

**EXPERIENCES OF WOMEN DIAGNOSED WITH HIV  
IN THE DOWNTOWN EASTSIDE**

**by**

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## **Abstract**

This paper examines experiences of five women diagnosed with HIV in the Downtown Eastside. Women living with HIV in this community experience multiple intersecting oppressions based on gender, class and ethnicity as well as stigma related to their HIV status and association with marginalized groups such as drug users and sex workers. Using narrative methodology this paper explores several areas relating to women diagnosed with HIV including themes of “life is over”, “stigma management”, “disconnecting from self and others”, “reconnecting with support systems” and “giving and sharing experiences”. The findings suggest that while women living with HIV in the Downtown Eastside face multiple barriers particularly when first diagnosed they are also able to engage with health and social supports and contribute to the lives of others and their community in a meaningful way.

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## **Chapter 1**

### **Introduction**

This study is about experiences of women diagnosed with HIV/AIDS, a subject I am interested in stemming from my career working with women in Vancouver's Downtown Eastside (DTES). In this community women experience and negotiate multiple intersecting oppressions every day. Using a narrative methodology this paper explores the progression of women's lives from the time they find out that they are HIV positive and the ways in which they adapt and manage their lives beyond this.

The use of narratives to gain understanding about women's lives can assist social workers in incorporating their experiences into the way we conduct our practice. For many years I have been involved with women in the DTES and have witnessed how women living with HIV cope and resist stigma and oppression. Having this connection to the community I have long held the view that an accurate representation of the lives of women is lacking. Women endure and overcome major health, social and political obstacles daily. There seems to be a focus in research and the media on women engaging in the sex trade or women who use drugs and alcohol without looking at the risks of blood borne viruses such as HIV or Hepatitis C and why women are at greater risk for contracting these.

The intersection of gender, addiction, historical abuse and class are often ignored when considering the ways in which HIV impacts a community. It is easier to blame women for the spread of HIV than to analyse the social inequalities contributing to such health outcomes. Unwarranted assumptions are frequently made about women living with HIV, and about why and how they contracted the virus. These assumptions include ongoing beliefs that women are solely accountable for their personal situations, including contracting HIV and other illnesses.

Women are also held responsible for the lives and choices of others, whether it be sexual partners, children or the community.

Gender disparities between men and women and accountability for the actions of men who perpetrate acts of violence and coercion against women and children are minimised or dismissed when considering the circumstances of HIV and transmission. Little attention is applied to the challenges of safe sex and transparency when engaging with others who use injection drugs.

Women are often given the role of designated caregivers to their children and expected to show greater responsibility. The same rules seem not to apply to men, their actions are not as readily questioned.

### **1.1 The Downtown Eastside**

The DTES has the distinction of being widely known as Canada's poorest postal code. A community existing on the margins of society, the DTES grapples with the impact of adverse poverty, high rates of substance misuse, homelessness and major health issues including Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS), Hepatitis C and mental illness. Representation of Aboriginal people in the DTES is disproportionate to the rest of the population. In this community "...status Indians are 9 per cent of the population" (Globe and Mail, 2009). The effects of both historical and ongoing trauma and violence are obvious and have a profound effect in the DTES where people experience daily stigma and discrimination.

The social issues of the DTES conveniently illustrate how "bad" life is for the people who live there. The community is used by film makers, artists and photographers to "tell the story" of the community from an outsiders point of view in" the dramatic and photogenic spectacle of social suffering in the neighbourhood" ( Culhane, 2004, p.594).

In contrast there are numerous examples of positive community development such as the growth of “peer” oriented programs and initiatives. Such programs encourage community members to share their expertise and contribute to the community in which they live and work. Peer programs encourage people such as drug users who have often been judged by society as worthless and useless to become active members and to “give back” as mentors and community ambassadors. Social enterprise abounds, from community gardens to fundraising sales of calendars and t-shirts. The community is filled with talent, determination and pride. A thriving art and music scene exists in the DTES and a strong representation of poverty and social activists live and work in the community.

