eat well I feel like throwing up and my head also aches me. When I wake up I don't work and plan my diet and medication. I can't go out when the sun is out." (03-Ethel)

"I have sleepless nights and sometimes I have to visit the wash room several times. My physical changes are a problem, my complexion has changed, and I was fairer, now I am darker. I have put on a lot of weight due to the medication." (01-Agnes)

I have grown fatter because of the medication I took before. Now I don't take any medication and I am fine." (05-Sue)

"After taking all these medication I have problems with my organs, like my liver has sclerosis and I am diabetic and there so many things in my body that are not working anymore, they are working a little bit.. Naturally I could eat everything I want and I use to be very thin but now I am very fat and I stopped eating everything because of my health." (03-Ethel)

Social Challenges

Social stigma and exclusion were issues raised by all the participants and although they have decided to keep their status a secret, they live in fear and exclusion and to a large extent experience internalized stigma. They spoke of the difficulty they experience and due to this experience they have resorted to keeping their status to themselves. From the research data it was clearly identified that the first few years after diagnosis were the most crucial times in the life of participants. Some wanted to kill themselves while others also kept the disease secret to themselves. For some it was a time to learn all about HIV.

"I was depressed even though I didn't go through difficult experience. My friend and the interpreter took me to a church in US, the church people know so they helped me a lot. Sometimes people go through all sort of stuff because they have a disease but I didn't feel that way. It's hard and sometimes it's difficult to stay alone and you will die and nobody will come and see you. It's difficult to live with people who would also discriminate against you because you have HIV. You don't want to expose yourself to people neither do you want them to know anything about your status. So I chose to stay alone. In the US my friends had their families and you can't call them all the time to talk to them. In Canada, there are more support groups and people around to talk to. I am fine here."(05-Sue)

"It is so scary to look for a job because they would like to check your blood test. If they know you are HIV positive nobody will employ you and the insurance companies will not accept you." (05-Sue)

"It wasn't easy and I can't believe I have HIV. I have learned to watch what I say and tell people. I don't trust anyone. I watch what I eat. My friends are these women from Voices." (02-Mary)

"Nobody knows I am HIV in Canada except the other HIV women. In the US when I was diagnosed with HIV I got all the needed support and encouragement. Nobody treated me differently. I was given everything that I need. I didn't have any problem at all" (05-Sue)

"It is very difficult and for me it is difficult when you have to deal with people who don't know you are HIV positive and you have to do things. Sometimes I feel so sick and when I have to meet my daughter's family, they are Italians and when they know I have HIV I don't know what will happen. I feel so sad and cry and everything because I be with them all the time

because it's not that easy and also not easy always explaining to them about me not having a job. It's very hard and I feel so low."(03-Ethel)

It is very hard to deal with people. We have a new manager in charge of my building a he is very inhuman. A social worker came to speak to him and I moved to a new place in the same apartment but I still have problem with him. I also have a problem with the doctors and dentist. I had my entire tooth coming out and I went to fill them because I have only 3 left." (03-Ethel)

"Stigma challenges I face are confusing. This is difficult. Scared of revealing my status. I don't have heterosexual relationship. Can't work. Scared of losing too much money." (04-Chrustine)

"I have never faced a problem because I have never told anyone. I don't have any physical symptoms and nobody knows I have HIV, I look normal like any other woman. However, sitting and listening to people with HIV, its hard to take and you don't feel like a human anymore, you feel you are a "thing" I feel discarded as I listen to the way other women with HIV talk about the way they are treated and knowing that I am living with HIV if I tell people about myself they will treat me the same." (01-Agnes)

A woman who is my friend through gossip went to tell my family members about my status. I look healthy so nobody knows about my condition or I have HIV unless I tell you. My family members also gossiped about me so much that I heard somewhere and I confronted them. I don't trust anybody and so that is why I don't want you to record my voice. I reported *the person who first gossip about me and she was legally charged for what she did." (02-Mary)*

Psychosocial Challenges

Although less work has been conducted on the psychological adjustment of women with HIV/AIDS, research has begun to examine their specific needs. The participants shared the numerous psychosocial challenges that they face daily. Their needs include lack of family and society support. And as indicated earlier, they saw the positive support from family members and relatives as inspiring which also had significant impact on their survival and progression in life. In their current situation they wish that their family members, relatives, doctors and the whole community would embrace them as women who are capable despite their condition.

"Basically, everything looks fine but most of my needs are just being able to come out and do what I have to do everyday, get out of bed and move around and do my daily work. What I hope to do is to get back to work and face life. I am facing a lot of problems now because my doctor sees me as sick right now and I can't go back to work to the company. I don't have the financial means now."(01-Agnes)

"I have accepted it and I see myself as a normal woman and a person."(04-Christine)

4.3.2 Family Level:

Family response and support

The women commented on the support they received from their family members in their present condition. According to some of them, their family members have been supportive and caring emotionally and economically while others commented on the impact of the lack of support.

"My family sympathized with me in a way that I don't like. It makes me feel less a person. There is no financial support from my family" (02-Mary)

"They don't care and I don't receive any support from them. I don't have friends now and the only people I will call friends are those from Voices" (03-Ethel)

"Some were more supportive than others and some still are. They call me and encourage me but I don't get any financial support from them." (04-Christine)

"I would say very supportive, my mother and sisters but I am not close to my brother. I have a great family support and I am very close to my sisters" (01-Agnes).

Experiencing friendship with HIV/AIDS

I asked the women to tell me about their relationship with their friends although they are now living with HIV/AIDS. Some of the participants commented on the good relationship they have with their friends. Some claimed they have lost their old friends while others have made new friends through their diagnosis. Others still have their friends despite their status or condition.

"My friends support me financially. When I am in the US my church gives me money and my friends helped me a lot. Those who helped me a lot were whites. I didn't face any discrimination from the community. I see my HIV doctor and I get all my support. To be strong and think positive. If you are HIV positive you have to give up drugs, alcohol, exercise, go to school eat well and good food" (05-Sue).

"My friends are very supportive. They take me out, hangout with me and they don't treat me different. They don't discriminate against me."(04-Christine)

"With my HIV I don't see all those people around me anymore. I use to help a lot of people but now I am alone and it's me and my daughter."(03-Ethel)

4.3.3 Community Level:

Narrow Understanding of HIV and Experience with doctors, other professionals and the health system

The participants' stories indicate that health care practices can prove successful or detrimental in their lives, their experiences and survival. They expressed their feelings, grievances, and pleasant experiences as they interacted with their doctors and the health care system at large. Mentioned, as particularly damaging, is the negative treatment they receive from some health care professionals. Despite the global campaign and all the education on HIV/AIDS, it is still surprising to note that prejudice and assumptions remain in relation to HIV/AIDS within the community and among health professionals. The women commented on how they were maltreated more by some health professionals and family members who are suppose to show care and support than any other group of individuals. In addition, the findings clearly revealed the narrow understanding of the HIV issue to some professionals that these women had visited. To some extent the women felt they were not treated well by these professionals because they lack adequate understanding of the disease and their needs.

"He was funny and said he did not know anything about HIV/AIDS and he was scared too so he immediately gave me a number of a lung specialist. The specialist didn't know I was coming in because of HIV/AIDS but thought it was because of a lung problem. When I went to see him and he asked me if I smoke and I said no and he asked me what my problem was and what he can do for me. I told him I am HIV+ person. He said let me check your lungs then since you are here. He checked and said your lungs are clean as a baby's. He said you don't have lung problems. He recommended me to see a doctor who specializes in HIV/AIDS. This specialist was very support and told me about Women's Health in Women's Hands and I can go there for help and also to see the HIV/AIDS specialists if I want to." (03-Ethel)

"He was supportive and told me that I won't die and this is not Africa. They are a lot of drugs. He gave me the right medication and also educated me on my nutrition." (02-Mary)

"Well my doctor was a Chinese when I was first diagnosed as HIV. He told me not to worry. He gave me the list of organizations that I can go to. He told me what to eat and not to eat. He told me to stop drinking and doing drugs because he knows I was doing drugs and drinking. He was very helpful but I didn't like the psychologist, he talks too much and sometimes he tells my doctor things about me which are not true. I stop doing drugs but the

psychologist tells my doctor I am still doing drugs. My doctor was good and I still see him" (03-Ethel).

"If I tell you I have bad experiences I am lying but I met the most wonderful people in my life. The best people I met in my life was when I had HIV." (05-Sue)

"I had an experience that I almost died and I refuse treatment and medication from the doctor because he was trying a new medication on me, which I refused. He was trying a medication on me and I felt it was my right to refuse any medication. I stayed in the hospital for a week and a half with a lot of pain then I told them I would leave and then I left the second week. I came back couple of days later to the rehab center because I lost mobility on my left side and so my doctor was very annoyed with me and again because I refused his medication. I had brain a tumor and they refused to operate me. I was weak and couldn't move around as much as I used to." (01-Agnes)

" I would say there isn't enough support for PLWHA" "She is very good. She will ask me how I am doing. She talks to me and tells me I won't die. The other doctors and nurses are also good and supportive. Well some of them are good not all. There should be a better health system, like going to the hospital and not waiting for long. There should be doctors and more HIV specialists and government should give more money for our services. The HIV centers should be all over and not just at one specific area. I like the health system but a lot more can be done. Well I will say it is better than other countries" (04-Christine).

Relationship with Community and type of social support received as an HIV/AIDS woman:

Some of the participants felt their relationship with the community is diminishing after their diagnosis. Most of the women have developed their own coping strategies although they feel neglected by the community. They see themselves as invisible within the community in spite of the human rights advocacy for PLWHA. In some cases the community through agencies such as Voices has supported them, however despite the importance of the services the VOP the agency lacks sufficient funding.

"Currently the community I live in is not a place I face any HIV challenges. In my community I don't think anybody knows I am HIV positive. I haven't told anyone I am HIV positive. I do voluntary work in the community with Voices of Positive Women and I am involved in HIV community work and support system. Aside this HIV work I am invisible." (01-Agnes)

"Now I have learnt my lesson. I gave myself to people but nobody was there to help me. I am just part of Voices. I don't do any community work or involved in any community activity. Voices was very supportive and sometimes I call on ACTS to support me when I have housing issues." (03-Ethel)

"Voices has helped me a lot. With Voices I have confidence in my self. The other women are supportive and we all share our story. We pray together. We talk about medication and nutrition. Supporting is good." (04-Chrustine)

4.4 Survival and Coping Strategies

The participants commented that HIV/AIDS does not only influence their psychological well-being but their entire survival and coping strategies. They face numerous challenges and they have to develop their own coping and survival strategies although some agencies and the community to some extent support them in these areas. Participants also commented on certain coping abilities and emotional strengths that they have developed over the years through Voices of Positive Women.

4.4.1 Individual Level:

Addressing needs and challenges as an HIV/AIDS woman

Although the government and some agencies within the community support them, participants claim they have to search for individual funding. They are not employed and so it is difficult for them to afford all the medication that is not covered by the government or the community agencies. The women also commented on issues such as housing, food and medication to be the greatest problems that they face. They have nobody and nowhere to turn to apart from the government and other agencies.

"My medication fortunately I pay through Trillium and my financial income is from my pension and my housing I pay through the mortgage because I get the same paycheck now."(01-Agnes)

Daily coping strategies (Nutrition, prayer etc)

In the face of the numerous problems that women with HIV/AIDS face, the participants had to develop coping strategies that will enable them to move on in life. They have to learn how to cope with internalized stigma, social stigma, family ridicule and depression as well as significant socio-economic challenges. The emotional challenges associated with daily medical challenges cannot be underestimated. The women were indeed survivors because some of them have lived with these challenges for over 10 years. It is amazing how they made it. Although they encounter many problems daily I see these women as victors in the face of HIV/AIDS.

