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Lived experiences of women surviving HIV/AIDS and intimate partner violence

by

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Abstract

In this exploratory descriptive study I investigated how women described their day-to-day experience of surviving HIV/AIDS and intimate partner violence (IPV) in Calgary, Alberta. Four in-depth interviews were conducted with two women. Five themes were identified: (1) surviving HIV/AIDS; (2) surviving IPV; (3) relationship between HIV/AIDS and IPV; (4) effects of HIV/AIDS and IPV; and (5) ideal care models. Participants in this study shared similar experiences but their consequences varied. IPV started early in their lives and was connected to later IPV and HIV. Participants understood HIV/AIDS but not IPV. They spoke easily about HIV, but there was a sense of shame about IPV. Care providers also did not talk about IPV. The intersection of personal, interpersonal and environmental issues is a very critical area that needs immediate attention. When care providers appreciate the nature and severity of challenges faced by women surviving HIV/AIDS and IPV, inclusive and non-judgmental strategies based on the principles of Ottawa Charter for health promotion can be developed to better serve this population.

Acknowledgements

I would like to express my gratitude to Dr. Thurston for her support and guidance and to thank all my committee members for their valuable contributions and their stimulating feedback that broadened my understanding.

Dedication

This study is dedicated to the following people: (1) the two women who shared their stories so that the world could know the challenges faced by women surviving HIV/AIDS and IPV; (2) the care providers who assisted in connecting me with the participants; (3) my children Thandi, Mxolisi, and Sandile who through their unconditional love, patience, and tolerance kept with me, even in the darkest days of my journey; (4) my God who gave me strength and wisdom to go on; (5) the women from the P.E.O. sisterhood (Philanthropic Educational Organization) in Calgary and Seattle (U.S.A) who were very supportive – with their warm hearts, they gave me reason to keep my head above the water; (6) my mother, three brothers, two sisters, and their families who believed in me and who gave me the will to reach out to the end; and (7) all my friends who were always with me in spirit, person, and good wishes.

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TO ALL I SAY, "GOD BE GLORIFIED."

Psalm: 139

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List of Symbols, Abbreviations and Nomenclature

Symbol	Definition
AIDS	Acquired Immune Deficiency Syndrome
HAART	Highly Active Anti-Retroviral Therapy
HIV	Human Immunodeficiency Virus
IPV	Intimate Partner Violence
PLWA	People Living with HIV/AIDS
STIs	Sexually Transmitted Infections
UNAIDS	Joint United Nations Programme on HIV/AIDS

CHAPTER ONE: INTRODUCTION AND STATEMENT OF THE PROBLEM

Research has documented Human Immunodeficiency Virus (HIV)[1] or Acquired

Immunodeficiency Syndrome (AIDS) and intimate partner violence (IPV)[2] as high

prevalence issues among women globally (Salazar, Baker, Price, & Carlin, 2003).

Although HIV/AIDS and IPV have been studied extensively as separate entities, recent

literature has revealed a connection between the two (Dutton et al., 2006; McKeown,

Reid, Turner, & Orr, 2002). Studying HIV/AIDS and IPV as intersecting issues is

essential in understanding both women's experiences and impacts on health policy

(Amoakohene, 2004; Bacchi, 1999). Additionally, understanding experiences of

surviving HIV/AIDS and IPV from women's perspectives will provide information that

could be useful in adding to new knowledge and effecting change in services channelled

to address these two issues. The process of understanding women's issues from their own

perspectives has become one of the underpinnings in health care (Piot, 1999).

The Problem

At the present time, there are services in place to assist women who are living

with HIV/AIDS and other services for those who are living with IPV. It is important that

people providing care to women exposed to both HIV/AIDS and IPV involve women and

use their input in the planning and implementation of services provided, otherwise such

services may not achieve their goals of serving the clients they are meant to help (Bacchi,

1999; Farrar & Thurston, 2003). Understanding women's lived experiences of surviving

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[1] Not all women infected with HIV will acquire AIDS. For brevity we will use HIV/AIDS from this point.
[2] For the purposes of this thesis, IPV refers to abuse a woman experiences from an intimate partner. The abuse could be physical, emotional and psychological, financial, or sexual. The intimate relationship could be short term or long term.

both HIV/AIDS and IPV may expedite the success of service outcomes and may also impact service delivery policy and future plans for health care.

Study Purpose

The purpose of this study was to understand from women's accounts what it is like to experience both HIV/AIDS and IPV and how it affects women's day-to-day lives. This study will add to the understanding of both issues and potentially speak to policy around them.

Conceptual Framework

A socio-ecological framework (Navarro, Voetsch, Liburd, Bezold, & Rhea, 2006) was adopted to guide this study of the experiences of women surviving both HIV/AIDS and IPV. Feminist and gender lenses were used to further understand the interrelationship and interdependence of these women and their environment (Squire, 1993; Thurston & Vissandjée, 2005; Wilton, 1997).

The socio-ecological framework incorporates interrelationships across individual health and social behaviours (Sitzman & Eichelberger, 2004). It includes community determinants of health and also emphasizes the interrelationship of people and their environment in influencing individual behaviours (Navarro et al., 2006). Researchers using a socio-ecological framework aim to explain how human interaction with the environment impacts people's holistic well-being (Sitzman & Eichelberger, 2004). In this context, the environment includes the economic, social, institutional, and cultural elements that affect an individual and in turn will affect the community's well-being (Green, Richard, & Potvin, 1996).

In exploring the lived experiences of women surviving both HIV/AIDS and IPV, I considered their social backgrounds, which encompassed education, religion, ethnicity, and economic factors such as employment status, household income, and housing situations. I also examined women's interaction with the environment, incorporating interactions with significant others (including perpetrators) and health and social service providers (collectively referred to as care providers for the purposes of this study). I chose these factors because they are related to other determinants of health and are interrelated with social discrimination, stigma, powerlessness, and socioeconomic policies (Health Canada, 1997; Rimer & Glanz, 2005).

To further understand the interaction of HIV/AIDS with IPV, this research was framed by several theoretical approaches that aim to understand women's experiences and health pertinent to inclusion of women's voices. These included critical feminist perspectives and critical theory in general, standpoint epistemologies, and gender and power perspectives (Gupta, 2000; Smith, 1999; Wingood & DiClemente, 2000). These theoretical perspectives assisted in contextualizing the experiences of women surviving HIV/AIDS and IPV.

These theoretical foundations also help in understanding the societal basis of HIV/AIDS and IPV as global concerns. The way women are exposed to these two issues does not occur randomly, but rather follows the already established social forces of power inequality, gender role inequality, and cultural expectations that shape how women are treated by their male counterparts. From the perspective of feminist standpoint epistemology, it is necessary to provide women with an environment without pressures from men because men have traditionally determined what women's needs are and how

they are interpreted. Smith (1999) also stated that women-to-women talk might be more productive in understanding women's personal experiences.

Figure 1: Schematic diagram of the conceptual framework

(Adapted from Rimer & Glanz, 2005)

Micro Level

The micro level is the most intimate and personal level determining the women's experiences. Each individual in a community makes an impact on how that particular community functions. The way society (including care providers) perceives women surviving HIV/AIDS and IPV will influence their self-image which in turn might influence their interaction with others, self-care, and utilization of available resources.

Interpersonal Level

The interactions that occur among the women and other community members, as well as care providers, need to be healthy one based upon respect, acceptance, and gender equality.

Community/Environment

In addition to an environment that identifies HIV/AIDS and IPV as priority issues, structures that are placed in the community to provide services need to be sensitive to the needs of women surviving HIV/AIDS and IPV. This approach to service would facilitate the design programs that are specific to the needs of women experiencing both HIV/AIDS and IPV and that also shape positive provider interactions with these women.

Significance of the Study

In this study I explored the experiences of women surviving both HIV/AIDS and IPV in order to understand their day-to-day life and relationships with other people and their environment. These relationships entail the social, physical, economic, and cultural processes that influence how the women understand their lives as survivors of HIV/AIDS and IPV. Understanding how the women make sense of their lives guided me, the researcher, to make some recommendations regarding how best to serve women with similar experiences. Once the results are disseminated**,** this knowledge may also impact program and policy development.

About the Project

This project is the product of my passionate interest in HIV/AIDS research, management, and community mobilization. As a young woman, mother, nurse, midwife,

educator, and researcher, I lived in the developing world during the inception of HIV in the early 1980s. Like many people, I had a choice whether or not to turn a blind eye to what the world was facing.

At this time, I look back and thank God that I never turned my back on the challenge, but rather faced it head on with other dedicated people who sacrificed their time, leisure, and sometimes their lives and families to face the mystery no one understood at the time. As a young nurse who loved to work in rural areas, I started with very basic strategies of prevention. I targeted the young people, to whom I first taught basic skills, like the dangers of sharp objects, not to share toothbrushes, and other precautions. This continued until the time when the group was ready to discuss sexuality issues. Without parents' support and continuation in their homes, this could never have been a success. The whole community saw the need for collaborative action. It is my dream to one day talk to some of the people I taught when they were young to get their view on how this impacted their lives. Another area of focus was our traditional doctors and churches.

The struggle continued in all areas of Botswana and there came a time when the government, chiefs, and other leaders realized the need to aggressively attack the "monster" of HIV. I felt my contribution was a drop in the ocean, but let me tell you, its outcome was massive. I extended my work on a voluntary basis, working nights, weekends, and holidays. I reached out to schools, churches, prisons, district multidisciplinary committees, and later at a national level through KITSO. KITSO, the literal translation in Setswana meaning "knowledge", stands for "Knowledge, Innovation and Training Shall Overcome AIDS" and is a task force in Botswana made up of a

variety of health professionals including social workers, who developed modules and embarked on professional training and research through collaboration with Harvard AIDS Institute-U.S.A, Baylor College of Medicine-U.S.A, and Ministry of Health-Botswana. Botswana is one of the countries to receive free access to Highly Active Anti-Retroviral Therapy (HAART) for those who needed it, beginning as early as 2001.

Another area of my development is the study of IPV as a component of domestic and gender violence. Through working with my supervisor, Dr. Thurston, who is currently the director of the Institute for Gender Research at the University of Calgary, I was introduced to this other sensitive and life challenging area. I learned through the classroom, as a research assistant, as well as in my own research project when I talked to women surviving both HIV/AIDS and IPV.

This study used an exploratory approach to learn about the experiences of women surviving both HIV/AIDS and IPV in Calgary. Using an ecological model and feminist standpoint epistemology, an interview guide was developed to address the areas of importance in women's lives. Agencies that give shelter to abused women and their children and agencies supporting women surviving HIV/AIDS were approached to assist with recruitment of participants. Further, networking played a key role in this process.

Two women participated in in-depth interviews. These interviews were recorded and later transcribed, and then thematic analysis was done through QSR-N6™, a qualitative software program that facilitated coding of data. Depending on the themes that came out of the data, follow-up interviews were done until there were no new emerging themes. A total of four in-depth interviews were done. However, difficulties with which these women were dealing with, including homelessness (that is no permanent address or

telephone), made follow-up a challenge. I depended on professionals at the service
agencies for making my contacts with the women.

In sharing their stories, the women talked about the challenges of surviving both
HIV/AIDS and IPV and how it affected their personal lives, health, use of services, and
interaction with others. Beyond the double impact of both HIV/AIDS and IPV, the
women revealed other social challenges they experienced: drug use; the sex trade;
homelessness; and trouble with the law. These challenges exposed the women to more
than five stigmatized and marginalized issues. As a result, the women continued to
experience stigma and discrimination, rejection and isolation as consequences that
impacted relationships with intimate partners, care providers and other people in their
immediate environment. They were labelled with pejorative names such as "AIDS case"
and at times faced threats of abandonment by their intimate partners.

Results of this study will make the voices of these women who survive both
HIV/AIDS and IPV available to the world. It will also add to the already existing body of
knowledge that addresses HIV/AIDS and IPV as social and public health concerns.

The rest of the thesis follows this sequence:

➢ Chapter 2: in this chapter I address the literature that gives the background to the
study by describing the extent of the problem and the intersection of both HIV/AIDS
and IPV.

➢ Chapter 3: here I describe in detail the study design and the methods that were
followed to carry out this study.

➢ Chapter 4: the results of the study, outlining the characteristics and social context of

participants as well as the thematic data are presented.

➢ Chapter 5: the results and how they relate to the literature are discussed. This chapter

includes strengths and limitations of the study and presents conclusions.

CHAPTER TWO: LITERATURE REVIEW

In this chapter I provide a review of the literature on both HIV/AIDS and IPV as global issues, with special attention to evidence that they are interrelated issues. The review is focussed especially on how women are affected by both HIV/AIDS and IPV. It begins with a review of the prevalence of HIV/AIDS, followed by that of IPV, and continues with a discussion of the literature respecting the intersection of these two issues and how women are affected. The review of literature reveals that women's lack of social and economic power puts them at risk for both HIV/AIDS and IPV, and this lack of power underlies the intersection of the two issues in their lives.

Extent of the Problem: HIV/AIDS

The genesis of the epidemic of HIV/AIDS can be traced to 1981. This global health issue has created a global concern. UNAIDS (2008) reported stabilization of the epidemic with 30-36 million people living with HIV in 2007 and a decline in new infections. The incidence of HIV varies from one region to the other. Southern Africa has been leading the epidemic for the past two decades, accounting for 67% of all people living with HIV and 72% of AIDS death. However, other regions, such as East Asia, Eastern Europe, and Central Asia, have experienced an increase in the number of people living with HIV (UNAIDS, 2008).

The prevalence of HIV in Canada has increased from 52,000 in 2002 to 58,000 in 2007; more women are being diagnosed with HIV and AIDS than in the past and now represent an estimated 20 per cent of all Canadians infected with HIV. Other groups that are more infected include men who have sex with other men, intravenous drug users, aboriginal people, and people from countries where HIV is endemic (Public Health

Agency of Canada (PHAC), 2006). It is also recognized that there is a population that has HIV/AIDS but remains undiagnosed.

The medical approach to HIV/AIDS management has focused on aetiology and who is affected and as such, remains at the level of care providers and agencies rather than exploring deeper into amending the social structures that influence the disease process. Some of these structures include power inequality at the national and personal levels, unemployment, poverty, inadequate access to resources such as education, health and social services, as well as stigmatization and discrimination. Since socioeconomic status is a main determinant of health and is directly influenced by an individual's education level, employment, and access to resources, it remains crucial to addressing HIV and AIDS. Education is the basis to improved social and health status. According to Kalichman and Rompa (2000), people living with HIV/AIDS (PLWA) who have low health literacy experience more disease severity than those with high literacy. They have associated poor health literacy with barriers to fully understanding one's illness and treatment, such as not comprehending the information given by the care provider. Further, Baker, Parker, Williams, Clark, and Nurss (1997) found that patients with limited functional health literacy reported poor health with more chances of hospitalization as compared to those with higher health literacy. Low health literacy was seen to lead to continued risk behaviours among PLWA, as well as adding to the burden of care experienced by care providers.

The medical approach to HIV/AIDS management has instigated strategies that serve medical personnel well but pay minimal attention to social, economic, and political conditions. This approach currently excludes information about how those infected and

affected understand their experiences around HIV and AIDS. PLWA have diverse

experiences based on factors such as gender, gender role, sexual orientation, ethnicity,

socio-economic status, and government policies, as well as the attitudes of individual care

providers. This diversity of experience results in the isolation of certain groups of people,

such as women, especially from minority populations; men who have sex with men;

intravenous drug users; sex trade workers; people from areas where HIV is endemic; and

aboriginal communities. The result is perpetual stigma and marginalization of such

groups and fear of being identified with the condition (Levitt & Rosenthal, 1999).