### **1.2 Personal interest in the Downtown Eastside**

I have been working professionally with a cross section of individuals in the DTES neighbourhood for 13 years. Primarily I have worked as a case manager, counsellor and researcher with people living with HIV/AIDS, women engaging in survival sex work and with First Nations men and women. My interest in women, specifically women living with HIV, comes from observing the lives of those on the margins of society and witnessing the courage and resilience against frequent structural and social barriers. The lens of HIV/AIDS paints a picture of women as being the cause of the spread of HIV and unable to manage their personal lives. As a result women who are HIV positive frequently endure scrutiny and judgement of their abilities to parent their children and be trustworthy partners.

Rarely highlighted are strengths of women and their ability to transcend this negative portrayal. I have witnessed an abundance of compassion, wisdom and resilience by women in managing their lives in the face of poverty, addiction, trauma and HIV/AIDS. It was one of the

aims of this thesis to capture these strengths as women told their stories of coping with their HIV diagnosis.

Building trust with women in this community is vital and has a profound affect on the way women relate to me as a person, and a professional, and vice versa. It took many years to get to know women in the DTES, how they live and survive. In the early days within this community I felt I could not relate to the lives of the people around me. I volunteered at a drop in for survival sex workers, with women who were engaging in a risky lifestyle every night. It was suggested to me by a teacher that I might “dig deeper to look for the similarities”. While I will never say I understand what this life is like for the women, I certainly can relate to common factors of being women, mothers, daughters and sisters. I have reflected and realised that “walking a mile in their shoes” might be not be possible allowing those with real world knowledge of life on the streets to be the experts and authors of their own lives breaks down many barriers.

Recognising the intersection of oppressions is needed to understand the lives of women living with HIV in the DTES. It is vital to be transparent about my privilege as a woman who is white and who has never had to deal with racism in the way that Aboriginal women and women of color have. Additionally I am afforded opportunities such as post secondary education and regular employment which places me in a position of power and choice. I have the ability to afford rent and put food on my table.

The use of language is another way in which stigmatization can oppress. In this paper I will refer to the participants as “women living with HIV” rather than “HIV positive women” as the lives of the participants are complex and the women are more than just HIV positive.

Despite the troubling backdrop of life in the DTES women, such as those in this study, are known to be involved, aware and active in their community. Women are resilient and resourceful

with a survivor's spirit. The invaluable presence of women in the community is the reason why I wish to explore their experiences in adjusting to the diagnosis of having HIV. I have often felt that women are silent voices in the DTES, their voices are co-opted by those who have the ability to speak louder or about the things that others feel matter. The case of many missing women from the community, some of whom have been since discovered murdered is difficult to ignore when working with women in the DTES. Many of the women were Aboriginal and HIV positive. Using the voices of women living with HIV to talk about their experiences, this study is a close look at women's reactions to discovering an HIV diagnosis and how they incorporate this news into their interactions with community, family and support systems, health, history, goals and aspirations.

### **1.3 Outline of the study**

Following this first chapter of introduction Chapter 2 will provide a review of the literature. In the literature review will be a discussion of the separate concepts of inter-sectionality and stigma and a brief illustration of the way in which the two intertwine. There will be a piece about stigma as it pertains to HIV, an overview of the literature related to women living with HIV and a discussion about women living with HIV in the Downtown Eastside. Chapter 3 will describe the methodology used for this study including the narrative methodology used, sampling and recruitment methods employed. Chapter 4 presents results including parts of the narrative which illustrate the themes and patterns emerging from the conversations. Chapter 5 concludes with some final discussion about the implications of this research for social work and ways in which the results can be applied to working with women living with HIV. In summary the goal of this study was to further the understanding of the experience of women living in the DTES and coping with a diagnosis of HIV.