"Basically I tried not to remember, It's difficult to remember what you were before HIV. You know what and who you were before HIV and it's difficult to accept what you are today and I tried not to focus on what I was before. What I want to do now or tried to do is I focus on what I want to be or tried to be. Being on medication as well makes you weaker than if you are not. I tried hard not to focus on my past and who I was. When I am not feeling very weak I spend my time to help my family, my sisters and mum and the kids. I do things that keep me moving around than sitting at one place. I will go out and help them at home and go out with the kids too." (01-Agnes)

"I eat well, sleep well, I don't smoke or drink. I always listen to the advice from my doctor. I go to the gym and I also get family support. I try to save energy and for instance if I work I have to stay at home for 2 days because my legs are not strong. Its like I have to recharge my energy. I am anemic." (05-Sue)

"I don't drink and do drugs anymore. I take my medication regularly. I go for regular check ups. I do some little exercises in my room. I eat well and sleep a lot. My daughter is also supportive and she encourages me to live as a happy woman with or without HIV. She inspires me a lot and I always think about my grandchild that will soon be born." (03-Ethel)

"I have been doing okay even though its tough I have to do with it and deal with the situation. Well just do with it!" (04-Christine)

"I try not to destroy my life. I don't drink or take hot stuff (pepper), I try to exercise a little at home everyday even if I am so weak. I try to be careful on what I eat. I buy soybean and take off the skin and boil it. This is the way I take care of myself. Now that my daughter is married I have a more time and I take care of myself because I wish to keep my time busy with her." (03-Ethel)

"I pray a lot and read my Bible. I eat well and I don't think about men all the time. I don't take medication for eight years now. My T-Cells are high and I am healthy. I don't drink or smoke. I sleep a lot and I don't do anything that can harm my life." (05-Sue)

"I read my Bible, go to church and pray with my sisters." (01-Agnes)

Coping with Stigma and social exclusion

According to the women, coping with stigma is one of the greatest challenges that they face in their lives, family and community as a whole. They have to stay away from certain family gatherings and meetings because they do not want anybody to notice any change in their life since these individuals have known them in the past few years. For example "*My in-laws always ask why I am not working but I tell them something else and because I want to save my daughter's marriage and happiness I avoid my in-laws a lot. I have only visited them once and even that I was very careful because I am not all that strong even though I look very healthy.*"

They are worried about symptoms such as coughing in the presence of others as well as regular washroom visits. Due to regular medical routine and certain physiological challenges such as diarrhoea and coughs they often want to stay at home. Almost all of them have kept their status secretly from the community for all these years as a way of dealing with stigma and social exclusion. Although they all claim they don't experience stigma within the community, I believe they experience some form of internalized stigma. I also believe that keeping their status secretly is a way of keeping them from all the discrimination in the community.

"I don't experience any social stigma." (01-Agnes)

"Well where I am staying nobody knows me and I keep it as a secret to myself even though it is hard. I only play wit my kids and talk to my fiancé."(04-Chrintine)

"Well I don't have any problem with the people in my area. Nobody knows about my situation. I get sick sometimes nobody knows it's HIV. But one day we had a new landlord who was very wicked and wanted to send me out of the house. He said I couldn't share the facilities with other people. I informed ACTS about it and the situation was resolved." (03-Ethe

"I have accepted myself. I don't have friends apart from the women at Voices. Because people don't know my condition nobody discriminated against me. But my family they treat me as if I am a sick person and sometimes I think they are showing pity on me which I don't like. I believe in my self and right now I am looking for a job. I love my children and I pray I get a job so I can support them"(02-Mary)

4.4.2 Family Level:

Financial Support

Participants also had the chance to comment on their family members and friends. Some of them claimed their families and friends were source of inspiration and strength and although they could not be supported financially, their presence in their lives play a very significant role in their survival. Participants also commented on insufficient support from family members and friends. Some have lost their friends while others have made new friends.

Well my family doesn't support me financially and I don't have any friend who supports me financially. My only support is from the government and that is not enough. When the children are going to school lets say if school is reopening I don't have money for them and what I get from the government is on welfare that is so small. It is only for rent and food. You can't buy clothes or anything. (02-Mary)

4.4.3 Community Level:

Availability and accessibility of resources

Again participants commented on the available and accessible resource that exists for women living with HIV/AIDS. They commented on the insufficient resources and the lack of access to the few existing ones in the community. According to them access or available housing, childcare support and medication for women living with HIV/AIDS is a problem that should be addressed urgently by the government.

"No there aren't enough resources or services for women with HIV/AIDS." (01-Agnes)

"There is money for shelter, food and medication but not sufficient." (04-Christine)

"Food, clothes and other support like someone coming to talk to us or there is a research like yours then we are given some money. There are not much support for us. For example the people with HIV who are on trial medications, the doctors should be closer and if a doctor is close and you are suffering and you need something he can help. Right now I am anemic and I

need this medication because each needle will cost me $28, each needle and not covered by government but if the doctors call the government we can have the needle for free but I don't know why they don't do that." (03-Ethel)

"Well they help you with medication as you go to the clinic and if you have any problem with rent they will also help you. I mean the HIV/AIDS support group" (02-Mary

"Some of them are okay. Voices is okay, they have program for us. ACTS has a lot but they are more dedicated to men. There has to be more support for Voices too. No there aren't enough resources or services for women with HIV/AIDS. Voices for instance needs more support, there is not really much for women. We have the Voices and other support groups. There has to be more support for HIV/AIDS women with children if we get housing is a good thing. Like me if you live alone but if you are living with someone and you can't pay the rent. You want to be alone and keep yourself by yourself you know! If someone rent with you and you don't know anything about HIV its difficult. If you also cough and cough and if you have TB then you might infect other people around you especially if they are children. So I think we should be considered for housing if we want one. It is not easy to live with people." (05-Sue)

Resilience

Despite their negative experiences with relatives, family members, community and health systems, the participants rarely placed full responsibility or blame on these individuals, groups or other significant others in their lives. They exemplified compassion and insightfulness as they articulated their experiences and inspirations in their narrations. While in one breath the participants shared experiences of stigma, isolation and disengagement resulting from the lack of community or family support and services, in the next they acknowledged the beautiful significant experiences in their lives although they are living with HIV/AIDS.

"I enjoy staying around my children and see them grow, I feel so happy and proud." (04-Christine)

"Being able to take care of my child. She is now married and I am very happy for her." (03-Ethel)

Recommendations

The participants also talked about the some of the things they have learned through these years of living with HIV/AIDS. Although their experiences sounded like recommendations, they appeared very passionate and emotional as they shared these experiences with me. Finally the women gave various suggestions that could reduce the plights and challenges of women living with HIV/AIDS. For me there should be more education in the schools, on TV and financial support from the government for Voices and us.

Professional support:

"We need people who care for us and would talk for us." (01-Agnes)

"We need psychologists that will understand us. We need doctors who we can trust and listen to us."(03-Ethel)

Leadership support:

"The issue of stigma should be addressed. To help build confidence and trust in African leaders so they can support women living with HIV/AIDS in Africa." (02-Mary)

Public Education:

"There should be more support for these women. There should be more program like Voices and these organizations should be supported to stay. We call each other and they call you to see if you are doing well."

"People like you need to trust us because HIV is not scary. There should be programs on TV and in schools so that people will know more about HIV/AIDS." (02-Mary)

Support and Resources:

"More funding, teaching and having more commercials for people with HIV. There has to be more support groups. More education and awareness needs to be made in the community. There should be more education in the schools, on TV and financial support from the government for us and Voices." (04-Christine)

"I am saying that there should be more housing support for women with HIV. Young people should abstain from sex. Don't try it. Even if the man is nice like God Himself don't do it. Young girls should be careful about men. How can you live your life taking drugs all the time? A man can have 3 girl friends and he would come after you please don't do it. Some men are infected but it doesn't show. Take care of yourself and have your condom 24hhrs a day. Wait and marry and enjoy yourself forever or go to the clubs and suffer forever." (05-Sue)

"There should be more camps and places where we can go for family members, children, friends etc. for reunion. I can't go on family trips with my kids or family because I don't have money for that but if there are scholarships and place we can go to that will be great." (04-Christine)

Although, the participants stated that more research could be conducted in this area, however, it is important that we don't too narrowly define what people should study based on their results of this study. Additionally, much knowledge and insight can be discovered if researchers from different racial and cultural backgrounds were to conduct the research. All the participants have provided many areas where improvement can be made to provide better services for women living with HIV/AIDS. Indeed, the aforementioned areas of improvement can create better services not just for women living with HIV/AIDS in Canada but also for all women.

In summary it can be noted that all participants in this study described a wide variety of recommendations for the improvement of services provided HIV/AIDS women. The family, healthcare providers, the community and government at large for enhanced services and resources provide a primary recommendation presented by the participants. In addition, education on the psychosocial needs of women living with HIV/AIDS among doctors, psychologists and healthcare providers will help in the provision of better services. In conclusion, participants also pointed the need for integrative services for women living with HIV/AIDS and also the need for more community support and future research activities.

CHAPTER FIVE

DISCUSSION

The goal of this study was to increase the understanding of the psychosocial dimensions of social stigma on the lived experiences of women living with HIV/AIDS (WLWHA), quality of life issues, survival, and coping strategies. The purpose of this section is to discuss current findings in relation to the literature to develop a clearer picture of the experiences, needs, challenges, and coping strategies of women living with HIV/AIDS on multiple dimensions (individual, family, community, health sector and society) and how their voices and experiences can contribute to policies and strategies for the advancement of the quality of life of women living with HIV/AIDS. I have demonstrated in chapter two that despite the adequacy of pharmaceutical and medical resources and services for PLWHA, there is lack of socio-economic and psychosocial support for women with HIV/AIDS. The participants told a story of the daily struggles in a community, which still stigmatizes PLWHA despite all the education on HIV/AIDS. These experiences indicate that inequitable resources and services exist for women with HIV/AIDS. They have also provided extensive data concerning their lives after HIV, diagnosis including lived experiences, survival, and coping strategies. Some of the data served to reveal the daily coping strategies of the women as well as the availability of resources and services for women with HIV/AIDS within the community. The participants demonstrated remarkable strength in confronting these challenges: many managed to balance internalized stigma, exclusion, and unemployment with their survival. These women strived to progress through these challenges by developing inner strength, individual coping mechanisms and survival strategies such as praying.

5.1 A Feminist Voice in the Face of HIV/AIDS

Originally, I asked the question of why an African young woman was interested in the lives of women living with HIV/AIDS in Toronto. I believe my position as discussed earlier and my role as an African woman influenced my quest in undertaking such a tough journey. Traveling along with these women through the three phases of their lives, that is life before HIV/AIDS, life after diagnosis and survival and coping strategies was challenging yet inspiring because I have acquired more skills as a women's advocate that can be transferred to Ghana. I also believe women's sexual health is directly affected by women's status in society. This status, and subsequent lack of sexual autonomy, not only increases risk for sexual health problems, it also decreases ability to obtain treatment and support when a sexual health concern arises.

Earlier in the AIDS epidemic women were simply ignored by the community and professionals. Once women could no longer be ignored they were blamed, they were viewed as vectors of the disease. Women must not be regarded as victims. They are, in many places, leading the way forward. In communities scattered around the globe, women and men are taking action to increase knowledge about the disease, expand access to sexual and reproductive health and educational services, increase women's ability to negotiate safer sexual relations, combat gender discrimination and violence and increase access to female-controlled prevention methods such as the female condom.

At its heart, this is a crisis of gender inequality, as women are still less able than men to exercise control over their bodies and lives (Lynch, 1991). Almost universally, cultural expectations have encouraged men to have multiple partners, while women are expected to abstain or be faithful to one partner. There is also a culture of silence around sexual and reproductive health. Simply by fulfilling their expected gender roles, men and women are likely to increase their risk of HIV infection. But the gender disparities go far deeper than sexual relations. Women in many regions do not own property or have access to financial resources and are dependent on men: husbands, fathers, brothers and sons, for support. Without resources, women are susceptible to abuses of power. Violence and the threat of it also limit women's ability to protect themselves from HIV/AIDS. They risk violence if they insist on protection (Lynch, 1991). They may stay in violent relationships because they have nowhere else to go. They may give in to male demands for unprotected sexual relations, even when they know the danger, such as living with an HIV/AIDS partner.