      Ingram, Jones, Fass, Neidig, and Song (1999) explored the social network impact

for PLWA and found that PLWA face some unsupportive reactions in their immediate

environments that impacts their psychosocial functioning and can result in depression.

Some of these unsupportive reactions include breaking the PLWA's confidentiality,

expressing doubt about the PLWA, acting judgmentally, and being insensitive. A report

from the National Academy of Science (2001) identified social and policy barriers to

HIV prevention, including poverty, racism, gender inequality, stigma, and lack of

political commitment. Further, domination of the medical approach has interfered with

HIV prevention efforts because of the lack of embracing the social structures that shape

an individual's practices and beliefs (Krishnatray, Melkote, & Krishnatray, 2006).

Krishnatray et al. (2006) referred to the medical approach as biased and one-sided

because of its blanket perspective and expert base which is not negotiable and has pre-

determined outcomes. The medical approach considers neither community strengths,

resources, nor specific needs, but rather comes with ready-made tools, making it

insensitive to local cultures and practices (Krishnatray et al., 2006; Goldstein &

Manlowe, 1997).

The initial strategy put forth for prevention of HIV/AIDS, for instance, focused on

abstinence, fidelity, and barrier protection, suggesting some form of promiscuity on the

part of people diagnosed with HIV. The strategy also gave the false impression that

women could avoid HIV infection if they were in a monogamous relationship. Although

research has proven that this approach is not valid because of partner infidelity either in

homosexual or bisexual encounters, it resulted in women in monogamous relationships

being excluded from prevention programs for a long time (Heise & Elias, 1995).

HIV/AIDS was initially associated with gay and bisexual men and later with

prostitutes (Cameron & Lee, 1999; Sowel, 1995). This association led to people who

contracted the disease being ostracized and resulted in stigma against all who were living

with HIV. It also meant neglecting other groups because of myths about the method of

spread of infection. Prevention programs in developed countries targeted men who have

sex with men, bi-sexual men, and later sex trade workers and intravenous drug users.

In developing countries, women were the first heterosexuals to be diagnosed with

HIV; however, this was due to their more frequent use of health services than men.

Research has shown that women's biological body structures, specifically the receptive

mucosal membrane in the genital tract, make it easier for them to contract HIV than men

(Kathewera-Banda et al., 2005; UNAIDS, 2006). Moreover, studies have also shown a

difference in vulnerability across a woman's reproductive life. Quinn and Overbaugh

(2005) stated that adolescent girls are more vulnerable than mature women either because

their immature genital tract exposes them to irritations and tears or because of their

behavioural high-risk activities. Biological changes, such as high levels of progesterone in pregnancy and those created with the use of hormonal contraceptives, also affect risk. Progesterone is seen to enhance susceptibility to HIV, interfering with the immune response to infection. Another vulnerability, according to Quinn and Overbaugh (2005), is linked to gender norms and beliefs around sex, sexuality, sexual risk-taking, and fidelity. The face of HIV/AIDS worldwide has now changed from being portrayed as only one group of people in society to one that cuts across the entire population.

How people define an illness will influence the management of that disease. The original perception of how HIV/AIDS spreads and its medical description directed an approach to management that followed the medical model of diagnosis and treatment. This approach conflicts with some cultures, gender roles, and political support. The approach suggested by Kleinman, Eisenberg, and Good (2006), which they refer to as the "cultural construction of clinical reality" (p.144), encompasses the interplay of biological, psychological, and sociocultural aspects of illness and appears to be more inclusive of the cultural diversity in defining and managing illnesses. Brach and Fraserirector (2000) refer to this kind of approach as based in cultural competency, which they consider a factor that would reduce racial and ethnic health disparities. They suggest that this approach goes beyond knowledge of cultural diversity to the acquisition of skills by care providers in dealing with culturally diverse populations.

A culturally competent approach would recognize gender and the fact that women's vulnerability to HIV/AIDS is rooted in almost every aspect of life across the range of health determinants, from their biological make-up to economic, social, and political conditions (Gordon & Crehan, 2000; Kathewera-Banda et al., 2005). Low

education among women continues to fuel their vulnerability to HIV; education would improve their access to information, the labour force, and increased self-esteem that would help them rise above the poverty line. Also, a gap in knowledge perpetuating the ignorance and stigma around HIV/AIDS is created by the lack of inclusive care services where HIV/AIDS is an integral part of every service provided to women.

The community expects certain roles of women, especially the caregiver role (Albertyn, 2000; Lewis, 2006; UNAIDS, 2006) because they are caretakers of others. Women diagnosed with HIV/AIDS face different challenges than men. They cannot take care only of themselves because others need their care and attention. Further, they often do not have others to take care of them, adding more burdens to their physical, social, emotional, and economic situations. The pressures from their multiple roles isolate women from social activities and adversely affect their self-care. Stress further weakens their immune systems and adds to quick diagnoses and stigma. Women are also exposed to further risk of infection by forced sex from their partners, as well as other forms of abuse, hence the greater incidence of HIV/AIDS among women than men for a long period of time. Moreover, violence or the fear of violence has been identified as interfering with women seeking HIV/AIDS information, voluntary testing, and counselling (Goldstein & Manlowe, 1997; Piot, 1999; 2000), further compounding the spread of HIV.

Women's vulnerability to HIV has been attributed to their biological make-up that creates a larger receptive surface area for infection than in males, and to social and cultural factors. Also, low education that leads to economic dependency on men and lack of ownership rights in other countries has worsened their vulnerability to HIV. In the

report "Using Rights and the Law to Reduce Women's Vulnerability to HIV/AIDS",

Albertyn (2000) places more emphasis on gender inequality and poverty that simply

relates men's power to women's powerlessness in order to understand the gendered

nature of HIV/AIDS. Using a feminist lens, the author contends that not all women,

irrespective of their vulnerability to HIV/AIDS, are the same as they vary by sexual

orientation, religion, race, class, and culture.

Studies examined the life experiences of women living with HIV/AIDS separate

from IPV. Moreno (2007), in her study with Latina women, outlined how HIV and IPV

share risk factors that impact both HIV prevention and management. The author related

IPV and HIV to childhood trauma such as sexual, physical, and verbal abuse. This in turn

affects women's ways of dealing with relational issues as it affects their trust, lowers

their sense of self-worth, and also results in self-blame. Jackson et al. (1999) found that

women living with HIV/AIDS reported gender-related issues pertinent to protection

against HIV, such as the importance of addressing gender inequality when designing

programs. To reduce women's vulnerability to HIV, one of the universal strategies

employed is to empower women so that they can be self-sufficient and reduce personal

risk-taking behaviours. Empowerment of women has been achieved through education,

job creation, community participation, and micro-lending, which aims to empower grass

root communities (UNAIDS, 2006).

Extent of the Problem: IPV

The World Health Organization (WHO) and other international agencies have

recognized violence against women as a global human rights issue (Lewis, 2006; Piot,

2000; Watts & Zimmerman, 2002; UNAIDS, 2004). IPV also affects men, but the rates

differ greatly (Statistics Canada, 2002). According to Piot (1999), IPV causes more deaths than other recognized epidemics such as malaria, cancer, road traffic incidents, and war. Piot further stated that in the United States, a woman is assaulted by her spouse at least every fifteen seconds, and in India about 45% of men abuse their female partners. In other parts of the world, women are used sexually for ritual cleansing. Sexual abuse of women is also seen as a weapon of war and as a sign of masculinity for men (Dunckle, Jewkes, & Brown, 2004).

In a survey by the Canadian Centre for Justice Statistics of 4,169 victims of criminal harassment reported to police departments in 2002, 54% of IPV victims were women, 26% were men, and 20% represented children (Statistics Canada, 2004). It is notable that the literature reveals that men who have intimate relationships with other men suffer more IPV than men who have intimate relationships with women (Hegarty, Hindmarsh, & Gilles, 2000; Statistics Canada, 2000; Tjaden & Thoennes, 2000; Watts & Zimmerman, 2002). According to Statistics Canada (2006), there were 28,000 incidents of spousal abuse in 2004 of which 84% were female victims and 16% male victims. This high prevalence has drawn the attention of social researchers and policy makers. Research has examined factors contributing to IPV and the consequences as well as approaches for prevention.

IPV is related to sexual and power imbalances between women and men. Johnson and Ferraro (2000) conducted an analysis of an unspecified number of articles published in 1990 and concluded that the articles helped to describe contexts of violence, issues of power used by men to control women, and the social effects of violence against women. Johnson and Ferraro (2000) stated that IPV revolves around political, social, economic,

cultural, and gender issues. These are power issues that vary across societal groups. The social aspects of IPV have many implications in women's lives, relating to economics, politics, health, justice, education, employment, and human rights. With reference to human rights, Wagman (2008) stated that IPV not only undermines women's rights to fundamental freedom but also increases their risk to HIV, other sexually transmitted infections (STIs), and reduced quality of life. Considering that 25-54% of adult females will experience IPV in their lifetime (Bonomi et al., 2006), IPV presents a challenge to women's health and well-being. Bonomi and colleagues stated that IPV exposes women to physical, mental, and psychosocial issues relative to the intensity and duration of the abuse. The authors further stated that lack of data on long-term effects of IPV has inversely affected screening and intervention measures by care providers.

Policies have addressed strategies to remove women and children from violent environments through the establishment of shelter houses and laws that punish the perpetrators (DeKeseredy, 1993). However, further recommendations have been stated in the literature to establish primary and secondary prevention strategies of IPV to be used in health care settings, such as routine screening and referrals, education as a public health approach, establishing community supports for abused women, as well as modification of law enforcement policies. All would be encompassed within the family, community, and socio-cultural environment within which women live (Bonomi et al., 2006).

Research has helped bring the social and health issues of IPV into the open through the quantification of cases, causes, and prevention strategies. However, less has been done qualitatively to delve into the personal life experiences of women who

experience IPV. Among the conclusions from DeKeseredy's report (1993), lack of scientific knowledge from in-depth interviews created a vacuum in the understanding of how women experience violence. In the last decade and a half this gap has been addressed and more accounts by women are available.

Intersection of HIV/AIDS and IPV

IPV is well recognized as a violation of fundamental human rights as well as a public health problem that overlaps with the HIV/AIDS epidemic (Lewis, 2006; Piot, 2000; Watts & Zimmerman, 2002; UNAIDS, 2004). Emerging evidence connecting IPV and the rapidly expanding HIV epidemic suggests a strong link between the two issues, especially among women.

Research conducted in South Africa revealed that experience of violence and controlling behaviour from male partners was strongly related to the increased risk of HIV infection among women (Dunckle et al., 2004). According to Human Rights Watch (2004), rape and sexual assault within marriage is not uncommon and husbands may physically force wives to have sex against their will even where there is a possibility of HIV infection. The threat of violence often results in women deferring decisions about sexual practices to their male partners, such as the use of male or female condoms, which the men often reject. For women who experience IPV, low self-esteem, substance abuse, and low power to initiate condom use leads to unprotected sex and are factors that make them vulnerable to HIV infection (Beadnell, Baker, Morrison, & Knox, 2000). A study conducted in South Africa among pregnant women revealed the link between IPV and increased risk factors for HIV, including having multiple sex partners, alcohol use, and engaging in unprotected sex (Dunckle et al., 2003).

Poverty has posed a major burden for most women worldwide, and this exposes them to risky behaviours that make them vulnerable to both HIV infection and IPV (Ward, 1993). Economically dependent women may submit to sex with infected husbands out of a fear of eviction and abandonment, or as a result of a husband's insistence on having children. Strategies to minimize women's economic dependence on men have been explored in the literature. To empower women towards self sustainability, there is a need for education beyond grade 12, skill training, and access to health care and micro-credit loans. A study by Krishnan et al. (2008) identified three economic interventions for poverty reduction among women: (a) conditional cash transfers based on certain behaviours, such as keeping children in school; (b) micro-credit loans through group lending models; and (c) skills and resources that would enhance the woman's ability to fulfill her economic goals.

While IPV can result in HIV infection, research has also revealed that IPV can be a consequence of HIV (Maman, Mbwambo, Hogan, Kilonzo, & Sweat, 2001; Medley, Garcia-Moreno, McGill, & Maman, 2004). For example, a study carried out in the United States (U.S.A) showed that 18% of women living with HIV reported disclosure-related violence (Glelen, 1997). Another U.S. study revealed that 4% of women living with HIV reported physical abuse after disclosure, and 45% reported emotional, physical, or sexual abuse following the diagnosis (Glelen, 1997; 2000).

While HIV/AIDS and IPV as global epidemics are now receiving international recognition, myths, cultural beliefs, and policies serve as barriers to considering the intersection of the two issues, undermining recognition of the impact on women's lives. The intersection of IPV and HIV infection has health consequences and impacts also

women's access to and use of health and social services. In addition to the anticipated progression of HIV to AIDS, women experiencing both situations are at risk of depression and high level posttraumatic stress that may result in cardiovascular conditions leading to heart attack or stroke and death (Du Mont, Forte, Cohen, Hyman, & Romans, 2005). There is evidence that HIV/AIDS and IPV are strongly related and women who are exposed to one have an increased risk of the other. Rooted in the complexity of this interaction is the socio-economic and gender inequality between women and men as seen in women's higher unemployment, lower education, and lower income (Krishnan et al., 2008). Some structural pathways have been identified in the literature for this interconnectedness and these include: (a) childhood trauma resulting in patterns of sexual risk behaviours in the future; (b) traumatic forced sexual activities increasing women's risk for HIV; (c) violent experiences limiting women's ability to negotiate safer sex; (d) disclosure by HIV positive women exposing them to abuse by their partners; and (e) repeated violent experiences interfering with women's use of health care services, creating a cycle of abuse and difficulty in coping (Moreno, 2007; Wingood & DiClemente, 2000). Experiencing both conditions may impact all aspects of women's lives resulting in social, physical, psychological, and spiritual disorders.

Research Questions

Two broad research questions guided the design and implementation of the study:

1. How do women describe their experiences of surviving both HIV/AIDS and IPV?

2. What is the effect of both HIV/AIDS and IPV on women's day-to-day lives?

Summary

HIV/AIDS is a global epidemic that is concentrated in certain populations with an increasing prevalence among women. The medical approach to HIV/AIDS has neglected the social structures that allow the epidemic to continue resulting in marginalization of groups and fear in identifying with the disease. Medical strategies largely ignore cultural and social contexts; for instance, a focus on monogamy implies promiscuity among people with HIV but ignores the fact that while a woman is more likely to be monogamous, her partner is not. Women were the first heterosexuals to be diagnosed with HIV. More recent work has called for an approach to prevention that incorporates cultural competency, recognizing the influence of gender on HIV in women, particularly the roles of economic insecurity and of care giving. Empowerment[3] is a key strategy for HIV prevention in women. IPV is another epidemic that disproportionately affects women and is rooted in social and economic inequality. Among the potential outcomes of IPV is increased risk of HIV infection. Many services and policies have been developed to address IPV. Lack of power leaves many women vulnerable to forced sex by partners who are HIV positive and to risky lifestyles, such as unprotected sex. IPV may also result from disclosure of HIV status. When IPV and HIV occur together they each exacerbate the impact of the other on women's health and well-being. Empowerment and access to economic independence are key to aiding women who experience HIV and IPV, whether separately or as simultaneous problems.