#### **1.4 Purpose of the study**

The purpose of the study is to provide some understanding of the process of adjustment that women with HIV go through when learning of an HIV diagnosis. Gaining understanding of this issue is important for social work practice for several reasons. Acquiring a broader picture of the lives of women who are often stigmatized, and who may not always feel comfortable about sharing their personal information, social workers can adapt their practice to be more inclusive and use appropriate methods for building trust with women. This in turn can reduce stigma and shame for women who live with HIV and open up access to services such as health care and social supports.

There is also a need for research for women from the DTES community who live with HIV. There is some specific research pertaining to women in this community who engage in sex work and drug use. While the women in this study engage in these two activities, enhancing the understanding of other issues women living with HIV experience provides a fuller picture of the complexity of women's lives. There is a paucity of research in regards to women living with HIV and this thesis is designed to provide further exploration of this topic. The majority of the research of women in the DTES is undertaken by epidemiologists, public health professionals especially nurses and anthropologists. There is very little research by social workers. There is a considerable amount of community based research particularly by sex work advocates and drug using networks. The primary interests of both is to create harm reduction services and to increase funding for these groups. Research from these groups may include men and women and while HIV and other health issues may be of concern they are not the primary focus of such research.

It is important to study the lives of women with HIV for a number of reasons. Understanding the barriers women face and the process of coping with a diagnosis are HIV provides avenues for

program development and allows for social workers to adapt their practice to meet women's needs. Women who are involved in research about their lives are made to feel that their needs and their experience valued. Many of the women in this research came from homes where addiction and trauma was prevalent. Research can also provide much needed information to develop strategies to assist in keeping families together and supported. Early intervention with children and families may also aid in cutting costs and burdens on social welfare systems. Research among stigmatized groups can provide education to those who may not have contact or understand the issues impacting marginalized citizens and who may perpetuate stigma through lack of education.

This research is very specific and quite narrow in scope. I am studying women with HIV as a common factor in their lives. Participants have been recruited from a very specific geographic area. Most of the women in this research are Aboriginal but the focus is on their coping process with the diagnosis, and therefore issues of oppression of racism and colonisation, while mentioned in relation to concepts such as inter-sectionality, will not be discussed in depth.

Research is a valuable tool in gaining a greater picture of women's lives and understanding the barriers women face. It also allows social workers to expand their practice especially in a community where professional and trained social workers are scarce.

## Chapter 2

### Literature Review

In this review of the literature I will present a brief overview of the concept of inter-sectionality as well as a discussion about stigma. I will discuss briefly these two concepts, inter-sectionality and stigma as they interrelate. Presented will be a discussion about stigma as it applies to women living with HIV. Expanding on this literature there will be a discussion about women living with HIV/AIDS and further discussion about women living with HIV/AIDS in the DTES.

#### **2.1 Inter-sectionality: A conceptual framework**

Inter-sectionality is a concept which “focuses on the very specific way that gender intersects with a number of other dimensions in the lives of women” (Johnson, 2002, p.7 ). Having early beginnings in the feminist movement of the 1960’s, inter-sectionality is a term coined by Kimberlee Williams Crenshaw, a scholar from the USA who theorized about the experiences of Black women living in poverty accessing shelters. Feminists continue to refine the definition of the concept of inter-sectionality (see hooks 1981, Lorde, 1984, Davis 1981, 1989). “Inter-sectionality allows a focus on the multiple lines of power and exclusion that circulate in everyday life; class, race, sexuality, gender etc. and importantly how these intersect through the multiple representations they invoke to shape people’s identities and experiences of everyday living. (Campbell & Gibbs, 2009 p.3)

In relation to women in the DTES the intersections of marginalization and oppression are many. Poverty, ethnicity and gender cross over to meet women who live with HIV as well as diminished mental, physical and social issues. Clearly there are numerous structural factors that place some women at a social and economic disadvantage. “At the simplest level, race, gender,

and class are implicated together because the fact of being a woman of color correlates strongly with poverty” (Kimberlee Williams Crenshaw cited in Fineman & Mytitiuk, 1994).