Whether in conflict areas or in the home, rape and sexual abuse make a mockery of the notion of safer sexual relations. In addition, poverty pushes some women into risky behavior or dangerous situations. With no other options in sight, they may resort to sex work to feed their families. Women and girls are susceptible to the growing trade of trafficking. In Southern Africa, many older men seek out young women and adolescent girls for sexual favors while providing them with school fees, food and highly sought after consumer goods (UNFPA Report, 2005). In countries that are hard-hit by the epidemic, particularly in sub-Saharan Africa, women have taken on the care of HIV/AIDS patients. They provide home-based care, take in orphans, cultivate crops or find paid employment to keep their families going. They clean, cook and nurse, often without access to clean water and sanitary supplies. Because of the additional work involved in caring for the sick, fields are lying fallow, children (usually girls) are being taken out of school to help and households are not being maintained (Crane, 1990).

Once infected, women often do not have access to the support and resources they need as women living with HIV/AIDS, mothers, caretakers of other HIV/AIDS partners and/or children. These findings are especially true for marginalized women such as women of color, poor women, and women who exchange sex for drugs or money. My research findings demonstrate the need for feminist approaches in understanding and addressing this issue. Such approaches must include an understanding of the needs of diverse women and an empowerment approach that will better contend with the health needs of all women. This must include the goal of ensuring women's control of their own bodies in particular gender sensitive resources and support for women living with HIV/AIDS.

5.2 Looking Back: Life before Diagnosis

One of my findings looked at the stimulating lives of the participants before diagnosis. This finding is not novel because they saw themselves as ordinary women who had careers and great dreams and vision in life. In fact, research by Ezzy (1998) has shown that prior to HIV diagnosis, individuals have high career expectations, intimate relationships and felt normal within society. What was intriguing about this finding was that all the women showed a sign of sadness and depression in their voice although they appeared strong: they wanted the best in life and had hope for the future. They linked their intimate relationship with family, employment and career to their aspirations to "be somebody great" as one participant emphasized. Although on first glance it seems counter-intuitive that the women are less able to cope with their current challenges, this finding can perhaps be explained in relation to the life history experiences of these women before HIV. Some of them expressed regret about their previous relationships with men, including those who got infected through their deceased husbands also regretted that intimate relationship. Participants' comments suggest that within the social, family, economic and employment context their evaluation of their success and aspirations in life were affected.

What does this finding mean for women with HIV/AIDS, professionals and individuals who work with HIV/AIDS? I believe that this finding negates the common perception of the promiscuity, life style and marital unfaithfulness. Rather than looking to blame women with HIV/AIDS, we must recognize that these are normal women who are living with one of the numerous diseases in the world. Therefore, rather than condemning and stigmatized women with HIV/AIDS, it is necessary to focus efforts on creating a society in which all women living with HIV/AIDS have equitable access to resources and services in the community and women and girls are increasingly protected from the disease.

5.3 Quality of life Issues (QOL): Life after Diagnosis

In this study, I was interested in the quality of life (QOL) of the participants particularly HIV/AIDS-quality of life issues. The main findings of this study revealed that, although the daily challenges of women are widely recognized, there remains concern about the quality of life of WLWHA. Participants commented that both physical and emotional aspects of their QOL to some extent have been affected. These include anemia, liver malfunctioning, fatigue, weakness, pain, malnutrition, diarrhea, nausea and vomiting, and sleep problems. Particularly troubling is fatigue. Beside these the women related lack of rest, poor diet, depression and anxiety, infection, pain, and medication side effects and reported by Adinolfi (2001) and Breitbart, et al,. (1998) as some of the quality of life issues they face. Significant change in diet and nutrition were identified as other side effects by participants as a major change and these have also decreased their functional performance as well as increased their risk of premature death and physiological weakness because they have to follow a strict diet guide and medication (Babameto & Kostler, 1997; Kotler, 1997).

The participants' stories attest to the profound impact of sleep disturbances, which included difficulty in falling asleep and frequent awakenings. These disturbances according to the women are caused by anxiety, depression, or HIVAIDS-related physical manifestations such as fever, diarrhea, pain, cough, and night sweats as reported by Phillips (1999). The women's stories also indicate that psychosocial, economic and psychological factors can also diminish QOL in persons with HIV/AIDS. As illustrated inadequate social support, ineffective coping skills, and lack of spirituality have profound impact in the lives of women with HIV/AIDS (Hays et al., 2000). Limited social support and unemployment among the participants predicted depression, which is itself a strong predictor of poor QOL in women with HIV/AIDS (Kemppainen, 2001; Soucy,1997). Medications used to treat HIV/AIDS among these women also affected their QOL, as drug regimens are inconvenient, requiring multiple daily dosing, and precipitated side effects impairing their social functioning. For instance, one of the women talked about the problems with her internal organs, which included her liver, which is being affected by sclerosis. My result again is consistent with research on the quality of life of people with HIV/AIDS (Douaihy & Singh, 2001). While this statement is true, it merits some caution. At present few studies have evaluated the changes in HIVAIDS-individuals' quality of life over time in connection with antiretroviral therapy use. More studies on this topic are emerging.

The current research and past literature indicate that the value and the quality of life of a woman with HIV/AIDS is an important component of HIV/AIDS which should not be underestimated in any context. Failure to integrate the quality of life of women living with

HIV/AIDS can result in inequitable life outcomes as women with HIV/AIDS struggle to cope with the daily challenges of HIV/AIDS without equitable resources

5.4 Internalized Stigma and Social Exclusion among women living with HIV/AIDS

According to Goffman (1963), stigma is an attribute that reduces a person in the minds of others. Such things as physical abnormalities, character blemishes and racial or religious affiliations can stigmatize a person. Stigma is deeply discrediting and signifies blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty. Stigmatized individuals, such as the women in this study, possess a characteristic that labels them as different in a negative way. Society exercises a variety of discriminatory tactics against these women and in these women; both the terminal nature of the disease and the societal implications resulted in the stigmatization that they confronted when others discovered their diagnosis.

The stigmatization associated with HIV/AIDS has been referred to as a second epidemic because of the considerable impact it has on the lives of the individuals (Chesney & Smith, 1999) with HIV/AIDS. When women are diagnosed with HIV/AIDS, the psychosocial implications, rather than the physiological impact, become the focus. The women in this study immediately adopted the stigma associated with having HIV/AIDS. In essence, they became what they feared. In adopting the stigma, they had to make decisions based on this new identity._Most of them decided to keep it as a secret. The findings indicated that most don't face stigma because nobody knows about their status. This is an evidence of internalized stigma. (Goffman, 1963) They fear being stigmatized so they don't want to talk about their status. The women knew they had to tell someone and whom they told became the major decision at the time. The person they chose was someone they trusted to keep their secret and offer support. Beyond this initial episode of sharing, the women struggled with telling anyone else. Many chose not to tell other people.

Even though HIV/AIDS is recognized as a highly stigmatized disease, there has been a lack of research on the internalization of this stigma by women living with HIV/AIDS. The findings of the research showed that the severity of stigma that these women encountered were profound. All the participants in this study reported experiencing internalized stigma related to their status. External social stigma was also evident as some lost their jobs, housing, friends and insurance after diagnoses. These results are similar to the findings of Crandall and Coleman (1992) that HIV/AIDS people experienced varying degrees of stigma related to their illness, including some who experienced no HIV-related stigma at all.

Naturally, the first problem encountered was disclosing their HIV/AIDS status. When telling friends and family members, the participants had to deal with their loved ones' irrational fears of transmission and moral judgments and the realization that these loved ones no longer viewed them in the same manner. This added further support to the beliefs of the women that they no longer were the same person. My findings are consistent with Crandall and Coleman (1992) and VanDevanter, Thacker, Bass, and Arnold (1999) who reported that lack of disclosure of HIV/AIDS status results in isolation, depression, anxiety, and alienation. The consequence of these could include not seeking health care, poor adherence to drug regimens, developing elaborate tales to cover HIV/AIDS-related illnesses, and loss of social support. My analysis revealed that stigma from HIV/AIDS has a negative impact on social interaction, employment opportunities, psychological well-being, and self-perception, a similar finding to Link, Struening, Rahav, Phelan, and Nuttbrock, (1997) and Miles, Burchinal, Holditch-Davis, Wasilewski, and Christian (1997). These findings are indicative of the double-edged sword of disclosure.

In addition, Fife and Wright (2000) also reported on the problems associated with stigma and health care for women with HIV/AIDS. Their study is consistent with the outcome of my findings in that some of these women were hesitant to access health care for fear of stigmatization and discrimination by some health professionals. Some are reluctant to take medications that identify them as being ill and require explanations. These reactions compromise their health care and negatively affected their lives. Despite these challenges which affected the quality of life of some participants, it must be noted that some also got the needed support and care from health professionals.

My study also indicted that the stigma associated with HIV/AIDS has multidimensional effects on women's health and well-being. The stigma was so overwhelming for the women in this study that after diagnosis, they never perceived themselves in the same way. They may have been mothers, sisters, wives, aunts, technicians, secretaries, childcare worker, factory workers prior to their diagnosis, but afterwards they became different women with HIV/AIDS.

The diagnosis overshadowed everything they had been, everything they had accomplished, and totally redefined who they were. Past successes were negated by the diagnosis. One participant blamed herself because she was a commercial sex worker. She had preconceived stereotypes regarding HIV/AIDS, and believed that the disease occurred only in the promiscuous, immoral, or drug-abusing female. The rest of the women identified their former partners or husbands as transmitting the disease to them. According to them, they were wives who remained faithful to their husbands while their husbands were not. My experience with PLWHA people in Ghana supports what the women told me about transmission, most of the women I worked with in a hospice (West African AIDS Foundation) were wives who were faithful to their husbands. In Africa, it is socially acceptable for men to have as many women as they can and most of these people practice unsafe sex. Two of the participants in this study who were African women could have been exposed to this situation in their previous marriages. While other research (Herek & Capitanio, 1999) also indicates that method of transmission affects the level of stigma, this was not true in this group of women. Those infected by their husbands suffered as much stigma as those who contracted the virus from a sexual encounter with an unknown individual.

At the time of diagnosis, the participants were already aware of the stigma associated with HIV/ AIDS. They personally faced the harsh reality almost immediately after diagnosis. Most of the women found rejection to be prevalent as they told family and friends, employers and coworkers, health care providers, and church members. The first persons told of the HIV/AIDS diagnosis were close family members or friends. Sometimes family members were supportive, but often this was not the case. The participants were devastated by their negative reactions. Some family members reacted with anger and disgust for years after the diagnosis. Friendships often suffered after the diagnosis was revealed. Some stories of potential rejection had happy endings; some still had their friends helping them and sticking to them. For example, one participant said "they take me out, hang out with me and they don't treat me different, they don't discriminate against me".

After obtaining the results of their HIV/AIDS status, the women in this study (as mentioned earlier), never saw themselves in the same way again. The enormity of the diagnosis and the resultant repercussions were overwhelming to the women. They had to deal not only with the threat of death, at times being advised incorrectly that it was imminent, but also, most importantly, with the stigma attached to this diagnosis. Though they knew of other women who had HIV/AIDS, all were aware of the negative beliefs surrounding this disease.

The women in this study found solace among themselves through Voices of Positive women despite the daily challenges that they face. To them "Voices" was a family and not just an organization". These findings highlight the importance of creating and sustaining support for women with HIV/AIDS and creating a community in which women with HIV/AIDS feel welcome and supported.

5.5 Relationship with doctors and Health system

Despite expectations by the participants that people in the health care arena were more educated and would be more accepting of people with HIV/AIDS, some of the participants found this not to be true. They also realized that acceptance by one provider at a site did not guarantee the same from others at the same site. Many health care providers reacted with hatred, disdain, and fear, with some physicians being the most vocal.