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[3] Empowerment in this context is used as a means to provide skills that enable a woman to effectively provide for herself and her dependants especially children. The skill could be tangible such as financial support or non-tangible like knowledge.

In the next chapter, I elaborate on the steps I took to carry out this study and how it impacted me as a researcher dealing with sensitive issues and vulnerable population.

CHAPTER THREE: STUDY DESIGN AND METHODS

In this chapter, I describe the process of doing this study and how it impacted me as a researcher. First is the approach that guided this study; second, stages of recruitment and interviews; third, data collection; fourth, data analysis; and finally the ethical implications.

Design

An exploratory qualitative study with in-depth interviews was used to explore the intersection of HIV/AIDS and IPV in women's lives. Exploratory qualitative designs are used when little is known about the area (Creswell, 2003; Morse, 1991; Richards & Morse, 2007). In-depth interviews, unlike structured surveys, enhance participant-interviewer rapport, resulting in a sense of trust and openness and allowing the participant to go beyond what is asked to what is taken for granted and hidden. As a result, qualitative interview methods capture more accurately the information that might otherwise be missed by using only structured questions and quantitative analysis approaches (DeKeseredy, 1993).

The epistemological stance taken in this study was influenced by my background of education, culture, and personal experience. As Feunmay (1991) and Denzin (1997) have said about the complexity of interpreting and understanding voices, researchers do not expect that another researcher will have the same interpretation as their own. In proposing that HIV/AIDS and IPV can be better studied and understood from the perspective of women's own experiences, it is understood that the experience of these two issues and their meanings will also differ from one research participant to another.

Methods

Sampling and Recruitment

Convenience sampling, a technique used in purposive sampling for qualitative research (Richards & Morse, 2007; Rice & Ezzy, 2002), was used to identify participants for this study – women who were surviving both HIV/AIDS and IPV. "Surviving" in this context referred to the experiences the women had been through or were currently experiencing. The women had to be living in Calgary, be at least 18 years old, be able to communicate in English, and be ready to disclose and talk about both their HIV status and IPV experience. The women could be in an abusive relationship or have left the abusive relationship and be currently living in a shelter or elsewhere.

To recruit participants, agencies that provided services to women who were living with HIV/AIDS (i.e., AIDS Calgary; Harm Reduction Department at the Calgary Health Region) as well as an agency that provided services to women surviving IPV (i.e., Brenda Strafford Centre) were approached. Networking was important for this study because locating and gaining access to participants was dependent on whether agency directors determined it appropriate to become involved. Getting to know the researcher personally and having the opportunity to ask me questions and receive explanations provided the directors with an understanding of the study and a basis for making the decision to refer potential participants for the study or not. The agencies that provided HIV/AIDS services agreed to assist me in making contacts with potential participants. However, the agency that provided services for women surviving IPV could not assist with identification of participants because they lacked information about their clients' HIV status. Following a review of the ethical principles to which academics are bound, the directors of the

agencies who agreed to assist me in participant recruitment connected me with the most appropriate staff member with whom to work.

The assistance of agencies helped me in identifying women who met the inclusion criteria. AIDS Calgary referred two women to the study. Appointments were made with each of the women, but these were cancelled when the women changed their minds about participating, with the only reason given being they decided they did not feel up to discussing the subjects (HIV/AIDS and IPV). The Harm Reduction Department of Calgary Health Region also referred two women to the study; my appointments to meet each of these women were successful and both were agreeable to participating in the study. To acquire informed consent, I explained to each of them the nature of the study and what participation meant. It was anticipated that two to three interviews would be conducted with each woman.

Sample Size

Although attempts to recruit additional women took place over six months, no other women were identified and the study concluded with two participants. Four interviews in total were completed, three with one participant and one with the other. Neither participant had a permanent address or telephone number so it was a challenge to maintain contact and arrange meetings to conduct interviews. I would leave messages for the women at the Harm Reduction Department, but I was dependent on the women visiting the office, receiving the messages, and calling me back. In total I spent about 8.5 hours with the first participant and about two hours with the second.

I consistently reported the extensive challenges in recruiting more women and conducting more interviews to my supervisory committee. Upon reaching data saturation,

that is, no more new topics being identified during data analysis (Denzin & Lincoln, 2000; Morse, 1991), I discontinued my efforts at securing further interviews.

Data Collection

As a researcher in this study, I entered the unknown world of women surviving HIV/AIDS and IPV and tried to understand the world from their experience. Through the process of face-to-face interviews, I interacted with participants to uncover and give voice to experiences of HIV and IPV (Rothe, 2000). The researcher as an observer and interpreter is never neutral in the process of interaction (Denzin, 1997; Denzin & Lincoln, 2000; Richards & Morse, 2007) and the interpretation is shared between the researcher and the participant (Garfinkel, 1984; Rothe, 2000). As such, the researcher is not seen as a neutral spectator but rather as what is described as the "seeing and knowing equation" based on the fact that what comes out of the women's stories is a result of the lived experiences of the participants as well as the values and experiences of the interpreter (Denzin, 1997; Rothe, 2000; Richards & Morse, 2007). Throughout the study, I kept notes of my thoughts and reflections on the process and used these to enhance my discussion of the results.

Once the participant provided informed consent, data collection followed several steps. The first step was to build rapport with each woman so that both researcher and participant could be comfortable with disclosure, given that the information that she was being asked to share was very sensitive. The women needed assurance that the person she was talking to was trustworthy. While the consent form addressed issues of data management and participant anonymity in reporting of the study, personal, face-to-face interaction and reaction to the woman's voice helped in creating trust.

Each time I met a participant, I greeted her by shaking hands and hugging, showing a sense of acceptance. This aided both of us because it relaxed the mood and the woman could feel free to talk. During an interview, I sat next to the woman, and when she became emotional, I touched her shoulder or hand and asked if she was okay and whether we should stop our conversation. If that was what she wanted, we stopped until she was ready to talk again. I offered her water and Kleenex, and also asked her if she needed a counsellor. Neither of the women needed a counsellor; they said they already had someone with whom they were working. Sometimes we went to eat lunch together and one participant told me that it was her first lunch after days of going without eating. I asked her why and she said it was because she did not have any place to cook and eat a good meal or anyone with whom to enjoy it.

During our first meetings, I introduced myself and described my background and the reasons for the study, and then I asked each participant to tell me about herself and collected some demographic data (Appendix 3). This led into the second step, that is, the in-depth interview wherein the participant was encouraged to tell about her experiences in surviving HIV and IPV. I used an interview guide (Appendix 3) to direct the first interview, and informed the participant that I would be taking some notes as additional prompts emerged from her responses and would use these to probe more deeply as the woman shared her personal experiences. The third step was another interview with the participant to follow up on the themes that were found in the data analysis that suggested areas to be explored for further details and clarification.

Throughout the interview, I was sensitive to the women's state. Interruptions were minimized when a woman was talking. Silent periods were allowed, timed by taking five

silent deep breaths before continuing with probes or other questions. One of the participants had a particularly emotional reaction during her interview. I gave her time to cry and then regain her composure. After ten minutes, I asked her if she wanted to stop and re-schedule another interview. I also asked if she needed counselling services or other supports to help with the emotional distress. The woman said she was already working with a support person so she did not want a referral, and she opted to continue with the interview.

At the outset of the interviews, permission was received from the participants to record the interviews. Two digital recorders were used at each interview to guard against loss of data through technology failure. Recordings were uploaded to a computer within three days of the interview and verbatim transcriptions were completed within ten days. In addition, I kept a journal for field notes and reflections. Field notes were immediately written up after each interview and stored in the research file as documents, identified by participant number, interview number, and date of the interview.

Participants were reimbursed with $50 for costs associated with the interviews, such as transportation.

Data Analysis

Data analysis was concurrent with data collection. Analysis followed the constant comparison method to constantly search for commonalities and differences as well as confirming and/or disconfirming evidence (Denzin & Lincoln, 2000). Themes that came out of the data analysis were used to shape and enrich the data collection in further interviews. Ongoing analysis followed the same sequence until no new topics that needed following were found in the data.

The interview transcripts were entered into QSR-N6™, a qualitative software program that facilitates researcher coding of data. Coding followed several steps; descriptive coding was done to store participants' demographic data (Richards & Morse, 2007). The next step was topic coding. Before engaging in this kind of coding, I read the interview text twice, during which I made notes to keep track of my reactions to the data (reflections) (Richards & Morse, 2007; Rothe, 2000). During topic coding, both small (line and sentence) and large (paragraph) descriptive texts were considered in the creation of categories. When coding, preliminary themes and topics that represented the participants' experiences emerged; either the actual phrases that the participant used or phrases to represent the text were kept in QSR-N6™ as Tree Nodes. Following this preliminary coding, I re-read the whole text again and also revisited the coding to check if the same categories were generated. The categories were then collated through analytic coding that delved deeper into the data. This was the stage that assisted me in the critical analysis of the data to explore and develop new categories (Richards & Morse, 2007); it also stimulated my reflections, as I further identified themes that helped to synthesize data as categories continued to emerge (Richards & Morse, 2007). Throughout this process, memos were developed to capture coding decisions. These memos were used to enrich my discussion of the results as they reflected my train of thought at the time of analysis. As I listened to the interview recordings and also during the thematic analysis of the data, I kept responding to what I got from the data by using phrases such as "yes, hhm, no, okay, etc..." This helped me internalize the data and also reduce the pressure on my chest.

The same coding procedures were followed in all the interviews, and constant comparison of themes was done by moving back and forth among interviews with the same participant, and between interviews with the two participants. Through this process to confirm or disconfirm a theme or topic in other text, trustworthiness was ensured.

Study Rigour

This study, which used a qualitative approach, considered rigour important to ensure trustworthiness, confirmability, dependability, credibility, and transferability of the data (Tobin & Begley, 2004). Moreover, literature acknowledges the diversity in the backgrounds of qualitative researchers hence varied views in the interpretation and quality of their work (Emden & Sandelowski, 1998); this is also supported by Guba (1999) and Guba and Lincoln (1989) as they emphasize the value laden interpretation of data. However, the common agreement towards quality in qualitative approach is rooted in the rigour of the entire research process. Rigour and trustworthiness are the two terms that are commonly used to describe the quality of qualitative research; however, their use is not consistent across the literature. Some authors use the two terms interchangeably and others place rigour to be the overall stem. In this study, I concur with rigour being the overarching stem wherein its process will determine the trustworthiness of the data. Guba and Lincoln (1989) describe rigour and trustworthiness in relation to credibility, transferability, and dependability of the data; this is also referred to as authenticity, trustworthiness, and goodness by Tobin and Begley (2004). These authors describe rigour to be a result of a thorough process in which the researcher explores methods in the course of the study, reflecting on all steps taken, including challenges and how they were

dealt with, and further, describing how themes were developed. This is done to ensure that conclusions are firmly based in the data.

To ensure rigour in this study, the following three steps were taken: (1) Follow-up interviews were conducted after analysis identified new topics that warranted clarification. For instance, it was considered whether the participant was consistent in describing or explaining her experience in a meaningful way. Follow-up interviews increased clarity of understanding through constant comparison of new topics that were found in the data. (2) Reading and re-reading the text ensured that important topics or themes were not missed. Re-reading prior to the second level of coding and analysis, which included generating categories and subcategories of themes, further promoted immersion (Richards & Morse, 2007). (3) Collaborative discussion with my supervisor and committee members encouraged clarity and consideration of different viewpoints and reactions to the data. This added to the explanation of themes and their connections.

The information I received from the women was overwhelming, which created emotional and psychological distress for me. At one time, P1 said to me "I can see that you are being stressed, your eyes are red.…" I told her that I am a human being, a woman, a mother, and a sister so there is no way I can be numb to her stories. Dealing with what the women told me in the interviews proved to be a hugely stressful experience for me and debriefing with my supervisor, Dr. Thurston, became very important and helpful. As an experienced researcher in women's issues, she asked me questions and paraphrased some statements to help me talk more about my feelings and find a way forward.

Further, returning to the published literature when describing and interpreting the data analysis provided another opportunity for rigour through the validation and/or clarification of the themes. Follow-up in the second and third interview with one participant also provided an opportunity for rigour as I discussed my thoughts and ideas with the participant and asked her for clarification or comment. This brought greater insight and understanding to both of us. Additionally, an audit trail was created in the field notes that captured all the steps, including difficulties encountered during the process from the first stage of creating rapport to the write-up (Richards & Morse, 2007).

It was a long walk for me to survive the vicarious trauma that I experienced in my interactions with the women who participated in this study. Making contact with them was a challenge because they were homeless and therefore did not have a permanent address or phone. Trust was a major factor and first needed to be established between me and the agencies I approached for assistance in recruiting participants and then between me and the women who agreed to participate. HIV/AIDS and IPV are sensitive issues. My focus was to understand the women from their own perspective without judging them in any way. To do this, before every interview, I would write down what I thought might negatively impact my hearing the women's stories. This included my cultural beliefs and values, professional background, and work experience. This was not to assume a neutral stance but rather to acknowledge those feelings and behaviours when they came and also to be ready to deal with them. Following the interview, I pictured the whole scenario and critically analyzed what transpired, my reactions and what could have influenced them, and what I could have done differently and why. This also helped me to prepare for the next meeting.

While generalizability has never been the primary aim of qualitative research, Morse (1999) argues that without the ability to generalize our data, there is less value to qualitative research. Morse went on to compare generalizability of quantitative research and qualitative research; she stated that in quantitative research generalizability is based on statistics whilst in qualitative research, it is assessed by the ability to transfer the theory built in one study to another study with comparable situations. Therefore, the transferability of a study is determined by its rigour. By providing a thorough description of my methods and results I aim to increase transferability, whereby readers can determine for themselves if the results match with their contexts.

In the next chapter, the results of the analysis are presented. I begin with a description of the participants followed by presentation of the themes identified.

Ethical Considerations

The research proposal was submitted to the University of Calgary Conjoint Health Research Ethics Board (CHREB), and the study began following ethics approval (Appendix 1). The participants in the study were requested to carefully read and sign a letter of informed consent (Appendix 2); they showed no difficulty in reading so it was accepted that they understood its content and meaning. No individual names have been used in reporting the research, thus ensuring their anonymity.

Only myself as the researcher, my research supervisor and the transcriptionist had access to the raw data. The original interview recordings and electronic transcripts were stored at the University of Calgary on password protected computers in a locked office. Data analysis files were similarly protected. Letters of consent and electronic data will be

stored by my academic supervisor for seven years in secure facilities at the University of

Calgary, as per University of Calgary Faculty of Medicine policy.

Care was taken in the presentation of results to protect the anonymity of the

participants. Grouped data were presented and quotations were edited to exclude

identifying information. Quotations were reviewed as a whole to ensure that in

combination they did not reveal identifying information.