Social workers are urged to consider these intersections when working with women and to maintain thoughtful analysis of this concept in our practice. It is important that privileged social workers, often white, in positions of power and dominance pay attention to our own locations. As Bishop (1994) reminds us “[Y]our ignorance is part of the oppression” ( p.100). Closely aligned with the concept of stigma, the intersections of oppression women encounter are exacerbated by the perpetuation of stigma in their lives.

## **2.2 Stigma**

Research on the concept of stigma has a lengthy history, constantly being refined and developed in order to adapt as society changes. Crocker and Major (1989) suggest “[F]or more than three decades, social psychological research on prejudice, stereotyping, and discrimination has examined both the content of stereotypes about a variety of social groups and the effects of these stereotypes on behaviour toward members of those groups”. (p.608). Theoretically complex, the number of different stigma’s and the relationship between stigmatizer and stigmatized is every changing and always under review. As Link and Phelan (2001) explain “...the stigma concept has been applied to an enormous array of circumstances. Each one of these is unique, and each one is likely to lead investigators to conceptualize stigma in a somewhat different way” (p.365).

In 1963 sociologist Erving Goffman wrote a series of seminal essays highlighting the theories of deviance and “spoiled identity”. According to Erving Goffman (1963) it was the Greeks who “originated the term *stigma* to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier” ( p.4). Prior to this the term “deviance”

was defined in 1895 by sociologist Emile Durkheim, representing moral shortcomings or weakness of those not conforming to the mainstream. Link and Phelan (2001) and Parker and Aggleton (2003) suggest that since Goffman's work, present-day research of stigma has changed, leading to "elaborations" and "conceptual refinements". Nowadays "stigma is viewed as being more dynamic and socially fluid, as opposed to the often stationary, objectified definition it is sometimes given" (Parker & Aggleton, 2003). For purposes of this study I refer to stigma as "...elements of labelling, stereotyping, separation, status loss and discrimination occur together in a power situation that allows them" (Link & Phelan, 2001, p.376).

Stigma keeps those who experience its effects isolated and removed from certain segments of society. People who are stigmatized take on the label assigned to them and often find it difficult to overcome feelings of low self worth. Connection with like minded others or allies can reduce the feelings associated with stigma, however stigma is subjective and therefore how an individual resists and copes varies widely dependent on the person.

### **2.3 Inter-sectional stigma**

As previously mentioned inter-sectionality and stigma are closely aligned. It might be argued that inter-sectionality does not occur without the existence of stigma. Women who experience multiple oppressions are socially marginalized in a way that they belong to several groups who are disadvantaged and discriminated against. For instance Campbell and Gibbs explain "[I]nter-sectionality provides a framework for understanding how layers of stigma can be transcribed from the social to the individual realm through the production of intersecting social identities". (cited in Boesten and Poku, 2009, p.5)

According to Berger (2004) "intersectional stigma represents the total synchronistic influence of various forms of oppression, which combine and overlap to form a distinct

*positionality*” ( p .4). Adding to these considerations is the daily survival for women such as those in the DTES where “[I]n terms of HIV risk, an intersectional approach posits that these complex systems of oppression (race, gender and mental illness) that lead to stigmatization and discrimination interrelate in specific ways that also affect women’s power in the sexual realm” (Collins, Elkington, von Unger, Sweetland, Wright and Zybert ( 2008), p .5).

Women are constantly required to weigh up how to access to means of daily living versus the risks associated with a woman who is HIV positive. These considerations are provided as evidence in the themes arising from this research, needless to say women on the margins have no choice but to maintain constant attention to the workings of their day to day lives when it comes to the intersections of oppression and stigma.