A rising number of articles suggest that provider experience is an important component in the care of persons with HIV infection. Several investigations have demonstrated that inpatient mortality for persons with HIV infection decreases as hospital experience with HIV increases, while controlling for severity of illness. One example that examined the relationship of patient experience with HIV care and outcomes is Laine et al. (1999). The participants in my study commented on limited economic resources and money, discrimination and fewer choices regarding where to seek care and proper treatment rendered them. According to them, the number of HIV/AIDS specialists and resources are limited and they had to travel all the time to downtown Toronto for specific HIV/AIDS treatment. Although some of the participants experienced negative relationship with doctors and the health care system, some also had good experience and this has affected their survival and quality of life.

5.6 Survival and Coping strategies

Most frequently mentioned by participants in relation to the survival and coping strategy is social support. The types of social support experienced by these women include supportive interactions (Turner, 1981), which include instrumental, informational, and/or emotional assistance Laine et al. (1999). According to participants, social support is a resource essential to "doing well with HIVAIDS. This also supports the findings of Lazarus and Folkman (1991) who identified social support as an example of an emotion-focused coping strategy. In a related manner, most women in the study also described their relationship with children, family, friends and significant others as an important and vital ingredients in their quest to cope with HIV/AIDS.

The participants in this study support the assertions presented in the literature review that social support is found to be a buffer for stress (Andrews, 1995). In a similar study, Nicholas and Webster (1993) also found that social support, the extent to which help is available from family and friends, correlated positively with coping capacity in persons with HIV. Specifically, among women with HIV infection, Hudson, Lee, Miramontes, and Portillo (2001) also found that perceived social support and social interaction were negatively related to distress. Another study reveals despite the numerous challenges for women with HIV, women can and do cope with the stress of HIV infection and live for many years if they have the caring support of others (Andrews, 1995). The current study showed that with the necessary medical and psychosocial support a woman with HIV could live for about 20 years post diagnosis.

Support from family members and caregivers, in conjunction with more traditional forms of treatment (Snyder, et al1991), can help HIV/AIDS women cope with the uneven but inevitable course of this disease (Moon and Snyder, 2000).

Chronically ill and dying patients should never be deprived of any psychosocial support from the community because no matter their condition they are still part of the community they live in (Kloeuw, 1996). According to Nowotny (1991), it may be possible to communicate negative information in such a way that the patient will receive it as a challenge rather than a death sentence. Indeed, patients infected with HIV may be able to cope effectively with the progressive effects of the disease when given realistic yet meaningful support from health care professionals and family members (Hall, 1994). As a result of actual or anticipated rejection by social networks, HIV-positive persons often develop bonds among themselves (Crandall & Coleman, 1992). This is also consistent with the findings of this study because participants see other members and themselves in Voices of Positive Women as friends and sisters. At VOP the women confide in each other and serve as a source of support to one another as interesting they trust each other more than their own family members.

5.7 Religion and Spirituality

Two of the participants highlighted religion and spirituality as prominent elements in shaping their coping strategies, survival and influencing their ability to benefit from supernatural strength. Reed (1986) and Barroso, (1993) in a study identified the important role spirituality played in the lives and coping process of women living with HIV/AIDS. She defines spirituality as one's frame of reference consisting of beliefs and attitudes of connectedness with something or someone greater than the "self". Spirituality then is broader than religiosity or participation in an organized religion. It is important to note that spirituality in my study is described as essential in the reconstructing of the lives of these women in response to their HIVAIDS condition. This is also consistent with Sowell's (2000) work on spirituality among HIV/AIDS people. His study showed how spiritual activities served as a inspirational resource for women living with HIV infection.

According to Gray (1997) there is a significant positive correlation between spiritual perspective and social support among HIV-positive women. Participants in my study felt they have no one to talk to or rely on during their lonely time so they kept praying and trusting in God for daily companionship and survival. They sometimes dealt with their challenges through prayer and the reading of the Psalms in the Bible. My research suggests that spirituality and acknowledgement of God through prayer were part of the daily practices or coping strategies of three of women and this positively influenced their lives and healing course.

5.8 Empowerment of Women with HIV/AIDS

Although most of the women in this study acknowledged the negative consequences of HIV/AIDS on their lives, most of them reported that HIV/AIDS has changed their lives in some positive way. HIV/AIDS was seen as a motivating factor for these women in making positive behavioural changes, including long-standing, problematic health related behaviours such as substance abuse, smoking, risky behaviours and healthy eating habits. A woman with a history of drug abuse for instance reported the most profound changes in her life. According to one participant she believes it's her prayers that have kept her healthy. However, perception and experiences of isolation, exclusion, stress, loneliness and sadness related growth were also identified.

Findings from my study again presented HIV/AIDS as a catalyst for resolving past differences. Identifying and interpreting their present condition has propelled participants to use the remaining time on earth to express and affirm love for loved ones around them. Another profound influence of HIV/AIDS on the women's experiences is reflected in their words; they felt stronger, more responsible and more caring and they spend more time with their children since they have no work now. Although they are not able to support their children financially as they planned, they are able to give them psychological, emotional and social support. These women remind us that while society continues to stigmatize them, their network strategies and illness as women with HIV/AIDS has decreased their dependency as they are forced to stand up for themselves, advocate for services and manage new challenges. Many women felt that HIV/AIDS resulted in positive changes in their valuing of their life; they love who they are and are therefore handling themselves in the best possible way. The patterns in participants' stories indicate that their level of change is related in part to the support provided by other HIV/AIDS women, social network and caring for their children. Some of the women in my study claim HIV/AIDS had a positive impact in their lives such as positive goal related changes, helping others through AIDS advocacy, peer support, education and care provision.

To some participants, HIV/AIDS was a setback for them as they had to stop their careers because of symptoms and disclosure of status after diagnosis, and they are normally described as sick and physically and emotionally weak. The findings reveal that the women have acquired more knowledge in terms of their sexual activities, diet and quality of life.

Empowerment research shows that life-history methodology serves as a form of empowerment and intervention for disadvantage women because women in such conditions are given the opportunity to voice their experiences (Jackson, 1988).

5.9 Resources and Services for Women with HIV/AIDS

My study summarizes new and emerging areas of research that are needed to guide policy and programmatic decisions on better ways of delivering health and support services to vulnerable women with HIV/AIDS disease. Currently, health and support services for these women are funded and covered by the Canadian government and other agencies although some of the participants claimed they have lost their life insurance after their diagnosis. My research indicates that the insufficient services and resources such as money, housing, food, clothes and medication can negatively affect the survival and progression of life among these women. My study is consistent with Fleishman et al (2003) who agrees with the need for multiple sources of coverage outlined by the participants such as HIV/AIDS care, variable levels of funding and diverse ways in which financing programs are administered at local levels. These contribute to inequities in access to HIV/AIDS services and the quality and cost of HIV/AIDS care. In sum all the women commented on insufficient resources and services for them and specifically a lack of psychosocial support.

5.10 Summary and Recommendation

Given the complexity of HIV/AIDS among infected women, an equally complex response is required at the micro, meso and macro levels. Although it is not possible to address all the issues raised, the following specific concrete recommendations are a start in this necessary procedure. It is important that health care professionals and psychologists are sensitized on the psychosocial needs of women with HIV/AIDS. There is also the need for more HIV/AIDS specialists as the findings of my research revealed that those available are insufficient. It is also important to note that these women themselves have taken responsibility of their lives through prioritizing their health, family care and diet and this is a practice that can be transferred to other women with HIV/AIDS in the world. My research indicates that future research can be conducted to examine the various sources of support and its overall impact on health outcomes, including risk behaviors. It is therefore important for community psychologists and other researchers to note that the psychosocial needs and challenges faced by women living with HIV/AIDS are rooted in the most fundamental structural and cultural aspects of any society.

It was also identified in my study that increased psychosocial support and social network proved beneficial to all the women. It is important to note that continued provision and support of these practices and services will increase the daily coping strategies of these women. I believe that broadening the scope of HIV interventions requires new collaborations across multiple sectors and disciplines with special emphasis on the psychosocial support and resources provided for women living with HIV/AIDS. The need for moving away from individually focused interventions towards concepts of community participation; community mobilization and empowerment cannot be underestimated. Community-led participation will bring about interventions that seek to engage the broader contextual factors relevant to women living with HIV. Bracht and Gleason (1990) defined citizen participation as the social process of taking part in either formal or informal activities, programs and/or discussions to bring about a planned change or improvement in community life, services and/or resources.

As suggested closer scrutiny of the experiences of women in other parts of the world is essential if we are to identify the most effective strategies for caring for those who are infected whether in Canada or elsewhere in the world. HIV and AIDS have remained low on the feminist list of priorities and the specific needs of women with HIV/AIDS have received relatively little attention in the planning of treatment services. Closer examination of the global pandemic suggests that gender issues in HIV/AIDS cannot be ignored because HIV/AIDS is becoming a women's disease.

In conclusion, resources for women whose multiple responsibilities present challenges to accessing health care should be developed. Such obstacles as lack of childcare, housing and transportation are problematic without the added complication of stigmatization. Even when available, how do women with HIV/AIDS arrange transportation and explain to childcare providers the reason for seeking health care without revealing their serostatus. Providing these two services while protecting their privacy would facilitate their receiving adequate health care. There are still many misconceptions about HIV/AIDS. Providing educational programs for churches, corporations, and civic groups will help to demystify this misconception. The women had stopped work because of their HIV/AIDS diagnosis. They are experiencing greater concern over possible loss of benefits, or workplace accommodation if there is a possibility of returning to work. They requested new policies for the reemployment of people living with HIV/AIDS after diagnosis. Violence, poverty, inequality and the lack of basic rights all need to be addressed if HIV/AIDS is to be brought under control and women living with HIV/AIDS are to have equitable access to services.

Women living with HIV/AIDS have identified actions that would improve their situations. They have called for recognition of their fundamental human rights and for decision-making power and consultation at all levels of policy and programs affecting them.

5.11 Transferability and Dissemination of study

I designed my research project with a built-in action component in which local stakeholders would be engaged in communicating the research findings to create awareness. I have decided to disseminate my findings ecologically at the three different levels outlined in my research project. I have submitted a three-page summary of my findings to Voices of Positive Women which will be shared among the participants and the agencies. I shared and discussed the research findings and recommendations with the steering committee in my three-paged summary. I had my abstract published at the International World AIDS in Toronto and also submitted a copy of the abstract to Division 35 of the American Psychology Association. Initially, I felt somewhat disappointed that the steering committee members could not talk about publishing of the research findings due to lack of funding for any community activity. I had hoped that the action resulting from this research might include communicating the findings through a community forum. Although community forums can be included in an action component, their absence does not reflect inertia. Action also includes engaging and inspiring others through publications.

I believe that in this regard, the current research was successful. The study could be used as an educational material in enlightening families, individuals, communities and academia. Posters, handbills, articles and other modes of presentation would be used in the dissemination process. The research documents will also be made available to all applicable bodies or partners.

5.11 Importance of this Research

This research is beneficial in that it contributed the voices of WLWHA to the scarce literature on their experiences, challenges, needs, quality of life, survival and coping strategies. The opportunity to discuss and reflect on their experiences and to hear from others who have similar experiences had potential benefits for these women. The understanding that emerged from my research may be used by steering committee members in advocacy, awareness raising, health care or other activities aimed at improving the quality of life and psychosocial support for WLWHA. I believe the Voices of Positive Women as an agency benefited from this research. Active involvement in the research (i.e. as members of the steering committee and recruitment partner) increased links to community resources and increased understanding of their own strengths and challenges and that of other agencies. An important outcome of my findings is the transferability of the research findings into other communities or the sharing of the findings among other women with HIV/AIDS. The strengths and coping strategies of these women can not be underestimated and can serve as a model for other women with HIV/AIDS in Africa and the world at large. The other potential benefit involves the communication of the findings and any resulting action that may occur. To raise awareness or to encourage or implement change, for increased supports to women living with HIV/AIDS.