Maintaining Ethical Boundaries

Talking to the women and giving them an opportunity to be listened to without

any structural obstacles made them want to continue the contact with me as someone to

whom they could talk, especially P1 who at times would call and ask if it was time to

meet. As a researcher, this became a challenge as to how far I needed to go in building

this healthy relationship with the participant. It is an ethical expectation that as

researchers we should keep a professional boundary with our participants to ensure that

we remain viewed as researchers and do not take on a role we cannot fulfill (e.g.,

counsellor) and that might change a participant's role without being explicit. Is this

always possible? Does the degree of involvement differ and what determines the

difference – is it personalities, the type of research, or areas to be investigated? Also,

what is the next step when I am already involved? At one point Dr. Thurston said maybe

this study could have benefited from participatory action research (PAR). PAR could be

the type of research to be employed when investigating women's sensitive personal

issues that need to be addressed and dealt with instead of engaging women by asking

them to recall what they have been trying to suppress for so many years, due to the pain

that comes with it, and leave them without any action taken. As researchers, we function

under the jurisdictions of ethics guidelines, designed especially to protect participants. Ethics reminds us that we are neither counsellors nor providers of solutions and there is a limit as to how far the researcher should interact with the participant in terms of offering advice. But what about the researchers' sensitivity to others? How can we ask them to remember those painful experiences without us (researchers) reacting to them as another human being? I do not see how we can best assist these individuals until we truly understand what they go through. This is how objectivity differs from subjectivity, and maybe as quantitative differs from qualitative research. As Mauthner & Doucet (1998) describe qualitative research, there is a balance between reflecting the voices of participants and that of the researcher and the theories and writers that they bring with them to the project. As described earlier, my bracketing and use of field notes aided in my reflexivity about the data and my own role in analysis.

To conclude, I remember saying to my supervisor, "maybe some of us who are sensitive to people's needs/issues should never do this kind of study." She looked at me and said, "then nothing will ever be done." It is therefore my belief that we need researchers, educators, care providers, and policy makers who are sensitive to other people's experiences in order to come up with appropriate strategies.

Closure of the Study

The relationship with P2 ended when she ceased to return calls and locating her became impossible. P1 continued to contact me after the study and she requested and arranged to meet Dr. Thurston. Although she was clear that the research had ended, she continued to update me on her experiences. The future of our relationship remains to be determined.

In the next chapter, the results of the analysis are presented. I begin with a description of the participants and followed by presentation of the themes identified.

CHAPTER FOUR: RESULTS

This chapter explores the results from women's stories as they recalled their life experiences guided by the two research questions: how do women describe their experience of surviving both HIV/AIDS and IPV, and what is the effect of HIV/AIDS and IPV on their day-to-day lives? The first section presents the participants' characteristics and their social contexts as survivors of HIV/AIDS and IPV. The remaining sections present the thematic results from the analysis of the interviews, identifying five themes drawn from the data. Section two addresses the question: how do women describe their experience of surviving HIV/AIDS and IPV? Section three addresses the question: what is the effect of HIV/AIDS and IPV on their day-to-day lives. Section four offers reflections on ideal models of care and the participants' own futures. Quotations from the interviews are used selectively to illustrate the results.

Section One: Participants' Characteristics and Social Context

The two women recruited into the study met the criteria of surviving HIV and IPV. They were aged between 30 and 35 years and had many life experiences in common: they had lived in group homes as youths, had not gone beyond high school in their education, were unemployed; used street drugs; and were involved in the sex trade. As well, they both lived 'on the street', that is, neither one had a permanent address.

The first participant (P1) has children who were conceived through rape and forced sex. She is a writer who uses her writing as a way of letting her voice be heard by the world. Most of her writing shows signs of rage towards what she views as the unfair

treatment and injustice inflicted by colonizers, who took advantage of Aboriginal[4]

people's good nature, abusing the women and children, and taking their most precious

gift, the land. She was very aware of systemic discrimination against Aboriginal people

and believed her experiences with abuse, drug use, and the sex trade were all rooted in

her childhood experiences, mostly in boarding schools and group homes. According to

DeMarco, Miller, Patsdaughter, Chisholm, and Gradel, (1998), HIV diagnosis motivates

some women to speak out and shape their own lives.

To work towards being drug free, she signed into one of the detoxification centres

in Calgary. She reported doing very well and was very proud of herself. She wanted to

pursue her desire to get clean and empower other women and children in regard to drug

use and HIV. While she talked freely about her drug use and HIV, she did not want to

address IPV in detail. Each time the topic of abuse was brought up in the interviews, she

would react with extreme anger. At one point, she said she did not want to talk about it,

because of the pain it brought to her.

She mistrusted the system that she believed was oppressive, and this led her to not

use the government run programs whether health care or the legal system. She suggested

that care providers considered her only as a subject of care services rather than a total

human being. She said that the care providers were more interested in the disease (HIV)

than in her as a person; as a result she was very selective about the services she used. She

wanted care providers who would look at her and see another human needing company

and acceptance, instead of just focusing on the disease.

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[4] Aboriginal is used to include First Nations, Inuit, and Métis ancestry.

The second participant (P2) who was Caucasian was planning to get her addiction certificate so that she could counsel other women with similar problems of alcohol and drug dependency. She said it was hard to remain sober, but she really would like to do so. Unlike P1, this woman did not have children and she was on HIV drug therapy, HAART (Highly Active Anti-Retroviral Therapy). She also talked of good family support from a mother and brother. I was only able to conduct one interview with this participant because of the difficulty in reaching her. I left messages at the agency where she went for personal assistance, but she never called back. One time when I called, I was told that she had been admitted to the hospital. I kept calling and leaving messages at the agency but she never called back.

Section Two: Surviving HIV/AIDS and IPV

Under this theme, I explore the lived experiences of the women as survivors of HIV/AIDS and IPV as they intersect, their influence on each other, and other challenges the women encountered in their lives. These challenges included drug use, self-abuse, and the sex trade. The sub-themes that captured these life experiences in relation to the interconnected experiences of HIV/AIDS and IPV include the cycle of abuse and self-abuse.

Relationship between HIV/AIDS and IPV

This theme is about the interconnectedness of HIV/AIDS and IPV, which is relevant both before and after HIV diagnosis. It shows how the two issues impact each other and also affect a woman's future actions, such as engaging in drug use and the sex trade. IPV started early in the lives of both women and was connected to life experiences that then put them at risk for more IPV and HIV.

P1 connected HIV to her childhood experiences of abuse, as well as partner violence. The trauma she experienced as a child and adolescent led to suicidal and other behaviours such as drug use and involvement in the sex trade. This abuse by others also led to self-abuse, which included causing physical harm to herself by going for days without food and water, taking only drugs and alcohol, as well as provoking other people with the intention of getting hurt. P2 got into drugs and the sex trade as a teenager, and this exposed her to IPV and HIV. Both women came to believe that they deserved the abuse. Their descriptions of how they contracted HIV suggested a form of self-negligence rooted in the cycle of abuse.

> P1: …after a certain period of time I decided I didn't care anymore. It all added up everything from my life and from being out in the streets with different partners. It all added up and I finally just, ah, I went out and I delivered [used] the used needles with some people that were HIV positive just because I couldn't kill myself, which I did commit suicide in all different ways and it never worked. I always ended up in the hospital or being saved somehow.

> P2: Um, like being at that age well I was messed up on drugs and doing needles and I wasn't careful and that's what happened.

These are examples of self-abuse as described by the women. There is also a sign of hopelessness, especially in P1, that led to engaging in behaviours exposing her to HIV and IPV. P1 had been HIV positive for about 10 years and P2 for 14 years.

Cycle of abuse

The experience of surviving HIV/AIDS and IPV negatively impacted the lives of the two women and created a cycle that was difficult to escape. Getting into drug use and the sex trade exposed them to HIV re-infection with a different strain of HIV and to other

STIs, such as Hepatitis C. It also exposed them to additional physical, sexual, and

psychological abuse by others and led to self-destruction and a desire to die, and hence,

attempts at suicide.

> P1: It [abuse] affected me and I decided I didn't want to
> feel anything because I wanted too much as a kid. So I
> started doing the drugs and the alcohol and I got into the
> needles and when I figured out a way and I couldn't
> commit suicide through everything else…you know, you're
> doing crazy things like ripping, taking the drugs from a
> drug dealer and thinking you know they will come back
> and shoot you or, you know, get somebody to beat, to beat
> you or kill you. Whatever, right. I did everything I could to
> try and get somebody to be, to kill me or I took pills or, you
> know, drank and did pills or hung, I tried to hang myself,
> everything. I tried everything.

The childhood trauma that P1 experienced contributed to her use of drugs and

alcohol, and work in the sex trade. She used alcohol and drugs to numb herself from the

pain she experienced during her childhood. She acted with the intention to aggravate

anger in other people such as drug dealers with the aim of getting hurt or killed.

Self-abuse

P1 indicated that her self-abuse started very early in life. She wanted both to

avoid feeling the pain of abuse experienced as a child and adolescent and also to gain

attention that seemed not to come.

> P1: I think it all had something to do with it because I just
> didn't care anymore. It all added up everything from my
> life and from being out in the streets, different partners all
> added up and I finally just, ah, I went out and I delivered
> the used needles with some people that were HIV positive
> (snap sound) just because I couldn't kill myself.

> P1: …but when I was a kid I did different things. I, you
> know, I'd take Gravol or, you know, go sniff inhalants or
> solvents. I just did a lot of other things to, to try avoid

> feeling what I was feeling so I'd, I'd slash my wrists, my
> wrists for I don't know for how many years while I was in
> the, ah, in the group homes, the government homes.

These statements further illustrate the extent of trauma P1 went through as a child and how it impacted her life. She stated that the experience made her go on the street as well as use contaminated needles with other drug users. Her suicide attempts started early in her life, but she used different approaches such as over the counter drugs and sniffing inhalants because those were the only substances to which she had access as a child. She also inflicted pain on herself by "slashing" her wrists several times in order to draw the attention of other people. The actions could have been a way of telling those around her that there was a problem and she needed help. However, in her telling of these experiences, she did not go into any detail of describing other people's reactions to her behaviours.

What P1 experienced influenced her feelings and actions and that may not even be understood at face value. This participant experienced many types of abuse from early childhood including physical, emotional, sexual, spiritual, and psychological. The abuse occurred at home, group homes, and boarding schools. In explaining this intense experience, P1 said everything left her feeling like, for lack of better words, a "piece of shit." This childhood trauma was part of a cycle of abuse by others, as well as self-abuse.

As a child, P1 experienced physical, emotional, spiritual, and sexual abuse that eventually led to a teenage pregnancy due to rape. She stated that all these experiences led to her current life style, which includes drug use, the sex trade, and being in trouble with the law. As a result, she became suicidal and did everything to try to destroy herself. However, immediately after she was diagnosed with HIV, she turned around and wanted

to live; she referred to this as a "blessing from above." The diagnosis caused her to not only want to live but also to find out who she really was and why things happened the way they did. This influenced the strategies she employed in her process of survival, such as working with a spiritual leader.

Based on what the women said regarding their choices of care services, it suggests the importance of culture and past experiences with care services in choosing a mode of care. P2 followed the conventional medical treatment and was comfortable with the service; on the other hand, P1 preferred to work with her traditional healer. This is supported by Royes (1999) who emphasizes the need to consider population characteristics such as life styles and beliefs in HIV/AIDS prevention and care.

Section Three: Effect on Day-to-Day Lives

Introduction

This section presents the theme "surviving HIV/AIDS" as a separate experience, that is, without intersecting with IPV as described in the preceding section. Here the main focus is on the life experiences of the women as survivors of HIV/AIDS. This is to assist me in capturing any life experiences that may be unique to HIV/AIDS. It also brings forward the different and similar experiences of the two women as survivors of HIV/AIDS.

Surviving HIV/AIDS

The women described a variety of personal experiences, including how they interacted with relevant service sectors, the challenges they faced, and the impact of HIV/AIDS on their decision-making.

<u>Wanting to live</u>

The women's reactions to their HIV status differed. P1 turned from wanting to die, following the experience of abuse, to recognizing that she wanted to live when she found out that she was HIV positive. In fact, she said HIV was "a gift from the skies."

> P1: …when I first converted [sero-positive] I thought, I thought that was basically the end of my life. I spent my whole life trying to commit suicide but then when I found out I was HIV positive, I figured out I wanted to live and that's what kind of turned my head; actually it's a gift from the skies and I don't know if you've ever heard anybody say that before.

This was not the first time I have heard such a response. In another study, I interviewed a participant who stated that his life changed for the better following an HIV diagnosis; he started receiving better health care for his psychosis problem and also started to realize that people cared about him (Calgary Coalition on HIV/AIDS, 2007).

Before P1 was diagnosed with HIV, there was a period when she wanted to die as a result of her childhood trauma. She did everything from using inhalants, aggravating anger in other people so that they would hurt or kill her, using drugs and alcohol, and using contaminated needles with other drug users. However, following her HIV diagnosis, she turned around to wanting to live and to achieving a better quality of life by getting clean from drugs, having improved relationships with her children, and empowering herself, other women and youth in relation to HIV and drugs. She never mentioned empowering herself or others regarding childhood abuse, IPV, or sex trade. This may imply that drug use and HIV are major challenges that need immediate attention, and need to be dealt with first before one can move on to address other issues.

P2, though she had similar experiences of staying in group homes and starting in the sex trade and beginning to use drugs in her teen years, differed from P1 in her feelings and reactions to herself and life. This may be because she did not experience the extensive sexual and other childhood abuse that P1did. This implies that childhood trauma can negatively impact one's emotional and psychological well-being. P2 accepted her situation and became willing to work towards coping with it. She registered with the Southern Alberta Clinic for her HAART treatment and spoke well of care providers as being supportive and caring. However, like P1, staying clean was a challenge for her. Both participants explained their efforts to change in order to reach the quality of life they desired following their diagnosis of HIV.

The quotes below are examples of how these women talked about their desire to change and the challenges they faced, which in turn led to frequent relapses. There was a time when P1 thought she was doing well while working with her traditional healer. Unfortunately she went back to her old habits of drug use and sex work. When I did the interviews with her, she was in a state of hopelessness and felt defeated. However, her prominent desire motivated her and she went on to book into a rehabilitation centre. P2 also faced challenges with staying sober (i.e. off drugs), adherence to HAART, eating well, and establishing and keeping intimate relationships because of the fear of being judged.

> P1: …to me it…was my wake-up call and start, you know, trying to live life and do something with myself and I did that for, for a little while. I saw a traditional healer and did a 180 degree turn around and took care of myself and got healthy and got help that I needed for my drug and alcohol issues and went to counselling and did everything for myself and I was doing pretty good.

> P2: Oh it's hard. Like there's lots, I have lots of questions
> about like I have to be on medication for the rest of my life
> and eat properly and, ah, try to get into a relationship with a
> man is hard because you have to try, to tell them and worry
> about the fear of being judged.

P2, though she engaged in risky behaviours such as drug use and the sex trade, never intended to die from those actions. Therefore, her HIV diagnosis was a wakeup call too because she turned around and wanted to improve her quality of life by being clean of drugs, getting her addiction certificate, and becoming an addiction counsellor so she could work with women with similar addiction problems.

In the statement below, P1 describes one of the tactics she used to employ when trying to kill herself. Here I see the conflicting interests of wanting to die and wanting to live. However, her saying she "got over that", that being the desire to die, suggested the over powering desire to live which maybe will continue to make her want to do the best for herself.

> P1: …Sometimes I would go out into a park and I would sit
> there with a case of beer and a rope and I would look at the
> trees and I would think, "Okay I'll just drink this case of
> beer and then I will just kill myself. And I will make it
> quicker." But then, after awhile, I got over that and I
> decided you know I want to live. I don't want to die.