## **2.4 Stigma and HIV/AIDS**

The role of stigma in the lives of all people living with HIV/AIDS is well documented in the literature. It has been stated that “stigma is more than simply discomfort or insult- it actually harms our health. It erodes our self-esteem, weakens our communities, and contributes to additional HIV infections” (Anderson, 2005, p.9). A complex, personal experience, stigma related to HIV can only be understood completely by the people whose lives are directly affected. Women living with HIV often experience “intersecting stigma’s” based on race and ethnicity and for being poor, drug users and sex worker. As Campbell and Gibbs point out “People living with HIV/AIDS can be thought of as living with multiple forms of stigma, rather than one, that serve to marginalise them in different ways. ( cited in Boesten and Poku, 2009, p.4)

The assumption that those living with HIV/AIDS became infected through some moral or offensive behaviour is central to the concept of HIV stigma. The “how” one became infected is

always at the forefront. Robert Klitzman, M.D (1997) found that “previous experiences and guilt over past behaviours exacerbate discrimination; and individuals vary as to which sources of stigma are “the worst” (p 52-53). Jarman, Walsh and De Lacey (2005) state “concerns about transmission risk led to a predominant research focus on women’s identities as ‘partners of heterosexual men or as mothers; victims or sources of infection rather than women living with AIDS/HIV” ( p 533-534).

Lee, Kochmen and Sikkema (2002) point out that “stigmatized individuals are also vulnerable to feelings of self hatred “and this in turn “is likely to negatively affect their mental health and their ability to manage their HIV disease” (p.310). Fife and Wright (2000) suggest that “the specific nature of the stigma associated with a serious illness may be dependent on whether and individual can be blamed or held accountable for its occurrence” (p.51). HIV positive people are often left believing that the perpetuation of HIV is their fault. For women “assumptions and the minority social position of most women resulted in views of these women as blameworthy ( Sandelowski, Lambe & Barrosso, 2004, p.125). Not surprisingly those living with HIV are often “less willing to put a face on the disease for the public” (Anderson, 2005, p.10). The picture of stigma is often presented by those who study stigma is one that is and “uninformed by lived experience” ( Kleinman et. al 1995, Schneider 1988 ; cited in Link and Phelan, 2001)

HIV related stigma impacts relationships with health care professionals, friends and family. Chesney and Smith ( 1999) state that stigma “deters many HIV-positive people from seeking medical care and from disclosing their sero-status to others because doing so can lead to rejection, discrimination, hostility and physical violence (cited in Lee, Kochman & Sikkema, 2002). This type of stigma and reluctance also prevents people from seeking HIV testing for a variety of reasons, stigma, fear and denial of risk factors.

## **2.5 Women living with HIV/AIDS**

There is a great deal of misinformation and misunderstanding of women's experiences when it comes to sexual behaviour. There are often assumptions by health care providers that some women may not be at risk for HIV and are therefore not tested. Lawless, Kippax & Crawford (1996) point out that "many women's accounts indicate that doctors make assumptions that HIV status is determined by membership of a 'risk group' ( p.1373). On the other hand those women who fall into high risk categories due to drug use or sex work involvement are often scrutinized and their ability to take care of themselves is questioned. In Canada, between 1979 and 1997, 7.3% of AIDS diagnoses were in women; this has increased over time and in 2007 women accounted for 19.1% of total diagnoses (<http://www.phac-aspc.gc.ca/aids-sida>, 2007). The number of HIV infections in women is rising. When reviewing statistics related to HIV it is important to note that some population groups will be over-represented. For example, women in communities with a high concentration of injection drug users and sex trade will have higher incidence of HIV. This is true of the DTES, however exact numbers of HIV/AIDS in any population are never known. HIV statistics are based on those people in the population who have been tested.

It is well understood that living with HIV/AIDS is different between men and women. In health care settings it has been found that that "(W)omen with HIV face barriers to care as a result of poverty, parenting responsibilities, histories of physical, sexual, or emotional abuse, and the predominance of male-dominated treatment settings" (Wood, S. A. 2006, p.10). Women in many urban centres, including the DTES engage in sex work often to support others, including pimps and boyfriends, and are forced to contribute financially to the relationship. Women are

therefore unable access regular health care because their lifestyle is such that conventional health services do not connect with them.