Finally, the community at large can potentially benefit form this project. I expect that the involvement of community members throughout the research process (i.e., Voices and Steering committee members) will lead to their mobilization as an increased understanding of the issues is brought to the limelight. Community partnership might be evident in the future activities of steering committee members that is communicating the research findings through writing letters to local newspaper, other community agencies, provincial authorities and policy makers. I also believe that the findings of the research will give a better understanding on the issues discussed and also increase the understanding and knowledge of the community on the issues. By doing this, the whole community will help demystify the myth surrounding HIV/AIDS. Throughout my research, I helped to build relationship and provide information to various members of the community. The knowledge of current, local research increases the likelihood of the findings being used. I trust that the steering committee members including Voices staff will communicate the research findings to the best of their ability. My research embraced the diverse background and cultures of women living with HIV/AIDS around the world, which I believe may also add to the body of knowledge existing on the issue. It is also important to mention that I was able to achieve most of my research goals and all the participants met the criteria for participation.

5.12 Limitations of Research

Drisko (1997) discusses the importance of assessing the transferability of qualitative research. He further notes that this assessment plays an integral part in providing guidance to research consumers about the appropriate application of the findings. My research could have been strengthened through collecting more data. Gathering additional and multiple perspectives could have generated richer information. Another research project could increase the number of stakeholders or steering committee, family members, health providers and others who are likely to influence experiences. Limiting my research to a small sample with one community although they are from different continents may also decrease the potential impact of the research. For instance, the findings from such a small study are unlikely to lead to the suggested policy changes. Replicating and building upon this research could better improve quality of life, psychosocial support, health care, services and resources for WLWHA. Such research could also increase the potential of implementing the recommendations.

My research was further limited by what may have been a biased sample of women living with HIV/AIDS. Due to difficulty in recruiting participants, I relied almost exclusively on Voices of Positive women for referrals. I do not feel that these women were representative of all women living with HIV/AIDS in Toronto because these women were members of Voices. It is possible that other women who do not belong to a group like Voices lack the strength and skills exhibited by the participants. There is a possibility that the HIV/AIDS counselors and steering committee were biased in determining which woman would be appropriate for me to speak with. Another research project might designate increased time and resources in recruiting participants.

Some limitations with regards to transferability can be found in this study. The study again is a tool that may be used to influence policies and other policy implications on the psychosocial aspect of HIV/AIDS. Although many of the participants had similar views of the issues of living with HIV/AIDS among women, because of the small sample size, only a minority of voices and perspective were heard and recorded. If a larger sample size had been used more variation of response may have been found. However, it is also important to note that participants did come from a broad range of ethnic background and ethnicity. In conclusion, I feel that the biggest limitation of this research is the absence of a clear and organized action component. I believe that the current lack of action results in part from the busy schedules and lack of resources available for HIV/AIDS agencies such as Voices. I believe that future action research should dedicate adequate resources to this component. All research is limited to the extent that time and funds are insufficient to communicate the research findings and take necessary actions. I believe that the participants, Voices, other women living HIV/AIDS, and other HIV/AIDS agencies could benefit from increased discussion and action around the issues highlighted in this research.

5.14 Personal Reflection and Lessons Learned

For several many years I worked, as a HIV/AIDS advocate in Africa and my goal in conducting this study in Canada was to understand and explore the services and resources available for women living with HIV/AIDS. _I also wanted to understand the coping strategies and the quality of life of these women. Torn between two continents I wanted to transfer the knowledge and skills that I had with me from Africa to Canada and vice versa. Conducting this study was interesting and enlightening though I had some challenges.

HIV/AIDS is often thought to be highly contagious. Based on this assumption people often suspect that individuals with HIV or AIDS pose a threat to the community at large. One of the things I learned from the women in this study is the fear of stigmatization from people around them. I believe this might be present among other women with HIV/AIDS as well as impact the effectiveness of HIV/AIDS prevention, treatment and care programs. The impact of social stigma has also resulted in the daily struggles with the issue of disclosure and the internalization of their status among these women. In some cases, the women knew that they have HIV for months but did not tell their family members for fear of stigma and its consequences, which may include isolation and abandonment. The striking experience here is the impact of internalized stigma, which may result in suicidal ideations, loneliness and other psychosocial challenges such as depression, isolation and sadness. These women must play a central role in stigma reduction and program development. Bearing the brunt of stigma, they have the life experience and knowledge needed to design and implement appropriate stigma-reduction responses. In particular, they can help combat the fear of casual transmission of HIV, the belief that HIV means immediate disability and death, and the feeling that people with HIV are somehow different from everyone else.

Women living with HIV/AIDS in general need a more gender and rights based capacity building / training to be able to analyse their experiences and distil advocacy messages to change their situation for the better. There is also the need for more resources, services, support and more HIV/AIDS trained staff. I believe female condoms should be made available in all health centres and should be free for every woman. There should be provision of food, clothing and living accessories for all positive women. There should be more clinics and centres catering just for women's health and being run by positive or affected women with women or HIV/AIDS health professionals. In addition HIV/AIDS women should be supported and empowered economically by the provision of skills training that will make them financially secure.

One surprising and interesting thing that I encountered during the interview and data analysis process was the high level of internalised stigma among the women though they live in individualistic society. One of them would not allow me to record her voice for fear of stigma and the reason why I was surprise was because I come from a collective society where we know what goes on the lives of the people around us. People shared their problems with each other as a means of seeking social support and care. Another striking thing is the availability of antiretroviral drugs for women with HIV/AIDS in Canada compared to its scarcity in most African communities where the disease is most prevalent. Finally, the activities of HIV/AIDS support and network groups for women with HIV/AIDS in Canada are amazing. Voices for instance provides psychosocial support, empowerment and services for women living with HIV/AIDS in Toronto which I find to be unique and could be replicated in communities such as my. Finally I would say that women living with HIV/AIDS should be given more support, resources and services not matter what is being provided now.

5.15 Conclusion

Among the participants in my research were secretaries, lab technicians and childcare workers. These women brought their knowledge and rich experience. Each participant was keenly aware of the value of life before and after HIV/AIDS and strongly motivated to move in life despite the daily challenges. Their daily inspiration from each other indicates that these women have a great deal of motivation to achieve a successful life. Patterns in their stories indicate that inequitable health opportunity can result in the decrease of HIV/AIDS quality of life among these women. The whole community stands to benefit from the experience, strengths and from the successful integration of these women into society despite their HIV/AIDS status. An important component of this research is the fact that I was able to interview women living with HIV/AIDS in a participatory manner. They trusted me and told me of their life experiences before HIV and after. They have taken responsibility for their lives and have identified actions that would improve their situations. They have called for recognition of their fundamental human rights and for decision-making power and consultation at all levels of policy and programmes affecting them. They have called for economic support for women living with HIV/AIDS in Canada and women in developing countries, support for self-help groups and networks, realistic portrayals of people living with HIV/AIDS by the media, and accessible and affordable health care. Among the participants of this study it was apparent that most of them have to take care of their children alone, they have to provide all their educational accessories and clothing. Four of them are single mothers and though unemployed because of their HIV status they are expected by family members and friends to go out to work. I believe this study with its practical responses and straightforward analysis can be a valuable advocacy and policy tool for addressing this complex challenge. The call to empower women has never been more urgent. We must all act now to strengthen the capacity, resilience and leadership of women living with HIV/AIDS.

From this study it can be suggested that members of the community need to change their attitudes and perceptions towards women living with HIV/AIDS. The Canadian community needs to embrace these women as part of the society and also give them all the needed support. Negative assumptions about women's roles and discrimination against them must be challenged and women must be empowered to help themselves and to protect themselves. Protecting women from HIV is not solely women's responsibility. Most HIV+ women were infected by unprotected sex with an infected man and this was evident in my interaction with the participants of this study. Most of them believed their husbands who are currently dead infected them. One of them said she was infected because she was not well informed on protected sex although she had multiple partners in the past. I must say that preventing infection and supporting women with HIV/AIDS is the responsibility of all of us. The need for the expansion of services and resources for women living with HIV/AIDS needs urgent attention. Women who have HIV/AIDS need access to treatment, adequate resources and services which can enhance their coping strategies and quality of life.

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Centers for Disease Control and Prevention
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DHHS AIDS Treatment Information Service
http://www.hivatis.org

HIV InSite
http://hivinsite.ucsf.edu

JAMA HIV/AIDS Information Center
http://www.ama-assn.org/aids

The Johns Hopkins AIDS Service
http://www.hopkins-aids.edu

National AIDS Education and Training Centers
http://www.ucsf.edu/warmline/aetc.html

Health Canada
http://www.HealthCanada.org

APPENDIX

Appendix 1 Request for Ethics Review of Research Involving Human Participants

All correspondence will be sent to your home department. Please check here __X__ if you need e-mail notification.

Principal Investigator(s) - Add rows as necessary.

Name	Department/ Faculty	Phone	E-mail	ID number
EDNA ARYEE	PSYCHOLOGY	884 0710 ex 3950	arye2144@wlu.ca	049002144

Thesis Supervisor or Course Professor (if applicable)

Name	Department/Faculty	Phone	E-mail
DR. TERRY MITCHELL	PSYCHOLOGY	8840710ex2052	tmitchell@wlu.ca

Full Title of Research Project

Listening to the Voices of Women living with HIV/AIDS.: A Qualitative Study Of Psychosocial Impact And Quality of Life Issues.

Summary of Proposal - Please give a half-page summary of your research proposal.

A lot of work has been done on the topic of HIV/AIDS however; most of these studies have focused on prevention and treatment (Snyder, 1999). The relationships between the psychological effects of social exclusion and stigma for women living with HIV and other psychosocial issues have not been adequately studied. In a similar manner, a great deal of research is centered on African cultures and the male population resulting in Canada's population of women living with HIV being understudied. The need for better understanding of the psychosocial needs, experiences, challenges quality of life issues and coping strategies of women with HIV infection is widely recognized (Center for Disease Control and Prevention, 1997).

The present research is aimed at exploring and documenting these understudied issues. A study of the relationship between the psychosocial context and its psychosocial impact on HIV positive women in Southern Ontario (Toronto) will increase understanding of the specific psychological impact, experiences, needs, consequences and coping strategies of living with HIV. The proposed research has the potential to benefit the lives of women living with HIV since it will give them the opportunity to voice their experiences, challenges and coping strategies through the life history methodology. The findings from the study will also promote knowledge and the realities of the psychosocial impact for HIV. The research again will contribute to the body of knowledge available on HIV and women. In conclusion, the study will also serve as a logical step in providing stakeholders, social partners and policy makers with in-depth information on the lived experiences from women's voices.

Participants will participate in three confidential audio-taped interviews which will take place on an individual basis with the researcher. A tape recorder and a microphone will be used to record the interview and will be placed in clear view of the researcher and the participant. The study will involve the researcher interviewing 5 HIV positive women in Southern Ontario. Generally, the interviews will follow a chronological order from life before HIV, current experiences all the way through coping strategies. We will be meeting three times during this study-the first part involves our asking questions about their life before HIV. The second session would last for about 2hrs which will also explore the experiences and challenges. The third session which is the final session will also be for 2hrs and questions will include coping strategies of HIV positive women among others. This contact will be only for this study and upon transcription of the information from the audiotape, data will be aggregated and tapes will be destroyed after 7years.

Category (please check appropriate box (es))

Faculty Research	
PhD level	
Master's level	x
Undergraduate	
Other (please specify)	

Thesis Research/MRP	x
Course Work	

Course number	PSY 699

Approved Research Funding for this Project (if any):

NA

Research Funding Applied for (if any), for this Project:

ONTARIO HIV/AIDS NETWORK STUDENT SCHOLARSHIP

Duration of Project:

Starting Date	MAY2005	Proposed Date of Completion	AUGUST 2005

Checklist of Attachments (attach all applicable documents):

X	Copy of Complete Research Proposal	x	Proposed Interview Questions
X	Proposed Information Letter to Participants, Parents, or Guardians	x	Proposed Questionnaire or other Instrument
X	Proposed Consent Form(s)	x	Proposed Telephone Script
	Proposed Oral Invitation to Young Children		Proposed Debriefing Statement
X	Confirmation of Supervisor's or Instructor's Review		

Agreement

I/we have read the University's current guidelines for the ethical conduct of research involving human participants, available on the Office of Research web page and agree to comply with them.