Below, P2 describes her future desires, following the cessation of her drug use, as she aims to empower other women with similar addiction problems. She wanted to focus on drug and alcohol addiction. Like P1, she did not mention IPV or sex trade as issues to be addressed. This may suggest that the women in this study saw addiction to drugs and alcohol as an underlying problem that exposed them to other challenging issues such as

IPV, HIV, and sex trade. As a result, they might have seen the need to address addiction

first in order to be ready to deal with the rest when they are in a sober state of mind.

> P2: I hope, I hope to work with ah I want to get my
> Addictions Certificate and be an addictions counsellor and
> work with other women that have had problems, not, not
> necessarily in HIV, but with drug addiction, alcoholism
> [etc.], I want to help people.

The women's insights gave them a sense of needing to take care of themselves,

first by working towards getting clean from addiction. They used multiple and different

approaches towards achieving their goals, including: accepting the situation and moving

forward, getting into a rehabilitation centre, praying, working closely with care providers,

and working with a spiritual leader. P2 had this to say:

> P2: Well I, I think I've come through it more accept,
> acceptance around it like it's not going to go away. I'm
> gonna deal with [ahha] you know I can't run from it like
> this is my problem.

Self awareness

Living with HIV created a sense of self-awareness in these women. They also

developed the desire to care for themselves. This reaction is supported by the literature.

Barroso & Sandelowski (2004) found that HIV diagnosis in women who abused drugs

was perceived as a lifesaving experience, acting as a catalyst to free them from the

destruction of drugs and alcohol.

P1was inspired to rediscover herself and wanted to know more about her culture

and heritage. In the statement below, P1 describes how HIV diagnosis made her want to

live and discover her roots, and gave her the strength to find her voice.

> P1: Well, it made me want to live and it also made me
> discover my, my heritage, my roots, my spirituality, made

> that stronger. I finally, finally found my voice, found
> myself after that. So it wasn't just wanting to live, it was I
> actually figured out who I really was and why I belonged
> there. What my purpose in life is...

It was interesting that this woman would express this desire, even when she was no longer willing to access care for either HIV or abuse.

What the women said suggests that an HIV diagnosis made them realize that there is quality life beyond being diagnosed, and maybe living with HIV is more tolerable and manageable than dealing with drug addiction. This creates a question of whether the decision is influenced by the stigma related to these different issues or the care and life-long effects of either.

Physical distress and lifelong treatment

The women considered HIV to be a burden because it came with physical ailments such as depression, neuropathy, and chronic fatigue. Some emotional consequences included struggling with relationships and dealing with the judgment from significant others who used the women's HIV status to humiliate them.

Like other people living with HIV and those using street drugs, the women had both experienced changes in their health status, including additional infections (co-infections). P2 identified the physical distress as neuropathy in her legs that makes her feel weak and tired; she described the tiredness as "chronic fatigue". P1 had Hepatitis C as a co-infection.

Need to protect others

Following their HIV diagnosis, the women did not express any signs of anger, which is a common reaction found in the literature (Stevens & Hildebrandt, 2004), but

rather took it positively and wanted to move on. This could have been one underlying

factor that influenced their desire to protect others.

The women faced challenges with their clients from the sex trade, specifically

their unwillingness to use condoms as a way of protection. They stated that most of their

partners did not care about the women's HIV status. They disclosed their status to their

partners but this did not change their reluctance to use condoms. Below, P2 describes

how her client did not care whether he contracted the disease, while she worried about

him and his children.

> P2: And he didn't care if he caught it, but I cared because
> he had children. I didn't want him getting sick.

This suggests a very important area for health promotion pertaining to HIV

prevention strategies and mode of education and evaluation. Given the age of the disease

(28 years now) and considering the amount of information available about it and how the

infection is transmitted, one would expect that there would be a change in behaviour for

the sake of self-protection. That many of their partners were still reluctant to use

condoms despite knowing the women's HIV status challenges the common notion of

associating the level of knowledge and with behaviour choice. Other authors have related

the reluctance by male partners to use condoms as a protection against HIV to a level of

knowledge regarding HIV transmission and prevention, personal sense of vulnerability,

and inaccurate prevention information (Becker & Joseph, 1998).

Although their partners were willing to practise unprotected sex despite knowing

that the women were HIV positive, both women said they insisted on protection because

they did not want their partners to get infected. However, it was difficult to determine

whether their motivation for insisting on protection during sex was rooted in empathy for their partners, not wanting them to become HIV positive, fear of refusal if partners became infected, or the legal requirements.

<u>Stigma and judgement</u>

The participants felt badly about being judged by the people they valued, such as their significant others. The fear of being ridiculed due to their HIV status made it hard to build relationships. However, accepting their own situation of living with HIV seemed to play a major role in surviving as they came up with future plans of empowering themselves and others through counselling and education.

In the quotes below, P2 describes her experiences regarding getting into intimate relationships, accepting HIV as a long-term condition, and her desire to get clean and empower other women.

> P2: Oh it's hard. Like there's a lot, I have lots of questions about like I have to be on medication for the rest of my life and eat properly and ah try to get into a relationship with a man is hard because you have to try, to tell them and worry about the fear of being judged. You are being judged by everybody that matters right.

> P2: Well I, I think I've come through it more (to) accept, acceptance around it like it's not going to go away. I'm gonna deal with [ahha] you know I can't run from it, like this is my problem.

> P2: I hope, I hope to work with ah I want to get my Addictions Certificate and be an addictions counsellor and work with other women that have had problems, not, not necessarily in HIV, but with drug addiction and alcoholism, I want to help people...

This woman expresses the fear she experiences when faced with intimate relationships. The fear is rooted in the judgement from her partners because of being HIV

positive. It seemed to make a huge impact as she refers to those who judge her as "everybody that matters." The impact may not have created such fear of intimate relationships if she had not experienced judgement from significant others. She demonstrated the need for personal acceptance of living with HIV and moving forward to empower other women with similar addiction problems. It has been identified by other authors that self acceptance of HIV leads to quality of life through changing an individual's lifestyle to a better position. They refer to this as positive state of mind (Clement & Tharyan, 2004).

Surviving IPV

In this section I address the women's experiences of IPV, without intersection with HIV/AIDS. It was difficult to focus on one issue, either HIV/AIDS or IPV, without interference of the other; however, taking this approach prevented me from overlooking any of the issues. In regards to IPV, I discuss the different approaches in which participants and care providers engaged to deal with IPV.

<u>Care providers not addressing IPV</u>

In the women's experiences, care providers (nurses, doctors, and social workers) who interacted with them during their visits for health services, like HIV/AIDS care, did not address IPV or follow-up on it if the women themselves raised it. As a result, the women felt that IPV was not important. They also described the care providers as being cold and too clinical. This came when the women were asked to respond to this question "How is the help you received or are still receiving regarding HIV and abuse (IPV) affecting your wellbeing?"

P1: ... You can't be cold and clinical. You can't be impersonal and just pull somebody in a social worker; Okay, so how are you feeling today? Anybody that says that to me I tell them you know what? Kick your ass and go back out that door until you can come in and say hi! How are you? How's your day today? So ah what can I help you with? You know rather than somebody saying who, how are you feeling today? Are you suicidal? Do I need to phone the ambulance on you?

P2: There's not enough help for women. Some way to help, to help us women break out of the cycle with the right kind of support and the right kind of people you know who can lift you up and say yeah you can do it, you can do it you know and then hook you up with the right services and set you up for you to be able to get your own place and the right people, right, whatever you need. There are not too many people that really, really help.

The reaction by P1 about how care providers treated her and her feelings towards that kind of behaviour suggests anger and desperation resulting from the inappropriate approach by care providers and their lack of recognizing the needs of women when they come for help. It is also suggestive that care providers did not have the skill and interest to assist women surviving IPV. Their approach to care did not seem to agree with P1's expectations. She stated the need for a multi-sectoral approach with a well-defined referral system for women to get better service.

P2 reported a lack of follow-up by care providers. When asked whether care providers made referrals for follow-up services when she presented IPV to them, she said, "Nobody said anything." She went on to say that all care providers would do was to feel pity for her and advise her to leave the relationship: "They just kind of oh that's not good. You should get out if it."

The failure on the part of care providers to follow-up on the abuse issues of the women could have contributed to the women's lack of knowledge of available services regarding IPV and not knowing where to go when experiencing abuse. P2 stated that maybe she could call the police.

> P2: Ah well I guess I could go to the police if it was that,
> that bad but ah or something that's important...

Saying that she could only call police "if it was that bad" suggests some degree of acceptance of abuse in the community that may be dependent on the degree of damage caused to the other person and the relationship between the perpetrator and the victim.

When asked what actions others could take to access information or services for IPV, the women suggested that people should search the Internet for more information and help because they were not aware of local resources that address abuse. "I think that if they're being abused they can probably try the Internet" (P2). However, they had not done so themselves. The statement by P2, particularly the reference "if they are being abused", implies that she does not consider IPV to be a problem for her. This could have a negative implication for her accessing help as she might not be identifying with IPV, and suggests a barrier to care.

Other than the spiritual support that the women received from their spiritual leaders, they suggested the need for care provider support, as P1 said, "Like good doctor support, mental support and maybe spiritual you know." This implies a lack of professional support for these women. The women received no information about available services for IPV and were left to feel that IPV was unimportant.

In addition to not wanting to talk about abuse, the women did not seem to want to deal with it. P2 said, "Just don't really feel I want to deal with it." When asked why she did not want to address abuse, P1 said it is due to shame. The concept of shame raises other issues. It makes me wonder whether this "shame" is implied in care providers not wanting to talk to women about IPV. Also, what could be rooted in this shame that makes abuse so difficult to be addressed by both care providers and survivors of IPV, even more than other stigmatized issues such as HIV/AIDS, drug use, and sex trade? This reaction might come as a result of gender power inequality that is not so explicit in the other issues; the pity felt by care providers towards the women and not wanting to further embarrass or hurt them through evoking painful thoughts; care providers' lack of skill in dealing with such personal issues like IPV; or possibly care providers being affected by IPV at a personal level.

Support system

A support system is the social, spiritual, emotional, and psychological comfort that is offered to an individual by others in the community. It could come from someone close or anyone in the society. It should be something that boosts mood and sense of worth. The women in this study perceived this support as giving them hope and the desire to move on. There were some commonalities in how they personally accessed or recognized it. The spiritual aspect took the lead in the approaches. P1 went to seek advice and guidance from her traditional spiritual leader and P2 went to church for the same services as well as to pray and talk to other people. The approaches of both women had the same goal of spiritual healing and creating a sense of belonging.

> P2: Well I go to church and I pray a lot, you know, and I talk to other people.
>
> P1: ...I thought, well there's got to be somebody behind this, you know, making order out of this. So, so I, I prayed for, you know, my first real prayer. And I said, "Well, hey, if you are really there, you've got to give me a miracle and help me get out of this, get out of this hell."
>
> P1: …that prayer then I was given, ah, well, there was an elder working with me and she gave me a, a ceremony and then once I did that ceremony I got, I got a vision and, and I started talking at the schools and the university…that's made me live.

The spiritual support that both women talk about appears to occupy an important aspect of their lives. Going to church gave them a place to pray and share common ritual practices that meant a lot to them. It also provided the opportunity to talk to other people; people perhaps who are different from those that they commonly interacted with in drug use and the sex trade. From what they are saying, this contact boosted their self-worth and sense of belonging. It also reduced their sense of isolation and social exclusion.

Not having knowledge of where to go for assistance limited the women's chances for support from agencies that help women surviving IPV. From these agencies they might have received more information related to IPV, shelter, referrals for training, job search and other opportunities, counselling, and support groups.

Effects of HIV/AIDS and IPV

Having addressed surviving HIV/AIDS and surviving IPV separately, I return to addressing the interconnectedness of HIV/AIDS and IPV and how it impacts the lives of women. It brings together how surviving HIV/AIDS and IPV affected the women's

physical, emotional, and spiritual wellbeing, as well as affected their general coping

mechanisms.

<u>Feeling of worthlessness</u>

The participants' experiences of abuse led to a lack of self-worth and the inability

to care for themselves. They also felt that they could not maintain relationships nor take

care of anyone since they could not care for themselves. Besides psychosocial, spiritual,

and physical impacts, they also experienced medical conditions that further interfered

with their day-to-day activities. These included chronic fatigue, poor nutrition, and

depression.

P1 expressed her feeling of inadequacy in maintaining relationships and taking

care of herself because of poor physical and emotional condition:

> P1: …and because I'm not, I'm not in a healthy; I'm not in
> a healthy state. I'm really unhealthy. I'm not good for a
> relationship. I'm not even good for myself. Like…I'm
> having a hard time taking care of myself…I'm way down
> on the bottom…I now think that engaging in to drug use
> and sex work could be part of this self-abuse.

> P1: …myself this time. I gonna make sure I die cause if I
> don't take care of myself, the body, the body is gonna die.
> So the only thing I put in my mouth was alcohol and a pipe.
> Crack pipe. I didn't eat. Maybe ate one meal a week or
> maybe a bag of chips a week. I never drank water. Never
> drank juice…because I wanted to die.

To explain her inadequacy in maintaining relationships and taking care of herself,

P1 referred to being "unhealthy and at the bottom", which suggests a sign of

hopelessness. She further connected being unhealthy to not eating well and not taking

good care of herself, referring to it as self-abuse through drug use and sex work.

Abuse, according to the participants, brings down one's self worth. This is because one is broken, emotionally, physically, and spiritually. As a result one feels worthless, not even worthy of living.

> P1: …It happened when I was a kid. That's because you
> think you're worthless. They break you down after so long.
> They mentally abuse you; they emotionally abuse you; they
> spiritually abuse you, whatever. And, and, and after a while
> you believe you're just nothing but a piece of shit.

The perpetual abuse that started early in P1's life affected her sense of well-being, making her feel she was nothing good. This might have led to bitterness and self-hate predisposing her to self-abuse through drug use and sex work and also the cycle of abuse.

Lack of trust and social relationships

The women's experiences reduced their trust in others and their ability to form relationships. Lack of trust came as a result of other people using their HIV status against them, especially those they had trusted (i.e., partners and significant others).

> P2: …verbal abuse, tell me that I wasn't good for anything,
> you know, and he could find somebody better; without HIV
> you know; he'd call me like, ah, AIDS case. You're just an
> AIDS case and bad names like that, hurtful names.

> P1: …I haven't been exactly speaking my truth. I haven't
> been telling anybody anything. I don't talk to people
> anymore. I stopped talking to people for about three years
> now. I didn't trust anybody. I thought, certain people were
> after me and I was scared for my life.

P2 expressed experiencing verbal abuse from her intimate partner that included derogatory names. This experience might bring someone's self-esteem down leading to mistrust that interferes with disclosure.

P1, on the other hand, decided to distance herself from others as a means to avoid being hurt. She used her HIV status to keep people away, especially potential partners. She saw this as a way to protect herself from the potential of being hurt in relationships through verbal and physical abuse and being judged because of her HIV status.

> P1: I always get worried, you know. Most of the time I used, I used that HIV as a way to push them away so they don't get involved… I'll just say. "Well, just so you know, I'm HIV and Hep C positive and if you can't deal with that, then that's your problem."

The lack of trust experienced by P1 went beyond the individual and community to a mistrust of government.