Lack of knowledge about women's requirements related to HIV/AIDS leads to assumptions and misinformation. According to Bunting (1996) this type of gendered discrimination can be "identified in more recent times when women's symptoms and opportunistic infections were not given the status of AIDS because these symptoms differ from those of men" ( p .68).

Women make up only 10% of clinical trial participants worldwide despite the growing number of infections (Webster, 2003, p.11). The research related to women and HIV/AIDS "targets women from marginalized groups such as sex workers or drug users, again emphasizing deviance as the source of infection" (Lawless, Kippax & Crawford, 1996).

Intimate relationships are often the source of infection regardless of a woman's risk factor. For instance partners may not be truthful with women about sex or shared drug use with other people. Women may also have difficulty in negotiating intercourse with protection due to fear of violence which also puts them at risk. Violence and control at the hands of men finds that women "...may have very little power to insist upon sexual partners monogamy or condom use" (Sacks , 1996, p .65)

For biological reasons "women are physiologically more susceptible to contracting HIV with male to female transmission estimated to be eight times more likely than female to male". (Quirk & Di Carlo,1998 cited in Duddy, 2003). This is due to women's cervix being made up of soft tissue which is easily ruptured during sexual intercourse as well as a greater surface area for abrasions and cuts to occur.

The gendered nature of HIV/AIDS and the risk behaviors and life circumstances of women becomes very noticeable when looking at the research and literature pertaining to women and

stigma. Women carry more responsibility because they are mothers and can carry the virus to unborn children. The guilt and shame associated with this risk increases the level of stigma for women who are judged for putting a child at risk. Additionally women hide their HIV status because of the fear of ill treatment of their children and the sadness that thoughts of mortality bring. Children are a great source of pride for most mothers and the thought of placing children at risk in anyway can cause great despair and extra efforts to hide HIV for mothers thus avoiding the stigma. Women may be further judged by people who believe that mothers who are drug users or sex workers cause harm to their children. This type of discrimination impacts families who are also forced to bear the shame of such opinions. Sandelowski, Lambe and Barroso (2004) describe the constant secret of hiding positive HIV as “stigma management” (p .126). Avoiding situations where their status may be revealed, or where their children may be affected by the exposure of their mothers illness can be highly stressful.

Jarman, Walsh and DeLacey (2005) found that “ the majority of the women maintained a tight boundary around their HIV identity, keeping their HIV status concealed in most of their relationships” ( p. 539). Rohedler and Gibson (2006) states that those diagnosed with HIV/AIDS were subject to the powerful stigmatizing discourses whereby they internalized these views and constantly tried to manage their “spoiled identity” ( p. 29). Living with HIV is a heavy burden to carry, with the fear of it always being revealed. Bunting (1996) suggests that the disclosure of an HIV diagnosis “...has played an unofficial part in many women’s greatest fear: losing custody of their children”. Being open about HIV can have devastating consequences for not only themselves but also for the families of the women involved.

## **2.6 Women living with HIV/AIDS in the DTES**

Despite commonalities in the HIV experience women in the DTES have some burdens and risks different to their counterparts in other parts of the world. Women in the DTES come from a place of marginalization and have multiple barriers in their lives. Poverty, addiction and traumatic life histories intertwine to create daily challenges for women. For most survival is the main focus when going about their daily activities. Literature about the DTES and specifically women's experiences in the DTES is quite limited. The focus is usually on women who are drug users, women who are sex workers, women who are Aboriginal, sometimes all of these. While it is true that women in these demographics may also be HIV positive, literature about the experience of women living with HIV is rare and the experiences and strengths of women are rarely discussed .