Signature of Investigator(s)	Date

NOTE: All student research projects must be accompanied by a signed **Confirmation of Supervisor's or Instructor's Review**, available at http://www.wlu.ca/research/humanethics.shtml. Any forms received without this page will not be reviewed until the supervisor has submitted the signature page with his/her signature.

Please consult the University's guidelines for ethical research (on the Office of Research web page http://www.wlu.ca/~wwwroff/humanethics.shtml) before completing this form. The initial process of review by the Research Ethics Board (REB) usually takes 10 working days after the Research Office receives a request (with all necessary materials). Projects of greater than minimal risk or proposals with inadequate/incomplete forms and supporting materials can take longer. The REB usually requests some changes and asks some clarifying questions. If changes and questions are stipulated, the Chair of the REB must approve the revised materials and accept the answers to the questions prior to any recruitment or research on human participants.

Summary of Purpose, Methodology, and Procedures

In order to assess your study's ethical implications and weigh the risks and benefits, the REB needs to understand your study's overall purpose, rationale, design, and methodological principles. Please summarize these below AND attach one copy of the full research proposal itself. **Please provide enough information for the REB to be able to assess the project. Insufficient explanations can cause delays in processing.**

Purpose (what question(s) does the research project seek to answer or investigate?)

1. What are the various levels of influence on women's experiences, needs, challenges and coping strategies of HIV?
2. How can women's voices and experiences contribute to policies and strategies for advancing the quality of life of women living with HIV?

Design & Methodology

Due to the highly sensitive nature of this evolving and understudied topic, I will be using a qualitative methodology to investigate the aforementioned questions. The use of this research design is also inline with the paradigm of critical feminism that guides my research; which emphasizes the importance of testimonial evidence when studying HIV positive women. For this study I will be collecting a sample of 5 women. Participants will be selected through a purposive sampling method and referral from the AIDS Committee of Toronto (ACTS) and Voices of Positive Women all in Toronto. Participants would be required to meet the following criteria in order to participate in the study:

1. Participants must be women living with HIV either late or early stages
2. Participants must speak English
3. Participants must be between 16-65 years
4. Participants could be of any ethic or multiple back ground
5. Must be living in Southern Ontario

I will be using non random sampling techniques to collect the sample for this study. I suspect that it will be difficult to find participants that satisfy my selection criteria; as a result I will be using a number of different sampling techniques. Primarily, I will be using haphazard, convenience or accidental techniques; however I also plan to use purposive techniques. From here, I will use a snowballing technique to acquire more participants if needed. Interested participants will be asked to respond directly to myself via a private telephone number. Upon contact respondent will be provided with an outline of the proposed research and some information about eligibility (please see Appendix 1 for the telephone script). Also, during this first contact all interested respondents will be asked to take part in a short questionnaire to determine eligibility (please see Appendix 2 for the telephone questionnaire). Once it has been determined that the respondent is suitable for the study, a date, time and place will be set up for us to meet and conduct the interview. All chosen participants will be encouraged to contact either myself or my research supervisor with any questions and will be provided with the appropriate telephone numbers. Individual audio-taped interviews will be used to collect the data for analysis. The interviews will be in-depth explorations of the participants' experiences, needs and challenges and coping strategies that uses a feminist life history approach (please see Appendix 4 for the interview guide). Following the completion of the interview phase of this research, typed transcripts will be reviewed until I become thoroughly familiar with each subject's experiences, needs, challenges and coping strategies as HIV positive women. From here I will form general themes and later group these themes into theoretical constructs which are directly related to my research questions. Finally, I will use the theoretical constructs to create a theoretical narrative (Auerbach & Silverstein, 2003; Glaser & Strauss, 1967). I will test for validity by using a negative case analysis (Erlandson, Harris, Skipper, & Allen, 1993). In terms of ethics, this study will adhere to the ethical considerations of informed consent, confidentiality, weighing risks and benefits, and the right to privacy.

Research Procedures

Outline the specific procedures or activities involving the participants. Exactly what will participants be asked to do?

Those individuals interested in participating in the research are asked to respond to me directly by telephone. Upon contact respondents will be provided with information about the research and about eligibility. They will also be asked to participate in a short telephone questionnaire to determine suitability for the study. Once suitably has been determined a time and place will be agreed upon to complete the interview portion of the study. These interviews will be conducted on an individual basis with the investigator. The interview will be in 3 parts as indicated earlier. In addition, the interviews will be audio-taped. On the day of the interview all participants will be presented with a consent form which outlines their rights. All participants will be given the opportunity to read and ask questions about the consent form until it is determined that they understand their rights and what is being asked of them. Before a participant may proceed in the study they must sign and date two copies of the consent form. One copy will be provided to the participant for their records. Upon the completion of the interview participants will be provided with a $20 honorarium.

How long will this take?

The interviews will be 5 hours in at the end of the three sessions. The length of the interviews is flexible to allow for the participants to express as much or as little of their experiences as they would like.

Will participants be asked to repeat this or any other procedure at a future date?

NO

Who will be conducting the research?

I will be conducting the research by myself

How will data be collected and recorded?

Research data will be collected through the use of individual audio- taped interviews. In order to record the interviews I will be using a tape recorder and a microphone. The microphone and the tape recorder will be placed in clear view of the participants and the researcher. All interviews will be recorded on to full size cassette tapes.

Proposed Participants

How many participants are involved?

5

Describe the potential participants in this research indicating gender, age range, any special characteristics, any group affiliation, and location

The participants will all be women living with HIV in Southern Ontario. For the purpose of this study I have stipulated that the women be from one of the following countries/region: North America, United States of America, Europe, Africa, Asia etc in the. All participants will be between the ages of 16 and 65 and must be HIV positive. Finally, all participants can belong to any ethno-cultural background. Although the participants may come from any area of Southern Ontario, I am focusing my search in the areas surrounding Toronto.

Recruitment of Participants

How and by whom will prospective participants be identified?

The sample will be collected in two ways. First, I will place posters advertising the research project in areas where HIV positive women will have access to the information. Some of these identified areas are the ACT and Voices of positive women (please see Appendix 5 for advertising posters). I will also liaise with these associations in Toronto and will also speak with members at the various HIV meetings and workshops I attend. I will. I will also ask staff to forward information about the research to any women that they feel would be appropriate and interested in participating. Finally, I will post information about the research at various HIV women's centres and community centres in Toronto.

How and by whom will they be invited to participate?

On the posters a phone number will be provided that interested individuals can use to contact me. During this initial contact over the telephone with me, interested respondents will be read to the telephone script (Appendix 1) which outlines the research and eligibility. Following this, participants will be asked to participate in a short telephone questionnaire (Appendix 2) to determine their suitability for the study based on my selection criteria. Using this tool I will determine if I will invite the interested respondent to participate in the interview portion of the study. If I decide that the respondent meets my selection criteria I will ask them to meet with me for an interview at a mutually agreed upon date, time and place even though I intend using a place at ACT or Voices of Positive Women .

Attach a copy of any advertisement, poster or letter used for recruitment. **NOTE: Even if the recruitment is being done by another person or agency, you must provide the REB with a copy of the recruitment letter.**

Children (Recruitment)

If young children are involved, attach a copy of the proposed ORAL STATEMENT ("script") to be used to invite their participation, worded at their level of understanding.

Copy attached		Not applicable	x

What measures will be taken to ensure that the children understand the research and their participation in it?

Free and Informed Consent - PLEASE USE THE ATTACHED "SAMPLE INFORMED CONSENT STATEMENT" AS A TEMPLATE FOR YOUR CONSENT FORM(S) AND/OR INFORMATION LETTER(S). THIS TEMPLATE HAS BEEN DEVELOPED BY THE REB AND INDICATES MOST NECESSARY INFORMATION THAT SHOULD BE PROVIDED FOR POTENTIAL PARTICIPANTS. FOLLOWING THE TEMPLATE WILL MOST LIKELY RESULT IN FEWER REQUESTED CHANGES TO THE FORM(S) AND LETTER(S) BY THE REB AFTER ITS INITIAL REVIEW OF YOUR PROJECT.

How will informed consent be obtained?

Informed consent will be obtained from all participants by having them read, sign and date two copies of a consent form on the day of the interview before the interview begins. One copy will be given to the participants for their records and the other copy will be retained by myself (see Appendix 4 for consent form).

The preferred proof of consent is a signed consent form. If a signed consent form is not being used, please explain why it is not appropriate for your research proposal.

N/A

NOTE: If you are doing a mailed or telephone survey, a signed consent letter may not be needed. However, participants must still be provided with adequate information about the project to be able to provide informed consent. A guideline for preparing the telephone survey script and the introductory paragraph or covering letter is included at the end of this document.

In research involving participants who are not competent to give a free and informed consent on their own behalf, free and informed consent must be sought from their authorized representative(s). In some cases, incompetent individuals may be able to give their assent to participate.

Children (Consent)

Do the proposed participants include persons under the age of 16? (If so, separate CONSENT FORMS or -- in the case of very young children, oral assent -- must be obtained both from them and from their parent or guardian, and -- if applicable -- from a school authority, agency director, etc.) Normally, persons age 16 and over may give effective consent on their own behalf.

Copy of all consent forms (child and parent/guardian) attached		Not applicable	x

Copy of consent from school, agency, etc. attached		Not applicable	x

Captive and Dependent Populations

Do the proposed participants include captive, dependent, or incompetent persons? If so, a signed CONSENT FORM must be obtained from the legal guardian. If the participants are capable of giving consent, a signed CONSENT FORM must also be obtained from them.

Copy of all consent forms (participant and/or legal guardian) attached		Not applicable	x

Research on Different Cultures, Countries, Ethnic Groups

Do the proposed participants consist primarily of persons from cultures, countries, or ethnic groups different from those of the investigator(s)?

No, the proposed research focuses on HIV positive women from all cultures including African women, this is a group that I hold membership in as I am of an African descent

If so, describe procedures to ensure sensitivity to divergent values, traditions, concepts of privacy, etc., and measures to offset any practical problems expected in construing valid consent, etc.

N/A

Risks

NOTE: This section refers to risks to the participants, not to the researchers or company/agency on whose behalf the research is being conducted.

Are there any potential physical risks regarding this research (e.g. exercise leading to muscle damage)?

No

Are there any potential psychological or emotional risks regarding this research (e.g. loss of self-confidence after poor performance on a memory test, regret over the revelation of personal information to an interviewer, disruption of family routine, long waits, boredom, revelation of personal information)?

Yes, there are psychological or emotional risks associated in participating in this research. Through this research I am requesting that participants divulge painful and traumatic experiences. These women will be asked to revisit not only the contextual circumstances of stigma, depression and discrimination as HIV positive women but the daily challenges, needs, experiences and coping strategies associated with living with HIV. As a result, the participants may experience emotional distress (e.g., sadness, shame, or anger) while speaking about these experiences.

If participants in the study are members of the organization being studied (e.g. employees of the company, members of a club, etc.), are there any repercussions regarding participation or non-participation in the research?

N/A

What are your plans to minimize these risks?

In an attempt to minimize the aforementioned risk, I will ensure that all the questions asked of the participants are directly related to the goals and purpose of the research in order to confirm that no undue emotional issues are stirred within the participants. In addition, upon completion of each interview the participants will be provided with the HIV crisis/distress service phone numbers and locations as well as counselling services that specialize in the psychosocial needs of HIV positive women. Wherever possible, depending on the services available in that area, I will provide resources that are professionally versed in working with HIV positive women..

Benefits

Describe any potential benefits (direct and indirect) to the participants, the scientific community, or society at large from this project being undertaken.

By participating in this study participants may gain the following benefits:

- Learn more about research in community psychology
- Given a chance to tell your personal story
- Could positively impact the way in which other HIV positive women cope with their experience and challenges by sharing your coping strategies
- Might feel satisfied by offering a beneficial contribution to the study of HIV positive women, an area where little attention has been directed in the past
- Will receive an incentive for participating in research

Explain why these benefits outweigh any risks.