> P1: It's never gonna happen. They're politicians. They're corrupt. If in an ideal situation they'd just give it all up and say, "Okay, well, I think we were wrong. I think we fucked you guys right up. I think we took a little bit too much from you and I think we have done so much wrong. I don't think we should just give it all back to you." But you know what? They're not going to relinquish anything, everything that they have worked hard for which they took from us. So by admitting that they even did wrong to us, you know, like the boarding schools and what not admitting that they purposely infected, you know blankets with smallpox way back when. They were committing genocide on our people like we weren't supposed to survive.

Abuse created a general sense of mistrust in this woman because she came to believe that everyone was taking advantage of her situation and experience.

Suppression of painful feelings

Sometime a general coping mechanism was to deny the effects of HIV/AIDS or IPV or both because of painful memories that come with it. The intention was to suppress these feelings.

> P1: I told you I was forced into that [sex]. I don't like
> talking about that. It gets me mad.

P1 made the above statement during her third interview when asked about the abuse part of her life, which she had said she did not want to talk about. She felt angry about many things, including her pain from the abuse that she experienced as a child, physically, spiritually, and sexually; the ill treatment by government in such things as group homes and boarding schools, and the perpetual injustice for the Aboriginal people; and the abuse she experienced in her relationships. This anger motivated her to write as an expression of her inner self, as she continued to say, "I felt hurt and angry at the same time..."

IPV destroyed the women's self-esteem; they felt worthless and not capable of doing any useful thing in society such as building relationships. This distress was compounded by their physical ailments including chronic fatigue, depression, and poor nutrition. The low self-esteem and the fear of abuse also expose the women to risky behaviours such as unprotected sex that predispose them to HIV.

Section Four: Reflections on Provision of Care & Future Prospects

Under this theme I describe the opinions of the women in relation to how they would perceive care provided to those with similar experiences of surviving both HIV/AIDS and IPV.

Ideal Care Models for Surviving both HIV/AIDS and IPV

When the women were asked what they thought would be the best approach to assisting other women who are in the same situation of surviving HIV/AIDS and IPV, P1 was very articulate in sharing her ideas. She recommended a comprehensive, non-

judgemental, holistic approach that focuses on the outcome rather than number of people

assisted.

> P1: Well, yes, it needs to be quality. It needs to take care of the whole, the whole picture. Not just one agency for housing, one agency for spiritual help, another agency for your [mental], yeah, mental health and, and, and, you know, a psychologist for your emotional. I mean, get people that are going and not even people that that, that, that have 20 plaques on their walls. Sometimes those people aren't worth crap because they don't know what the heck they're doing and they have the teachings from the books, but they don't have it. They don't have what it takes to help people, really.

> P1: Yeah, well you know, if, if you open up a house for prostitutes you don't have a traditional healer there you know, um, have that traditional healer working with them, massage therapist, you know, have a, a whatever it is, sweats or church or however that turns out to be for the person that's in there.

P1 also perceived care providers as cold and clinical, not viewing clients as

humans with diverse needs and challenges. She thought them to be too detached from

their clients. She suggested that the choice of primary care should be up to the individuals

or clients, not imposed upon them by care providers. P1 also suggested that organizations

needed to address the issues presented by the clients, not cater to the expectations of the

donors. These agencies should also address the individual as a complete being rather than

dividing services, such as spiritual, mental, and physical. She further suggested that

education, support, and treatment should be included as part of care.

> P1: …maybe start up a program where, where it's not about statistics and funding or funding depending on how many, you know, statistics you have or, or what's going on as, as far as how many people are coming for help. How many people you have helped and what's the success rate of this so called project or this, this agency. …it's not about, you

> know, the quantity…that's all it is about right now is quantity,…they've all got to have their statistics and they all have somebody to answer to so there's a lot of bureaucratic red, red tape and bullshit.

The difficulties that P1 had encountered created in her a sense of disbelief that any change was possible despite the desire to seek solutions.

> P1: Well, there's nothing, there's nothing that anybody can really do about the way the agencies are and certainly nothing I can do and there's nothing I can suggest because everything is the way it is for a reason, I guess. And I just have to accept that for the way it is, right.

The ideal care model suggested by P1 was inclusive and non-judgmental. She described a sense of being forced into a stereotyped kind of care system that is not comprehensive in its approach and leaves clients with no choice.

Participants' Future Prospects

The women related their future to their past and how it influenced their present.

Empowering self and others

Both women had dreams of empowering other women and children concerning the issues of HIV and drug use.

> P1: Empower others especially young people and/or other women with similar challenges.
>
> P2: I hope, I hope to work with ah I want to get my Addictions Certificate and be an addictions counsellor and work with other women that have had problems, not, not necessarily in HIV, but with drug addiction, alcoholism [etc.], I want to help people.

How they would get to achieve this was another challenge that they needed to address first. However, their spiritual belief systems seemed to give them strength and hope.

<u>Strategies for empowerment</u>

The participants even had strategies they would like to employ in their journey as they helped themselves and others.

> P1: Finding my voice, well…. The minute I could face my life and, what was done to me and what I did to other people, and I could face the truth and then I could finally speak the truth once I was able to accept it.

> P2: I hope, I hope to work with ah I want to get my Addictions Certificate and be an addictions counsellor and work with other women that have had problems, not, not necessarily in HIV, but with drug addiction, alcoholism [etc.], I want to help people.

As a process towards successful recovery, the participants identified disclosure in the form of sharing their experiences with other women and youth to bring some kind of healing to them, as well as contributing to stopping the cycle of addiction and HIV. (They did not talk about abuse or the sex trade in this process.) Both women expressed the belief that someone like themselves who had been through HIV and IPV, addiction, and street life was in a good position to help other girls and women. However, they first needed to accept the truth about themselves, as P1 said, deal with their addiction, and get addiction certificates. Though the participants identified addiction as a barrier to recovery, I would think that unemployment and homelessness might also be obstacles.

Summary

In this chapter I presented the main themes and subthemes that emerged from the data. Talking to the women about their experiences as survivors of HIV/AIDS and IPV revealed other things that I did not anticipate as a researcher. These included the experiences the women went through as children, such as sexual abuse, physical,

emotional, and spiritual abuse, which contributed to their choices that led to street life, drug use, and exposure to HIV. The two women in this study had similar as well as different experiences, and how they reacted to them varied based on the root cause, its intensity, and cultural background or ethnicity. Thus, there are both similarities and differences in what they had to say. The women expressed some knowledge regarding HIV/AIDS but a lack of knowledge in regards to IPV. They expressed a need for change and a desire to use their experience to empower other women and youth. They identified approaches to care and care provider support as important issues.

CHAPTER 5: DISCUSSION OF RESULTS

Introduction

In this chapter I discuss the themes that emerged from the data as participants described their experiences in surviving both HIV/AIDS and IPV as presented in the results. Section one addresses the question: how do women describe their experience of surviving HIV/AIDS and IPV; and section two addresses the question: what is the effect of HIV/AIDS and IPV on their day-to-day lives. Section three offers reflections on ideal models of care and on the participants' own futures. Section four presents a visual representation of women's life experiences and how they are intertwined using the socio-ecological framework of Rimer and Glanz (2005). The final section is the conclusion and study strengths and limitations.

The results demonstrated the intertwined relationships of HIV/AIDS and IPV, considering personal, interpersonal, community, and environmental factors that impact this relationship as well as the value of culturally sensitive approaches to care as evidenced by one participant's willingness to work with her spiritual leader. This complexity is visible in the previous chapter, especially in the discussion of the two themes Surviving HIV/AIDS and Surviving IPV, where the difficulty in staying focused on one without referring to the other reveals the intertwined relationship.

The interviews with the two women who participated in this study shed light on how they perceived themselves as survivors of HIV and IPV in relation to their day-to-day living. They revealed their knowledge in regard to HIV/AIDS, IPV, and services pertinent to what they were going through, as well as their attitudes and beliefs. Their belief systems were shaped by their cultural and religious background, length of exposure

to HIV/AIDS and IPV, and other variables in their immediate environment. The intersection of HIV/AIDS and IPV and how it affects the day-to-day lives of women who experience both of these issues was revealed through the five themes that emerged from the data, the concepts of life experiences, and the literature.

Section One: Surviving HIV/AIDS and IPV

Under this theme I describe participants' reactions to their HIV diagnosis and IPV experience. I start with describing what it meant to survive HIV/AIDS followed by their description of surviving IPV.

Surviving HIV/AIDS

Based on my past experiences in HIV/AIDS work, I had anticipated encountering huge barriers in discussing HIV because of the perpetual stigma and the lack of trust of interviewers or researchers, but the opposite was true. The participants in this study were comfortable talking about HIV/AIDS. They easily identified with living with HIV, drug use, and involvement in the sex trade.

Their decision to live following their HIV diagnosis meant that the participants in this study had to start taking care of themselves (e.g., be clean from drugs), even putting themselves first, which was something they may never have done previously. These actions gave them hope for the future. This hope was not only for themselves but also extended to others who needed help. They wanted to teach other women and youth about the dangers of drug use as well as HIV prevention.

It is not uncommon for people who are newly diagnosed with HIV to react adversely to the diagnosis. According to Stevens and Hildebrandt (2004), most women react to their initial diagnosis of HIV or AIDS with denial, fear, anger, depression, and/or

suicide attempts. Such reactions interfere with many interventions geared towards assisting individuals living with HIV/AIDS in regard to management, self-care, disclosure, and prevention of further spread of the disease (UNAIDS, 2000). In the current study, the participants did not describe reactions of denial, anger, or suicidal thoughts as identified in the literature. Instead, their diagnosis inspired a desire to live and included good intentions for taking care of themselves and for the well-being of other women and children. However, one might look back and ask whether their reactions were influenced by their specific past experiences, lifestyles, spirituality, and personalities. Perhaps, their previous experiences, such as child abuse and drug use, were, in a way, more traumatic than either the HIV diagnosis or what consequences they knew would come as a result of being HIV positive.

Literature reveals childhood trauma affecting an individual's psychological, emotional, and social behaviours in adulthood. Some of these effects include depression, low self-esteem, sexual dysfunction, post-traumatic distress syndrome, and dissociation (Nemeroff, 2004; Roesler & McKenzie, 1994). In a study that explored the effects of childhood trauma on survivors of the Holocaust, Yehuda, Halligan, and Grossman (2001) associated childhood trauma to risk for victimization in adulthood, resulting in experiences like rape and other types of violence. This evidence resonates well with the experience of P1. Her childhood trauma resulted in depression and a desire to destroy her life. She knowingly exposed herself to the risks of HIV, through sharing needles with other intravenous drug users, as one of the means she used to try to commit suicide. However, following her HIV diagnosis, she immediately turned the idea of wanting to die around and made the decision to live. For her, the HIV diagnosis also brought the desire

to know more about her roots and heritage. She referred to her HIV diagnosis as a

"blessing from above." Barroso and Sandelowski (2004) report that an HIV diagnosis to

women who use drugs can turn out to be a "life saving" point in their lives (p.4).

According to the authors, the HIV diagnosis motivates the women not to abuse drugs and

to become better parents and social beings.

P1 felt HIV/AIDS brought more attention from care providers, but with little

consideration for the patient's personal values and needs. According to this participant,

care providers were more interested in the disease than the people themselves. Her view

is supported by the literature that little attention has been given to factors that impact risk

behaviours and the broader social context of HIV/AIDS as a social, political, economic,

and cultural issue (Goldstein & Manlowe, 1997; Krishnatray et al., 2006). Also in the

literature, it is evident that HIV brings more attention to and a brighter future for, some

people through increased access to health care treatment and other social services that,

without HIV, might otherwise be difficult to access (Rabkin, Remien, & Wilson, 1994).

HIV/AIDS as a burden of care is a concept that is addressed in the literature as

affecting caregivers, especially women and girls in developing countries (UNAIDS,

2005), leaving them with no one to care for them but themselves. The idea of burden of

care is also seen in the primary care approach, affecting general practitioners (specialized

and non specialized), mental health practitioners, nursing and social work practices, as

well as community agencies focusing on either HIV and AIDS, drug use (detoxification

centres), or abuse (women's shelters). Ronald et al. (1992) brought attention to how this

perceived burden impacts all areas of practice and supports the widely accepted

conclusion of an increase in care cost due to frequent hospital use (e.g., increased

numbers of admissions, and especially visits to emergency departments) and cost of treatment (UNAIDS, 2005).

Stigma associated with the disease is a major difficulty for people living with HIV/AIDS. It impacts life experiences and programs addressing HIV/AIDS (UNAIDS, 2000). Others have noted that stigma contributes to a reduced level of disclosure by women who are diagnosed with HIV/AIDS, as well as affecting their intimacy and protection practices and interfering with their accessibility to care services because of fear of being ridiculed, judged, and rejected (Moreno, 2007).

Stigma and fear of the consequences of disclosure could be significant in the continued spread of HIV. Very little is known about people who engage in unsafe sex practices and knowingly expose themselves to HIV, whereas there have been more studies about people who know they are positive and continue to engage in unsafe sex and knowingly expose others to HIV (Marks, Burris, & Peterman, 1999). Some do so out of anger and bitterness that comes with the diagnosis, but the fear of the consequences of disclosure (i.e., stigma) may be another reason for this irresponsible behaviour. According to Marks et al. (1999), some of those who test HIV positive change their sexual practices following their diagnosis, but more than 70% continue to engage in unprotected sex, exposing their sex partners to HIV. The authors further stated that some HIV positive adults do not reveal their HIV status to their sex partners. The level of disclosure is higher among HIV positive women than men. Another group of people who could be spreading the disease unknowingly are those who refuse to get tested. This refusal could result from a lack of knowledge of HIV, or because of a fear of what will follow after being diagnosed, denial or lack of access to confidential testing.

Perkins, Prestage, Sharp, and Lovejoy (1994), in their study, found that sex worker respondents reported reluctance by male clients to use condoms. Sex workers' responses to such reluctance varied according to their sexual orientation, age, and experience in sex work as well as whether they had received training. They refused service, talked about HIV/AIDS, or talked about the house rule. Sex worker education aimed at creating personal change, empowering the sex trade community for full ownership of their actions, and increasing options to exercise control over their health through healthy choices. The women in this current study never mentioned any kind of training, and their reaction to clients who were reluctant to use condoms included disclosing their HIV status, which showed a willingness to protect others.

The reluctance to use condoms by males leaves one to wonder whether such individuals already know their own HIV status but do not want to disclose it to the women, presume themselves to already be positive even without testing, or do not care about the risk for themselves. This is an area that other researchers could study to better understand this behaviour, and hence help in planning prevention strategies. Seen through a feminist lens, men's attitudes towards risky behaviours, such as unprotected sex, are attributed to gender inequality. Women's economic and social inferiority contribute to partners' controlling whether or not they will have unprotected sex and consequently making themselves vulnerable to HIV (Flood, 2003). Condoms decrease men's sexual pleasure by acting against their definition of "real" sex, and thereby interfere with their masculine identity (Flood, 2003). Neely-Smith (2003) has argued that men's resistance to condom use coupled with women's submissiveness means that women have minimal power in decision-making about sexual practices that could prevent HIV/AIDS.

For the participants in this current study, surviving HIV/AIDS brought different experiences at personal, interpersonal, and community levels. Their diagnosis with HIV brought a positive reaction to life, with the desire to empower themselves and other women. Moreover, these women faced challenges such as stigma and reluctance by their sex partners to use condoms, which exposed them again to HIV and other STIs.