A number of authors have described the living conditions experienced by women in the DTES including Brennan & Giles (2004), Culhane & Robertson (2006) and Miller, Strathdee, Spittal, Kerr, Li, Schechter and Wood (2006). It is known that HIV/AIDS in the DTES is “significantly higher among women than among men, and about twice as high among both male and female Aboriginal intravenous drug users than among non-Aboriginals” ( Spittal et al cited in Culhane, 2003 p. 596). and in “2002 it was found that HIV incidence rates among female injection drug users in Vancouver are at about a 40% higher than those of male injection drug users” ( Spittal, Craib, Wood, Laliberte, Li, Tyndall, O’Shaughnessy & Schechter, 2002 cited in Duddy, 2003). These statistics are considerably higher than those of the national average due to the elevated risk factors associated with the high number of drug users in the DTES and Vancouver. HIV is of epidemic proportions in the DTES and as such the statistics are considerably higher than the rest of the country.

Research also indicates that “(W)omen of Aboriginal ethnicity are highly overrepresented in this community with estimates in 2000 suggesting that close to 70% of women working in the lowest paying tracks in Vancouver were young, Aboriginal women (Currie, 1994; Culhane 2003; Farley 2005 cited in Shannon, Shoveller, Chettiar, Allinot, & Tyndall, 2008). In the DTES community “approximately 90% of the people who inject drugs have contracted Hepatitis C” (Brennan &Giles, 2004). High numbers of women with HIV also have Hepatitis C.

Women who engage in sex work and illicit drug using are often pushed out to industrial areas and back alleys where their personal safety is frequently compromised. For women in the DTES HIV risk is increased in their attempt to maintain daily survival.

In conclusion the concept of inter-sectionality as well as theory related to stigma has been presented in this literature review. A brief discussion about the concepts of inter-sectionality and stigma as they intertwine has also been provided. Following this is a discussion about stigma associated to HIV/AIDS and also further exploration about stigma to women living with HIV/AIDS. Finally review of the literature related to women living with HIV in the DTES has been presented.

## Chapter 3

### Methods

#### 3.1 Narrative

Narrative methodology crosses over to almost every academic medium discipline, from psychology, counselling and social work. It is also consistent with oral history traditions such as First Nations storytelling. According to Reissman (1993) “The study of narrative does not fit neatly into the boundaries of any single, scholarly field” (p.1). Therefore for the purpose of this research I will refer to narrative research as “any study that uses or analyzes narrative material” (Lieblich, Tuval-Mashiach, Zilber, 1998, p.2).

The women who participated in this research were known to me professionally. Having this established relationship was useful in that there was an ease between myself and the women. I was familiar with the conditions women experience in their lives on the street and living in the DTES community. They did not need to go into great lengths about street culture or drug experiences as I already had this professional knowledge. On the other hand having previous awareness of the participants required that I be fully conscious of my role as a researcher and to try and not bring any previous information of the women’s lives into the conversation. I was aware that I needed to be open about my research role in this study and keep this and my professional role very separate. Having familiarity with each other made it easier as getting to know each other upon first meeting was not necessary. I made it clear to the women I spoke to that while I had some professional knowledge about their situation I knew very little about their history or what life was like living with HIV.

A great deal of the literature refers to the way in which narrative is interpreted being dependent on the various people hearing the account. As Riach (2009) explains “the challenge of

conducting analysis or presenting findings in a way that sensitively captures the multiple levels of research encounter remains one of the biggest challenges for the qualitative researcher” ( p.356).

Narrative methodology was used for this research to allow women to open up about a very sensitive subject. According to Reissman (1993) “Narrative analysis allows for systemic study of personal experience and meaning: how events have been constructed by active subjects” ( p .70). Methodology relying question and answer type approaches would not have provided women with the space to share their stories as openly as they did. “Analysis in narrative studies opens up the form of telling about experience..” and for this research I felt narrative would allow for this to occur (Resissman, 1993, p .2)

In the work I have done with women living with HIV I have found that understanding the needs of clients and building trust occurs through the retelling of stories. Working with Aboriginal women who often come from communities where oral story telling is important I wanted to utilise narrative for this research as a way to make women feel more at ease. Kohler Riessman (1993) suggests that “...less structure in interview instruments [is preferred], in interest of giving greater control to respondents” ( p .55). Narrative form offers more freedom and deviates from the researcher asking the question and the person responding feeling compelled to answer, often with yes and no answers.