The benefits outweigh the risks for the proposed study because even though the participants may experience uncomfortable emotional reaction(s), there are many benefits from being able to hear their stories. As a trainee community psychologist I believe that being able to tell one's story not only has the benefit of allowing all of us as members of a society to learn and heal, but it also is very powerful in a healing journey of an HIV positive woman. In addition, by virtue of these women re-experiencing the emotional feelings surrounding their abuse they will also be showing resistance to despair and taking charge of their healing process. Indeed, as expressed in the attached research proposal the psychosocial impact of HIV is a serious challenge in our modern age especially where women are the most affected. As a result, any research that would seek to explore and document this is readily needed.

Privacy and Confidentiality

How will you protect the identity of participants during the conduct of the research?
How will you ensure the anonymity and unidentifiability of individual participants in the publication or other release of the study's findings?

If you plan to tape or film the participants, describe how you will ensure confidentiality with respect to those tapes, films, or transcripts.

All information gathered in the study will be strictly guarded, and will not be revealed to other parties unless a letter of consent is received from participants. Data from the telephone questionnaire will be assessed to determine the suitability of interested respondents. Once this has been ascertained and interviews have been booked these questionnaires will be destroyed. All participants will be assigned a number instead of their name and this will be used on future documents containing their information. The file that links the participants' actual names to the assigned numbers along with all other information containing names will be kept in a locked filling cabinet, the key to which only I will possess. Once all security measures have been completed, a pseudonym will be assigned to these numbers. The pseudonyms will be used during the interview in place of the participants' names. This method will prevent the participant's actual name from being linked to the data collected. After the thesis has been defended, all personal information regarding participant identity will be destroyed (including all audio tapes, transcriptions of interviews, and copies of summaries). All audio tapes will be kept in a locked filing cabinet at all times expect for when they are being analyzed

Who has access to the data?

Only I will have access to the data

Specify procedures to ensure the secure storage and eventual disposal of raw data.

All confidential material including audio-tapes, transcripts, and documents containing any identifying information about the participants will be kept in a locked filing cabinet which will be located in my office in school. These documents will be kept in this secure cabinet at all times. The key to the cabinet only I will possess and will be kept on my person at all times. Once the thesis has been defended all data will be destroyed this includes all participant research files, audio-tapes, transcripts and other documents that contain participant information.

Quotations - If you would like to use quotations in any write-ups or presentations, participants must be told in the information letter/informed consent statement (or orally as the case may be) that quotations may be so used. Participants must also be told whether or not any quotations could allow them to be identified. You might consider in some cases informing participants that they will be able to vet any quotations before they are used in write-ups or presentations and that they may participate without being quoted.

Are you using quotations from any of the participants' responses?

Yes

Will participants be identifiable in these quotations? If not, how will you ensure this?

No-I will write the exact quotations without any indication to the respondent

Can participants consent to taking part in the project as a whole, but not having their quotations used in the final report? If so, you might want to consider a separate line on the consent statement relating directly to the use of quotations.

Compensation of Participants

Will participants be rewarded or compensated, financially or otherwise?

All research participants will receive a $20 honorarium for their participation in the study.

If so, please provide details and justification.

The $20 honorarium is being provided to all participants in order to reimburse them for some of the costs (e.g., transportation, child care, income loss) that they may have incurred as a result of attending the interview. In addition, the honourarium is being provided to reimburse the participants for sharing their valuable time with me. At the completion of the interview the honourarium will be provided. If a participant decides to withdrawal from the study and does not complete the interview they will still be provided with the $20 honorarium

Deception or Concealment

Is any deception or concealment necessitated by the study's design?
No

If so, please describe and justify its use. Attach a copy of the debriefing statement to be used immediately afterward.

N/A

Information from Third Parties

Does the study's design require that information about the participants be sought from a third party or any other source, e.g. employers, case workers, family members, teachers, official records or files?

No

If so, explain. The INFORMATION LETTER and CONSENT FORM(S) must refer to the intended use of such information, and written authorization for access to it (or, where appropriate, CONSENT FORMS from the third parties themselves) must be secured.

N/A

Ethical Training of Research Staff

Investigators are responsible for ensuring that research assistants, secretaries, data entry personnel, interviewers, volunteers, or other staff know and comply with all the University's guidelines for ethical research. Outline below the measures planned to conduct or confirm the ethical training of any such personnel.

N/A

Feedback to Participants

Will feedback regarding the study's findings be provided to the participants?

Yes

If so, how will participants receive the information?

All participants will be given the option of receiving a copy (via mail or e-mail) of a summary of the findings of the research by August 2005. Participants interested in receiving a summary will be asked to provide me with their contact information following the completion of the interview. This information will be kept completely confidential as with all other documentation containing identifying material. The information will be stored in a locked filing cabinet and destroyed following the defense of the research results. In addition, all participants will be invited to contact myself during the month of September (following the defense) in order to receive or view a complete copy of the research findings.

Will any other agencies/organizations receive a report regarding the study's findings?

No

Appendix 2: Telephone Script; Outline of Participation

My name is Edna Aryee and I am a female researcher, an HIV/AIDS advocate and a Master of Community Psychology candidate in the Department of Psychology at Wilfrid Laurier University. I am conducting a study into the experiences, needs, challenges and coping strategies of HIV positive women. The purpose of this study is to assess the psychosocial impact of HIV on women despite the abundance of medical and pharmaceutical advancement in the fight against the disease. Again the research is aimed at exploring and documenting the benefits and barriers of using a life history approach when working with HIV positive women, and finally to generate ideas and strategies that can be used to transform policy in this area. I am looking for women living with HIV who are willing to participate in the study. The selection of individuals for an interview will be based on the answers that they provide to a short telephone questionnaire. The main criteria for selecting individuals will be to achieve a group of participants who are women living with HIV/AIDS either in the late or early stages, they must speak English and must be between 16-65 years. Participants could be of any ethic or multiple back ground and must be living in Southern Ontario.

Participants will have the opportunity to meet with me to be interviewed about their experiences, needs, challenges and coping strategies as HIV positive women. Generally, the interviews will follow a chronological order from the life before HIV progressing all the way to the challenges of living HIV and coping strategies and strengths in order to get a clear understanding of the benefits and barriers of using a feminist life history approach when working with HIV positive women. All participants will meet individually with the researcher. At the end of the three interview sessions, participants will receive a $20 incentive for completing all the three sessions. Those who might be able to complete one session, will receive a $ 5 incentive and those who complete two sessions will receive a $10 incentive.

If you have any questions about this study, please feel free to contact me or my research supervisor Dr. Terry Mitchell. My phone number is (519) 884-2623 and my research supervisor's phone number is (519) 884-0710 ext. 2052. We will return your call as soon as possible.

Thank you; do have any questions at this time?

Appendix 3: Telephone Selection Questionnaire

Questionnaire

Name ____

1) Where you born in North America, South America, Africa, Asia, Europe etc?

YES **NO**

1a) If you answered no to question 1, Can you trace your ancestry to one of these countries?

YES **NO**

2) Are you a woman?

YES **NO**

3) Are you between the age of 16 and 65?

YES **NO**

4) Have you been diagnosed by a health professional as an HIV positive woman?

YES **NO**

5 How long have you been living with HIV?
0-12 months ( ), 13- 24 months 9( ), 23 months and above ( )

Are there any special accommodations that you need if chosen for an interview?

Please write your answer below-

____

Appendix 4: Informed Consent

WILFRID LAURIER UNIVERSITY
INFORMED CONSENT STATEMENT
PROJECT: Listening to the Voices of HIV affected Women: A Qualitative Study of Psychosocial Impact and Quality of Life Issues

Researcher: Edna Aryee Research advisor: Dr. Terry Mitchell

You are invited to participate in a research study which is being conducted by Edna Aryee, a Master of Community Psychology candidate in the Department of Psychology at Wilfrid Laurier University, under the supervision of her research advisor, Dr. Terry Mitchell. The purpose of this study is to document and explore the experiences, needs, challenges and coping strategies of women affected with HIV in Southern Ontario. Based on the experiences of HIV positive women the study will assess the benefits and barriers of using a feminist stance when working with HIV positive women. The information that is collected will be used to better understand the experiences, needs, challenges and coping strategies of HIV positive women along with their coping strategies and strengths.

INFORMATION

By choosing to take part in this research study you will be asked to participate in three confidential audio-taped interviews which will take place on an individual basis with the researcher. A tape recorder and a microphone will be used to record the interview and will be placed in clear view of the researcher and the participant. What I my research trying to achieve is to explore and document the life histories of HIV/AIDS infected women the personal experiences, challenges and coping strategies as well as gain insights on how your voices can bring about transformative change in the services, support and resources for women living with HIV. I will interview 5 HIV positive women in Southern Ontario and generally, the interviews will follow a chronological order from life before HIV, current experiences all the way through coping strategies. We will be meeting three times during this study and the first part of the interview is part of our meeting today. This session will last for one hour and I will asking you questions about your life before HIV, your demographic background, including your ethno-religious background and potential emotional responses to diagnosis such as depression, among others at the end of the introduction. The second session would last for about 2hrs which will also explore your experiences and challenges. The third session which is the final session will also be for 2hrs and I will ask you questions about your coping strategies. This contact will be only for this study and upon transcription of the information from the audiotape, data will be aggregated and tapes will be destroyed after 7years. By participating in this study, you will help community psychology and academia produce and document valuable research in the area of psychosocial challenges of HIV-positive women in Southern Ontario.
(Questions on ethno-religious background is a way of exploring the impact of religion and ethnicity in the coping strategies and social support resources for women living with HIV as portrayed by researchers such as (Miran 1998))

RISKS

As the principal researcher, I have an understanding that through this research I am requesting that you discuss experiences and memories that may be painful or traumatic to you. As a result, many feelings including sadness, shame, or anger may be experienced. In an attempt to minimize the risks associated with participating in this research I have ensured that all the questions asked of you are directly related to the goals and participants can also omit the answer to any question or withdraw from the research at anytime. At the end of the interview you will be provided with phone numbers and locations of HIV crisis/distress services as well as counselling services that specialize in the needs HIV positive women in your area.

BENEFITS

By participating in this study you may derive the following benefits:

- You can learn more about research in community psychology
- You will be given a chance to tell your personal story
- You can positively impact the way in which other HIV positive women cope with their experience and challenges by sharing your coping strategies
- You may feel satisfaction by offering a beneficial contribution to the study of HIV positive women, an area where little attention has been directed in the past
- Once we have completed all the three sessions of the interviews and all your questions and concerns have been answered, you will receive a $20 incentive for participating in the research. Those who complete only one session will receive a $ 5 incentive and those who complete two sessions will receive a $10 incentive.

CONFIDENTIALITY

I would like to explain to you what you should expect as you participate in this research. The whole interview sessions will be tape-recorded and to protect and respect your privacy, anonymity will be used during the interviews and this is of utmost importance to me as the principal researcher. You will not be asked to identify yourself by name or in writing; however, you will be given anonymous identification number which will solely be used during transcription. You can also take on a different name for the purpose of this research if you want to. Your responses will be kept completely anonymous and this means that your identification is pseudononymous and kept confidential by myself and my supervisor. Consent forms will be collected and stored separately from questionnaires and there will be no way another person will know about the participants in the study. You have to know that it is your right to participate or not to participate in this study. You also have the right to withdraw at any point in time during this study. All material will be kept for 7years after which they will be destroyed. Finally, I would like to inform you that confidentiality in this study could be broken if there is any immediate threat on a participant's safety.

COMPENSATION

Thank you for your participation and support throughout this study. I have been well-informed from your life stories and if any other questions do arise in the near future please do not hesitate in contacting me or Dr Terry Mitchell by telephone or by email. For participating in this study you will receive an honorarium of $20. At the end of the three interview sessions, participants will receive a $20 incentive for completing all the three sessions. Those who complete one session will receive a $ 5 incentive and those who complete two sessions will receive a $10 incentive. I will have to ask you to initial a document stating receipt of incentive.