Surviving IPV

The participants in this study were reluctant to talk about their childhood abuse, although P1 connected it to what she was experiencing as an adult. Its emotional impact influenced the decisions she made, such as drug use and sex trade. They easily identified with living with HIV, drug use, and involvement in the sex trade, but there was a sense of shame about being identified as a "victim" of violence and childhood sexual abuse. One might wonder why there is shame and stigma around violence, especially childhood violence, but not these other issues. This is what makes me think that the trauma of childhood abuse is part of what participants in this current study did not want to discuss in detail. However, literature suggests that sexual child abuse that was done a long time ago and by a significant other may not be remembered easily either because of embarrassment or forgetting (Williams, 1994). Irrespective of their experience, neither woman in this study knew where to go for help. They never took any initiative and kept everything to themselves, and as a result, blamed themselves. This self-blame led to self-neglect, self-abuse, and, in one case, wanting to die.

Here we see an unwillingness to identify as a "victim" of abuse from both women and one would wonder whether this is essential for sex workers or for surviving on the street. However, they may have felt shame and therefore did not want to talk about their

experiences or the memories of violence could have been too overwhelming. The women also stated that care providers were not addressing the abuse when they presented it to them. Does this compound the stigma, and hence shame, related to abuse, resulting in the women being even less willing to talk about it? This was my reaction as I empathized with what the women said. Depending on what the women experienced and to what extent, their abuse has impacted their day-to-day functioning in such areas as self-care and use of available resources in health care and support services. Self-abuse, in the form of self-imposed physical harm, alcohol and drug use, as well as going without food, was reported by these participants.

According to the women in this study, care providers did not talk about IPV and this made the women think that it was not important. The non-addressing of abuse also prevented women from gaining knowledge of available services. The literature suggests care providers do not know about the connectedness between the risk factors of abuse and consequences of HIV/AIDS and IPV (Tufts, Clements & Karlowicz, 2008). This lack of knowledge could be contributing to failure in addressing and managing the issue, implying a need for integrated learning so that all care providers at all levels are capable of identifying and managing the complexity of HIV/AIDS and IPV in the health and social structures.

Research in Canada and worldwide has identified IPV as a major health care issue (Romans, Forte, Cohen, Du Mont, & Hyman, 2007). However, there appears to be incongruence in education, practice, research, and policy. These are structures that need to be addressed simultaneously for better outcomes in addressing IPV if we are to empower service providers with knowledge and skill and design appropriate programs.

This in turn will support principles of population health and health promotion that aim at allowing the communities to take charge of themselves and as a result be part of programs and services that address their issues, which would improve the overall wellbeing of its citizens (Potter & Perry, 2008).

Relationship of HIV/AIDS and IPV

It is clear in the literature and from this study that there is relationship between childhood abuse and alcohol and drug use which eventually leads to cycles of abuse which significantly reduce a woman's self-image. According to Zierler (1991), childhood stressful situations, such as sexual abuse, expose a woman to cycles of abuse in adulthood that predisposes her to HIV. The participants in this study felt they were no longer good enough for anything, be it caring for themselves or creating relationships. Though they were involved in the sex trade, they never considered themselves adequate for any intimate relationship. They said they were not capable of any relationship because they were unable to take care of themselves.

There is a common belief that women who have been sexually abused as children or young adults develop a feeling of dislike towards themselves that is equal to hatred and which can develop into self-abuse. Childhood sexual abuse is strongly related to a lifetime history of IPV and high-risk behaviours such as drug use and exchanging sex for drugs, money, or shelter. Frequent changes of casual sex partners, drug use, and involvement in the sex trade are more common among people who have been abused than people who have never been abused (Cohen et al., 2000). Such high-risk behaviours would expose women to further IPV and HIV and other STIs (Dube et al., 2003; Zierler

et al., 1991). P1 described her life in a way that was consistent with this pattern of self-hatred and the desire to harm oneself following childhood abuse.

Furthermore, Wolf (2005) reported that young girls who have been sexually abused are not able to relate to their immediate environment, including peers and adults. Interference with an individual's ability to build relationships as a result of abuse is also evident in this study where the participants considered themselves incapable of having an intimate relationship or trusting anyone, which may have contributed to their involvement in the sex trade. The participants attributed this to being unwell physically and emotionally, hence not being able to take care of themselves or anyone else. Considering this body of knowledge, one might want to probe further into the internal feelings of abuse as a child. This proved difficult in this study, however, as the women were reluctant to talk about childhood abuse; P1 said it was because of the pain that comes with it.

Some studies attribute repeated physical and sexual trauma, such as the abuse that these participants endured, as well as other social factors, such as ethnicity compounded by discrimination and marginalization, to increased chances of assuming the risky behaviours that predispose individuals to HIV (Wyatt et al., 2002). Also, women who are involved in the sex trade turn to excessive alcohol use or illegal drug use as a way of numbing themselves when they face their customers, who are mainly males, as well as decreasing the internal pain that they experience (Wechsber, Parry, & Jewkes, 2008; Burke, Thieman, Gielen, O'Campo, & McDonnell, 2005). This use of drugs, however, adds to the cycle of abuse and risk behaviours that expose them to HIV and other STIs, as

women under the influence of drugs may not be in a position to negotiate safe sex or to resist others' violent actions.

Self-blame was one of the mechanisms used by the women in this study to cope with both HIV and IPV. This is supported by Little and Kantor (2002) who stated that battered women suffer from low self-esteem, and as a result, feel bad, guilty, inadequate, and worthless (p.138). Furthermore, Clement and Schonnesson (1998) attributed the feeling of guilt and sense of worthlessness to societal expectations of personal responsibility regarding one's protection against HIV and other STIs as well as the ability to stay or leave an abusive relationship.

Effects of HIV/AIDS and IPV

Based on experiences in interactions with the people around her and within the health and social structures, P1 developed mistrust of caregivers. This resulted in under utilization of health care services. Researchers have reported mistrust of health care services by minorities being rooted in their cultural diversity, expectations for care, as well as past experiences. Some care providers are said to be judgmental, disregarding individual personal respect and quality of life (Neely-Smith, 2003). This would include discrimination and unfair treatment of racial and ethnic minorities who receive lower quality health care as a consequence of historic and existing inequalities experienced at various levels of care.

Literature reveals trust as being a foundation for use of care services. A study by Battaglia, Finlay, and Liebschutz (2003) brought forward some areas considered relevant for care providers in building trust with their clients, including: (1) persistent interest in their well-being; (2) engagement at a personal level rather than abstractly, which suggests

insensitivity and lack of understanding – referred to by the women in this study as "being cold and too clinical"; (3) commonalities such as ethnicity or life experience; (4)characteristics of respect and confidentiality and being non-judgmental; and (5) confidence in what s/he is doing at a personal and professional level. Literature also reveals trust as being essential to disclosure by survivors of IPV. Considering what Battaglia et al. (2003) say in regard to trust and disclosure, the level of trust between the participants and the researcher in this study could have impacted the degree of disclosure and determined what they felt comfortable in sharing with me, particularly regarding their experiences of abuse.

Literature also revealed that patients would rate a higher quality of care and satisfaction if they were assisted by those who were of the same race or ethnicity (Smedley, Stith, & Nelson, 2003; Sohler, Fitzpatrick, Lindsay, Anastos, & Cunningham, 2007). Congruent with what Piette, Heisler, Krein, and Kerr (2005) and Schneider, Kaplan, Greenfield, Li, and Wilson (2005) have said about mistrust of care providers, this study also found mistrust associated with underutilized care services, lower satisfaction, and poor adherence to education and treatment recommendations. The participants in this study mentioned mistrust in care providers, dissatisfaction with the care attention they received (no attention to abuse issues; treatment of HIV, the disease, but not being recognized as a whole person). This impacted their wellbeing, resulted in their not accessing services, and contributed to their lack of education about their health issues, especially in regards to IPV.

Considering the identification of mistrust of health care services by a minority population as a common barrier to accessing services in society, culturally appropriate

programs that involve the diverse population of Canada and Calgary need to be the focus in health care. Other studies also recommend inclusion of diverse populations in the caring professions as well as strategies geared towards building good client-care provider relationships (Sohler et al., 2007).

Section Two: Reflections on Provision of Care & Future Prospects

The results lend themselves to strategies recommended by the Ottawa Charter (Potter & Perry, 2008) a foundation of public and population health promotion.

Ideal Care Models for Surviving both HIV/AIDS and IPV

The ideal care approach as suggested by participants requires a reorientation of health services as recommended by the Ottawa Charter. The participants in this study revealed high levels of dissatisfaction with the current approaches used in care services. Rooted in this dissatisfaction was the insensitivity of care providers who were only interested in the disease (HIV) and not women as human beings. One participant echoed feelings similar to participants in the Battaglia et al. (2003) study who preferred to work with care providers who were engaged at a personal level and also showed characteristics of respect, confidentiality, and non-judgmental response. This concern, accompanied by expectations of getting care at both personal and physical levels, suggests a need for a comprehensive, inclusive, and collaborative care model as proposed by the women in this study. This proposed model would consider clients to be humans with diverse needs and challenges. The Client-Centred Approach (Stewart et al., 2000) meets these suggested criteria.

Inclusive models aimed at abolishing racial and ethnic inequalities are geared towards eliminating health disparities (Griffith, Moy, Reischl, & Dayton, 2006).

Disparities across racial and ethnic groups were observed where African Americans received lower quality care with no access to basic care needs, such as health insurance or a regular physician, as compared to Caucasian Americans. Inclusive models are consistent with the socio-ecological model described by Rimer and Glanz (2005); such a model would embrace women's challenges and consider social, environmental, and behavioural aspects of wellbeing when designing services. Reducing inequalities requires strengthening community action and creating a supportive environment for people living with HIV/AIDS and/or IPV. This will involve creation of healthy public policies or enactment of regulations, such as those affecting Human Rights.

Stewart and colleagues (2000) found out that patient-centred communication brought positive perceptions to care as well as better recovery from their concerns, better emotional health, and fewer diagnostic tests and referrals. Overall, this approach was associated with improved health status and increased efficacy of care. A similar model was described by one of the participants in this study. She wanted a model that would embrace clients as human beings rather than focusing on the diagnosis or disease.

These participants need empathetic, supportive, and structured services that provide a stable home environment with external supports and resources, and good role models who are not discriminatory, condemning, or judgmental. They need to be assisted and motivated step-by-step throughout the process until they are mentally and socially stable. This approach has been described by Hall, Baldwin, and Prendergast (2001) as "vocational assistance" (p.232). Continuous support will help in rebuilding the women's self-esteem, and thereby improve their ability to deal with the traumas they experienced and enable them to face the future. It is up to the community, including policy makers, to

come up with improved, appropriate programs that can assist this increasing vulnerable population with the help it needs to have greater well-being and a better quality of life.

Participants' Future Prospects

Following their diagnosis of HIV, the decision of the study participants to want to live and change for the better brought a sense of a brighter future. As a result, these participants began to develop a sense of self-worth that was a drastic change for them. Getting the chance to stay clean and move forward was the driving force to a better future. Their desire to stay clean from drugs also brought a sense of direction, demonstrated by how they willingly signed up for detoxification and counselling programs. They verbalized their desire to quit using drugs and get clean and to empower other women and youth. With this desire, the women also demonstrated hope and faith in God the creator, which also gave them strength to move forward.

However, study participants had challenges that created obstacles to their progression to cleanliness from drugs. In particular, peer pressure caused them to relapse. They would go into the rehabilitation programs but when they stepped out, they went immediately back to the unfavourable environments that frequently exposed them to the same practices and people who were involved in the circle of drug use, the sex trade, and abuse – the things from which they wanted to move away. These challenges have also been identified by other authors. Laudet, Magura, Vogel and Knight (2000) stated that most clients in recovery programs struggle with the emotional and socio-economic issues as well as the ability to stay clean.
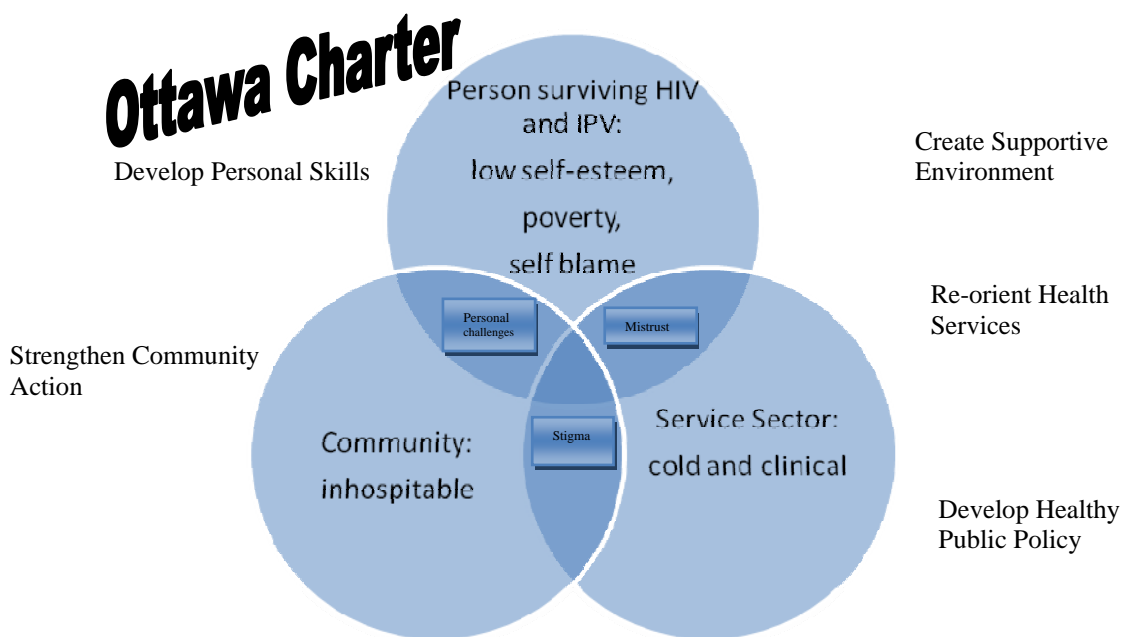
Section Three: Socio-ecological Model Outlining the Interconnectedness of HIV/AIDS and IPV

The intersection is a dynamic relationship among affected individuals, communities around them, and the availability of responsive and appropriate services. The six primary strategies of the Ottawa Charter were used to understand better the implications of the intersection between HIV/AIDS and IPV among women who survive both conditions.

The interconnected relationship between HIV/AIDS and IPV that was revealed in the data and in my mind as I was writing this chapter influenced me to come up with the pictorial socio-ecological framework, adapted from the model of Rimer and Glanz (2005), in Figure 2. As I have said, it was hard to focus on either HIV/AIDS or IPV and not have the other immediately come into the picture. This suggested the interconnectedness of these issues, and further persuaded me about the complexity of this relationship. This picture depicts what the participants experienced in relation to how they felt and how they were treated by others and the system.

Figure 2: Socio-ecological framework illustrating HIV and IPV survivors` day-to-day experiences with themselves, other people in the community, and the systems (government and non-government).

Ottawa Charter

Develop Personal Skills

Person surviving HIV and IPV:
low self-esteem,
poverty,
self blame

Create Supportive Environment

Re-orient Health Services

Strengthen Community Action

Personal challenges

Mistrust

Community:
inhospitable

Stigma

Service Sector:
cold and clinical

Develop Healthy Public Policy

The intersection of the two issues, HIV/AIDS and IPV, and the themes identified are linked to the strategies identified in the Ottawa Charter. This reinforces that multiple strategies are required to address the intersection of these complex issues. Moreover, the smaller intersection of all three circles stood out to me as a very critical area that needs immediate attention. This is an area that is hard to reach or penetrate or even to be understood by researchers, policy makers, and care providers. It represents the centre of personal experiences of women surviving HIV/AIDS and IPV, and suggests the multifaceted levels of the issues as it goes beyond health into other determinants of health. If better understood, this area will shed light on programs that will provide appropriate services to the women surviving both HIV and IPV. It calls for strengthening

community action through which women will be involved throughout planning and evaluation of the services provided to them. At the personal level, the participants in this study came from disrupted families and suffered traumatic life experiences, such as childhood abuse, and as a result, they experienced feelings of worthlessness and engaged in drug use and unprotected sex, exposing them to HIV. Drawing from the Ottawa Charter and building healthy public policies will enlighten care providers in diversifying approaches to service provision and health care. The women will then feel empowered, accepted and as a result they will be self-accepting. As a result of environmental factors, these participants were also susceptible to drug use and sex trade because of peer pressure and lack of opportunities. Peer pressure from those they most associated with, such as those using drugs and those involved in the sex trade, interfered with their efforts to change and stay clean from drugs. This inhospitable and unsupportive environment also led to the feelings of rejection, being judged, stigmatized, and ridiculed by the people around them. This led to the mistrust and an inability to build relationships. At the community level, the participants also experienced little support and lack of appreciation as human beings. They experienced further stigma, discrimination, and judgement, which compounded their mistrust and resulted in them not feeling they were part of the system. These participants could benefit from the developing personal skills that would help them deal with the day to day personal challenges; creating supportive environment by care providers will also add to skill acquisition hence feeling less stigmatized, increased self-esteem and the willingness to participate in community action. This however is viable through re-orienting health services by embracing the differences in the population served by the system. Acknowledging the cultural diversity is a key in this situation.

The socio-ecological model further assisted me in understanding the interrelationships of experiences of women surviving HIV/AIDS and IPV, such as childhood trauma and how it exposed them to further IPV, drug use, and the sex trade that exposed them to HIV and other STIs. Looking at this model represented in a Venn diagram, the smaller part of the diagram, that I may call the "flower", shows the interlinkages that this study contributes. This came out as a unique form of interrelationship of all the factors discussed above. Looking closer, there is nothing in the very middle. Why? I do not have an answer to that, however, I presume these are the complex issues which come as a result of all that the women went through as well as those factors that, as researchers, policy makers, educators, and care providers, we do not yet understand. This highlights the need for critical consideration to understand better these participants` experiences in order to guide the approaches used in designing most appropriate strategies through the principles of the Ottawa Charter. This framework helped me appreciate the causes and consequences of HIV and IPV and the implied approaches to intervention through the health promotion approach; but did not provide the understanding towards the women's ability to withdraw from drug use, sex trade, or IPV. This suggests that multidisciplinary collaboration is needed to address this core.

Study Strengths

The study methodology included a rigorous interviewing and follow-up process with the women that added to the rigour of the study. A regular process for contacting the women was established: phone calls to the service agency to leave messages for the women, messages given to them whenever they would go to the agency, the women calling me from the agency or other places where they had access to a phone such as the

Drop-In-Centre, and speaking to them on the phone to set up appointments to meet for

interviews. Based on what happened in between setting the appointment and the day of

the meeting, we would either meet as arranged and agreed upon or they would not show

up if they were not feeling well, in which case I would begin the contact process again. In

some cases when we met, the woman was too exhausted and I would postpone our

interview to another day.

The rich descriptions of challenges (physical, psychological, emotional, spiritual

and economic) faced by the women in this study will contribute to the knowledge about

barriers to service use as survivors of HIV/AIDS and IPV that are compounded by

homelessness, the sex trade, and drug use. It is important to understand these struggles

because they are recognized as a growing problem in Calgary. As care providers

appreciate the nature and severity of challenges faced by women surviving HIV/AIDS

and IPV, strategies can be developed to better serve this population.

The study provided an opportunity for the women to talk openly and freely about

their experiences. Our meetings were free from the expectations and restrictions that they

would normally face when they visited the care or social services, such as structured

questions care providers need to ask in order to provide their services. They saw me, the

researcher, as someone who was interested in them as human beings, not in the disease,

as one of the women said. This might have contributed to P1's willingness to continue

with the interviews and extend our interaction.

Study Limitations

I have identified three possible limitations to this study. First, like in many other

studies that depend on self-report, recall bias may be an issue as the women went back in

their past in speaking about their life experiences. Beyond relying on the women's memory and perspective of their experiences, the women could be selective about what they wanted to share and to what extent.

Second, several recruitment sites for the study were identified based on my social networks and those of my supervisor, specifically HIV/AIDS agencies and women's shelters in Calgary. The two women who participated in the study were recruited from the same place, and this resulted in them having several things in common. This could introduce bias, as other women surviving HIV/AIDS and IPV but with other life circumstances, such as stable homes, addresses, and incomes, were not represented.

Third, there may have been a limitation to data collection, caused by my background as a health care provider and also my ethnicity, which is different from that of the participants. These factors could have influenced the way I asked questions and the way I reacted to the women's responses. It could have contributed to the difficulty the women had in talking about the abuse they experienced in childhood; however, this could also have been related to my underestimation of the amount and extent of the violence they had experienced.

Conclusion

With evidence already available in the literature about the connectedness of HIV/AIDS and IPV, this study illustrates the significance of listening to the voices of those women who travel the road of experiencing both issues. HIV/AIDS and IPV are concerns that, separately, have been extensively studied, and as a result, programs have been put into place to address them. However, there is a complexity that lies in the personal experiences of those who are survivors of both issues.

This study sheds light on interrelationships of these two issues and how women experience them. The feeling of worthlessness, along with oppression and discrimination, leads to an overall sense of hopelessness with which comes defeat, and this poses a challenge to service providers and policy makers on deciding which intervention strategies to use. One of the participants represented those who feel desperate to share their experiences and at the same time feel neglected, unrecognized, and ignored by the system. As a result, her only coping strategy was to give up on everything, including herself. The effects of this behaviour were seen as self-neglect, self-abuse in the form of alcohol and drug abuse, involvement in the sex trade, and suicidal attempts. However, the internal human desire to survive persisted through all the negative feelings of hopelessness. In addition to self-determination, the environment plays a role in the ability to succeed.

Unlike their experiences of being neglected and ignored, these participants needed constructive support, respect, and understanding that would embrace their full participation in program development. The participants saw a brighter future before themselves that would also benefit others in the society. They planned to empower themselves and other women and youth in the community in relation to HIV/AIDS and drug use. However, there was another body of information that the women felt reluctant to discuss, that regarding IPV and childhood abuse. Recurring stigma[5] and discrimination accompanying HIV/AIDS and IPV was seen as impacting disclosure and causing underutilization of services. This implied screening for violence needs to be an integral

[5]Here stigma is used as a stereotype labelling because of the participants' experiences resulting in to shame.

part of care provided by professionals to women. Also, there is a need for the one-stop

shop care approach that promotes diversity and cultural safety.

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APPENDIX 1: LETTER OF ETHICS APPROVAL

FACULTY OF MEDICINE | UNIVERSITY OF CALGARY

OFFICE OF MEDICAL BIOETHICS
Room 93, Heritage Medical Research Bldg
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2007-10-01

Dr. Wilfreda E. Thurston
Community Health Sciences
University of Calgary
Calgary, Alberta

Dear Dr. Thurston:

RE: **Lived Experiences of Women Living with HIV/AIDS and Surviving Intimate Partner Violence**

Ethics ID: **E-21018**

Student: **Ms. Josephine N Mazonde**

The above-noted proposal including the Thesis Proposal (Approval of Proposal dated May 3, 2007), Consent Form (version 2.0). Project Proposal has been submitted for Board review and found to be ethically acceptable.

Please note that this approval is subject to the following conditions:
(1) appropriate procedures for consent for access to identified health information have been approved;
(2) a copy of the informed consent form must have been given to each research subject, if required for this study;
(3) a Progress Report must be submitted by **October 01, 2008**, containing the following information:
   i)   the number of subjects recruited;
   ii) a description of any protocol modification;
   iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
   iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
   v) a copy of the current informed consent form;
   vi) the expected date of termination of this project.
4) a Final Report must be submitted at the termination of the project.

Please note that you have been named as the principal collaborator on this study because students are not permitted to serve as principal investigators. Please accept the Board's best wishes for success in your research.
Yours sincerely,

Glenys Godlovitch, BA(Hons), LL.B, PhD
Chair, Conjoint Health Research Ethics Board

GG/emcg
c.c. Adult Research Committee   Dr. T. Noseworthy (information)   Research Services   Ms. Josephine
N Mazonde (Student)
Office of Information & Privacy Commissioner

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APPENDIX 2: LETTER OF CONSENT TO PARTICIPANTS

CONSENT FORM:

TITLE: Experiences of women living with HIV/AIDS and surviving intimate partner violence

SPONSOR: This study is not sponsored by any designated organization. However, the student is supported by a Canadian Commonwealth scholarship.

INVESTIGATORS:
   Researcher: Josephine N. Mazonde
   Research Supervisor: Dr W.E. Thurston
   Co-Researchers /Committee Members:
   Dr L. Meadows; Dr L. Radtke; Dr A. Robinson Vollman

Date: _____

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

This study explores the experiences of women who have or are still experiencing violence in their intimate partner relationships and also living with HIV/AIDS. The end product of this study may have applications to health services by informing care providers about lived experiences of women surviving IPV and also living with HIV/AIDS.

You are invited to participate because you have experienced both IPV and HIV, you can communicate in English, you are over 18 years of age, you are willing to talk about your experience, and you are freely willing to participate in this study.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to understand from your own stories, how it is to experience both HIV/AIDS and IPV and how that experience affects your day to day life.

WHAT WOULD I HAVE TO DO?

Your participation is voluntary, so you may choose not to participate without any effect on the services you receive from any shelter or service provider agency. Participation

involves 2 – 3 in-depth interview sessions lasting not more than 2 hours each. I am going to ask you questions about IPV and HIV/AIDS and so the outcome of this research depends on your willingness to talk about your experiences of living with both. In these interviews, you will be asked general questions about your experiences with intimate partner violence and HIV, their effect on your life and your journey in dealing with these experiences. All interviews will be tape recorded to make sure that your responses are recorded accurately without having to interrupt you as you talk.

You are volunteering to participate so you may stop at any time, and you are free to not answer any questions you don't want to answer. You may stop the interview at anytime, and/or reschedule it.

WHAT ARE THE RISKS?

There could be some emotional distress caused by the recalling of the past experiences. In this case you will decide whether to continue with the interview or discontinue.

ARE THERE ANY REPRODUCTIVE RISKS?

Since this study does not involve use of drugs or any form of chemicals, there are no reproductive risks involved.

WILL I BENEFIT IF I TAKE PART?

Finding space to talk about the experiences of surviving HIV/AIDS and IPV will in a way relieve you from tension that you might have been accumulating for some time. Also, the information from this study may provide better understanding of what women who survive both HIV/AIDS and IPV go through and may impact relevant policies and programs.

DO I HAVE TO PARTICIPATE?

Participation in this study is voluntary and you may withdraw from the study at any time without jeopardizing your personal status or health care. You may withdraw from this study by telling the researcher that you do not feel comfortable talking about HIV/AIDS and IPV. The researcher can also withdraw you from the study if she thinks you are not comfortable talking about the two conditions or being too emotional. However, counselling support will be in place for in case you need some assistance. You may discontinue the discussion any time you feel like you do not want to continue and you can also decide which questions to answer or not answer. If you withdraw from the study, you may decide whether to allow the researcher to use the data that she has already collected or not.

WHAT ELSE DOES MY PARTICIPATION INVOLVE?

Your participation involves frequent interaction with the researcher which can be at any place where you feel comfortable to talk. Such sites may include your home, agency that provides service to you, agency that has been identified by the researcher to provide space for the interview, or any other place where you feel comfortable.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You are not expected to pay anything and you will not be paid. An honorarium in the value of $50 will be given to you as a form of appreciation for your participation after every interview. The study will not cover any costs for travelling, meals or parking. The researcher will make it a point to see that you don't incur such expenses by choosing the most convenient place for you.

WILL MY RECORDS BE KEPT PRIVATE?

All of your information will be kept very confidential and your name will not appear anywhere in the final report. You will be assigned a code that will be placed in a computer file rather than your name. All interviews with codes will be transcribed and the files saved into a locked and password protected computer. In the transcriptions, any references to names will be removed so anyone reading them will not be able to identify you by any names mentioned. The tapes and any paper used for the interview will be securely locked in a cabinet that will only be accessed by the researcher. Service providers or my committee members will not have access to your specific responses. Once any identifying information has been removed, my supervisor will have access to the information.

Your identifying information will never appear on any final reports. Quotes might be used from your interviews in the final report, but again, anything that might allow others to identify you will be omitted or obscured.
If you like, arrangement can be made for you to get the summary of the study and invitations to community presentations and conferences. You will be asked about your preferred methods of obtaining this information.

IF I SUFFER A RESEARCH-RELATED INJURY, WILL I BE COMPENSATED?

There is no anticipated research related injury for this study. However, if in the event that you suffer injury as a result of participating in this research, no compensation will be provided to you by the University of Calgary, the Calgary Health Region or the Researchers. You still have all your legal rights. Nothing said in this consent form alters your right to seek damages.

SIGNATURES

Your signature on this form indicates that you 1) understand to your satisfaction the information regarding your participation in the research project and 2) agree to participate as a research subject.

In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Research Supervisor: Dr. W.E Thurston
(403) 220-6940

or

Researcher: Josephine N. Mazonde
(403) 210-2138

If you have any questions concerning your rights as a possible participant in this research, please contact Bonny Scherrer, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

Participant's Name	**Signature and Date**

Researcher's Name	**Signature and Date**

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference. The investigator has kept a copy of the consent form.

I would like a copy of the summary report _____Yes _____No

I would like to receive the summary report in the following way:

_____

NB: This Consent Form has been adapted with modification from "The Healing Journey" study with permission from Dr Radtke at University of Calgary.

APPENDIX 3: INTERVIEW GUIDE

First part (Part A) of this interview guide contains areas that would impact on women's lived experience of HIV/AIDS and IPV in a broadest sense. Probing for these socio-ecological areas and determinants of health will give more understanding of how they interact in a woman's life. The second part (Part B) will give women the opportunity to talk about their experiences as a whole.

Part A
- What is your –
  Age?
  Education?
  Religion?
  Employment status?
  Relationship to the perpetrator?
  Length of exposure to HIV/AIDS and IPV?
  Parenting situation? e.g. number and age of children; custody arrangement
  Household income?
    Has the household income changed or has it remained the same? What determined the change?
  Housing situation?
  Ethnocultural background?

Part B
- Tell me about living as HIV positive woman.
- How did you find out about your HIV status? (Probe: service/help).
- Tell me about your abuse experience (the probes will cover physical, emotional, economic, sexual, personal image etc.). (Probe: service/help).
- How did your experience for HIV and abuse affect your life as a woman, parent, partner, colleague etc.?
- How is the help you received or are still receiving regarding HIV and abuse affecting your wellbeing?
- Given an opportunity, what would you suggest as the best way to assist women who are HIV positive and also surviving violence?