CONTACT

If you have questions at any time about the study or the procedures, you may contact the researcher, Edna Aryee via email at arye2144@wlu.ca. You may also contact the study advisor, Dr. Terry Mitchell, at the Psychology Department, Wilfrid Laurier University, Office N2075A, at (519) 884-0710, extension 2052 or tmitchell@wlu.ca. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project you may contact Dr. Bill Marr, Ethics Committee, Wilfrid Laurier University, (519) 884-0710, extension 2468

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. You are also free to omit the answers to any question you prefer to leave blank. If you withdraw from the study before data collection is completed your information will be deleted or destroyed after 7years.

FEEDBACK AND PUBLICATION

The completed research results will be printed and kept in the Department of Psychology, Wilfrid Laurier University, Waterloo, Ontario, N2L 3C5, Canada. This study may also be submitted for publishing in one or more community psychology, women and HIV journals. You may obtain information about the results of the research by contacting me directly by telephone or e-mail in September, 2005. In addition, all participants will be given the option of receiving a summary of the research findings by mail or e-mail by August, 2005.

The principal researcher will solely transcribed and analyze the collected data and the results will be shared with you next by August 2005

CONSENT

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature______________________________

Investigator's signature______________________________

Date______________________________

Appendix 5: Demographic Instrument

1. What is your current age? ______________________________
2. In what country were you born? _________________________________
3. Do you have a religious affiliation? If yes, please describe______________________
4. In what year were you diagnosed with HIV ___________________
5. Have you ever been diagnosed with Depression? ☐ No ☐ Yes , If yes, were you diagnosed with depression before you became HIV positive? ☐ Yes ☐ No
6. Have you ever had suicidal thoughts? ☐ No ☐ Yes , If yes, did you have these thoughts before you became HIV positive? ☐ Yes ☐ No
7. Current Relationship Status
   - ☐ I am single
   - ☐ I am married or in a committed relationship
   - ☐ I am separated or divorced
   - ☐ I am widowed
8. Living Arrangements (Please check all that apply)
   - ☐ I live alone
   - ☐ I live with a partner/spouse/significant other
   - ☐ I live with parents
   - ☐ I live in supportive housing
   - ☐ I have dependants (children and or parents)
9. Current Work Status (Please check all that apply)
   - ☐ Working full-time
   - ☐ Working part-time
   - ☐ Paid leave
   - ☐ Retired
   - ☐ Student
   - ☐ Homemaker
   - ☐ Seeking Employment
   - ☐ Community Volunteer
10. What is/was your job/ occupation / profession? ____________________________
11. Highest level of Education you have completed
    - ☐ Elementary School
    - ☐ Some High School
    - ☐ Completed High School
    - ☐ More than High School
    - ☐ Completed a University or College degree

INTERVIEW GUIDE/RESEARCH INSTRUMENT

Part 1- My Story before HIV-
Before Diagnosis and Demographic Background

Thank you for coming and participating in this study. I am conducting this research as an academic requirement. Please I need your for full participation and your confidentiality is deemed important. Thank you

(I will use the following probes as a guide in case a woman is not able to narrate her story- Family Background, Socio-economic background, social life and level of awareness about general information on HIV/AIDS?)

Thank you for agreeing to be interviewed. This first interview is an opportunity for us to get to know one another a little and to become more comfortable with the interview process. As you know there will be a series of three interviews in this women's life history research study. This first interview is to learn about you and your life prior to your diagnosis of HIV. The second interview will focus on your diagnosis and the first two years of living with HIV. You will have an opportunity to reflect on how you, your life, and your relationships have been affected since your diagnosis with attention to your experiences of social support and social stigma. The third and last interview will be about your experiences of living with HIV, how you have coped, what strengths you have gained, what social supports you use, what resources you would like to see developed for other women. I am interviewing women such as your self in order to increase understanding of the experiences, strengths and needs of HIV positive women with the goal of increasing sensitivity to women, decreasing stigmatization, and improving resources for HIV positive women.

SIGN CONSENT FORM

1. *Do you have any questions before we begin? I am going to turn the tape recorder on now, is that ok? Are you ready to begin. Thanks, --name—please tell me what about yourself as a young adult. What was your life like prior to being diagnosed with HIV?*

2. How would you describe yourself before HIV?

3. Please walk/talk me through an average weekday, and an average weekend day before your diagnosis. (eg begin when you woke up- what time, what did you do?)

4. Please tell me about your relationships and your role in your family before HIV?

5. Please tell me about your friendships?

6. How would you describe your health before your HIV diagnosis and what was your experience of the health system? Did you have a family doctor?

7. *And your community? Please tell me about any community activities you were involved in (religious, athletic, volunteer, etc)*

8. We are coming to the end of this first interview… please tell me about anything else that you would like me to know about yourself, your life before your diagnosis.

9. Let's end the interview by talking about something that you enjoy a great deal and or are very proud of.

Thanks for sharing so much with me. It has been a pleasure to spend this time with you and to learn so much about your life. Thank you. I look forward to our second interview which will be date---, time-----, place…… Does that still work for you? I will call you--- days in advance to confirm our interview. Is this the best number to reach you at -----? You can also reach me at number-----

Part 2-Living with HIV

Thank you for coming today and for your willingness to participate in this second interview it was wonderful to speak with you last time. Thanks again for your willingness to be interviewed and to share about your life. Today's interview will involve your story of diagnosis and the first two years of living with the knowledge that you were HIV positive. We will explore issues of social support and social exclusion. You will have an opportunity to reflect on how social stigma and relationships with your friends, family, health care providers and community have made you feel? Do you have any questions? I am going to turn on the tape recorder now. Are you ready to begin? Thanks.

1. *Please tell me the story of how you learned that you were HIV positive. Begin wherever it feels right to you.*
2. *With whom did you share this information?*
3. Please describe an average week day, and an average weekend day in the first year after your diagnosis. (eg begin when you woke up- what time, what did you do?)
4. How would you describe yourself at this time. Your thoughts, feelings (hopes, fears, sadness), *physical changes…*
5. *Please tell me about how your family responded?;* What kind of support do you receive from your family members? How would you describe your current experience within your family?
6. How did your friends respond? What have your learnt about friendship through this process of coming out as HIV positive?
7. And how did were your relationships in the larger community affected by your diagnosis? Who did you tell? Did you stay active in the community? What barriers/challenges were there to remaining active? What supports were there for you in your community?
8. *What experiences, if any, did you have of social stigma or exclusion related to being an HIV positive woman?*
9. How did your doctor respond? Did your stay with your family doctor? How would you describe the care and support you get from the health care givers/center that you go to for treatment. Please tell me about your experiences within the health system- positives? and negatives?
10. Please tell me about any other significant experiences that you would like to share with me.

11. What is the most important thing you learned from your diagnosis and first two years of being an HIV positive woman?

12. What would you like other, family members or health professionals to learn from your experience?

Thanks for sharing so much with me. It has been a pleasure to spend this time with you again. I look forward to our third interview which will be date---, time-----, place...... Does that still work for you? I will call you--- days in advance to confirm our interview. Is this the best number to reach you at -----?
You can also reach me at number 519 884 2623

Part 3- Survival and Coping strategies

Thank you once again for coming and participating in this third interview. As you know today's session is about surviving coping strategies and lessons learned about living with HIV., please I need your for full participation. Once again your confidentiality is deemed important.

[NOTE TO EDNA- at this point Summarize what you as the researcher believe you have understood as their story of a life before and at the time of diagnosis—say to participant please let me know if you feel that I have understood what you have shared and you can change, correct or elaborate and add to anything in your life story.] Today we will discuss your surviving and coping strategies and lessons learned about living with HIV with a focus on how family, friends, health professionals and communities can be more sensitive to and supportive of women living with HIV.

I appreciate your full participation. Once again your confidentiality is important.

1. How would you describe the way you address your needs and challenges as an HIV positive woman?
2. Can you describe some of your coping strategies that you use daily in your life? How would describe the coping strategies that you receive form your family and friends?
3. Please tell me how you have you coped with experiences of social stigma or social exclusion in relation to being HIV positive?

4. What resources are available to you from your family and friends? What resources are needed for family members of HIV positive women?

5. Can you describe some of the resources made available to HIV + women at the various health centres

6. Tell me about your accessibility of these resources?

7. Overall, how satisfied are you with the resources and services you receive from family members, caregivers, government, health centers etc

8. What are some of the resources provided by the community to women in your situation?

9. Overall, how would you like the outcome of the research to be used for/

Recommendation-What services and resources might be useful to improve your experiences and coping strategies as women living with HIV/AIDS?
Is there anything that I might have missed that you would like to tell me at this time?

Thank you for coming if you need any clarification or more information
Please contact
Edna Aryee-phone-519-884-2623, email arye2144@wlu.ca
Or my supervisor-Dr Terry Mitchell, email tmitchell@wlu.ca

Appendix 6: USE OF QUOTATIONS CONSENT FORM

The researcher involved in this study may present findings from this study at professional conferences or in written publications in psychology journals. From time to time, it is useful to present short excerpts from participants' responses to help explain or illustrate certain concepts. Before using these excerpts, I will remove any identifying information. However, I will use quotations from participants who have given their prior consent. Your consent to the use of specific quotations is voluntary; you may decline without penalty. Your responses will still be included in the aggregated (group) results even if you don't consent to the use of the quotations. You can choose to provide "blanket" consent for any excerpts (you consent at this time to the use of any excerpts drawn from your responses), provided that the researchers omit identifying information. You can choose to be contacted in the events that the researcher should wish to use specific excerpts from your responses and to only make a consent decision at that time. If you choose this alternative, you will be asked to provide your secret code ID and contact information that we can use should we need to contact you.

CONSENT

---------NO, Please DO NOT use excerpts of my responses for presentation purposes.

--------YES, the researcher may present excerpts of my responses at professional conferences or in publications, provided that identifying information such as names and specific locations are omitted.

-------YES, the researcher may CONTACT ME to ask permission to present specific excerpts of my responses at professional conferences or in publications. Identifying information such as names and specific locations will be omitted. I will choose to either give permission or decline it if I am contacted. I have provided my contact information below.

Name---------------------------------------Email---Phone--

Appendix 7: Contact Information

1. AIDS & Sexual Health Info Line

To speak to one of the counselors, please call:
Toll free: 1-800-668-2437
Local: 416-392-2437
The mainline 1-800-686-7544

2. Toronto People with AIDS Foundation
399 Church Street, 2nd Floor
Toronto, Ontario M5B 2J6
t: (416) 506-1400
f: (416) 506-1404

Benefits & Assistance Case Manager
Nitto Marquez x636
nmarquez@pwatoronto.org

3. Location
399 Church Street, 4th floor
Toronto, Ontario,
Canada, M5B 2J6

Phone
416-340-2437 (AIDS): Main Switchboard
416-340-8484: Voicemail

Support referral links

1. Distress Centres of Toronto
   416-408-HELP (4357)
   Self referral at 416-595-1716

2. Preventing Suicide -Canadian Mental Health Association
   8 King Street East, Suite 810
   Toronto ON M5C 1B5
   Tel./Tél.: (416) 484-7750
   Fax: (416) 484-4617
   General Inquiries: info@cmha.ca

3. Survivors Support Programme
   10 Trinity Square
   Toronto, ON M5G 1B1
   Canada
   Contact: Karen Letofsky or Betty Ann McPherson, Programme Coordinator
   (416) 595-1716

4. Call 911

Listening to the Voices of Women Living with HIV/AIDS

CALL FOR RESEARCH PARTICIPANTS

- **Are you a woman living with HIV/AIDS!**
- **Are you interested in taking part in a research that could impact?**

Please your participation will be rewarded and all your calls or emails will be confidential.

Please contact: Edna Aryee,
416-650-3397, 519-884-2623 and Dr Terry Mitchell,
tmitchell@wlu.ca, 519-884- 0710 Ex 2052

Thank You!