### **3.2 Research question**

The overarching question guiding this thesis is *What are experiences of women diagnosed with HIV in the Downtown Eastside?* The intention of this research is to highlight the process of coping with an HIV diagnosis and exploring areas of strength women employ throughout this journey. The behaviours women use in order to resist the stigma and stereotypes warrants further

enquiry and discussion. Given the prevalence of poverty among those with a chronic, progressive illness such as HIV, I was interested in looking at the lives of women with such an illness and contrasting the journey as they move forward from when they are first diagnosed.

### **3.3 Sampling and recruitment**

For the purpose of this study, the only criteria required was women who self identified as women and who lived with HIV/AIDS. Because it was important to delve deeply into the women's stories only five women were interviewed. Recruitment efforts were limited to the Downtown Eastside.

Women interested in this study were invited to participate through a recruitment poster displayed in two buildings in the Downtown Eastside run by Neighbourhood Housing Society (NHS). (See Appendix A). Participants made contact by telephone or in person. Three participants lived in one of the buildings where the recruitment poster was displayed, and contacted me by phone to arrange an interview. The other two women came forward through word of mouth and approached me in person. Having previous professional familiarity with the women who approached me I did not request proof of HIV positive status as I was already aware that all five women lived with HIV. In the end five women, four women who are Aboriginal and one Euro-Canadian responded to my invitation and participated in this research.

Upon contact women were provided with a verbal description of the study and an outline of basic probes to be used. I explained to the respondents that the questions included how life had changed since finding out they were HIV positive as well as the impact of the diagnosis on their mental, physical and spiritual health. In addition, the impact of diagnosis relationships including family and friends, intimate relationships, family and friends, health professionals, social service

providers and the community as well as the relationships they have with themselves were of interest.

### **3.4 Interviews**

Initial individual interviews were conducted for this research. Each interview was recorded for the purpose of transcribing and later analysis. Four of the initial interviews were conducted in the homes of the women and one was held in a professional office.

The questions in the interview guide were designed to be open ended and broad in order for the women to respond in any way they chose (Appendix B). Open ended questions offer “greater control to respondents” while such questions provide the opportunity to open up the discussion ” in case the respondent has trouble getting started” Riessman (1993, p .55). I began with the following or a variation of the question “*How did you react when you found out that you had HIV?*”

Follow up questions were developed but not utilized. These included the following:

*“What impact has having HIV had on your life in general?”*

*“What, if any, are the positive things about having HIV?”*

*“Have you decreased or stopped any activities which might have been considered unhealthy?”*

*“Have you increased or started activities which might be considered healthy?”*

The women spontaneously answered these questions so posing these questions to them was not required.

### **3.5 Ethics**

Women’s safety and confidentiality was a major consideration throughout my research process. Upon initial contact and when setting up the interview, I spoke to all of the women

about the deeply personal nature of the data sought through this study. I ensured that the women understood the difference between my professional role and the purpose of our research interviews. I assured women that their confidentiality would be protected. I informed women that I would be the only one transcribing their interview and that portions of the interviews would be published in the study with names and identifiers removed.

Due to the personal nature of the interview topic I knew that there was potential for the women to become distressed and I was clear that the tape could be stopped at any time. I made sure I had a cell phone and contact information for various community resources should any of the women request it.

### **3.6 Honorarium**

Prior to the start of each interview, the participants signed a consent form (see Appendix C). At completion each woman received a \$20 honorarium as compensation for their time. I issued a receipt with each payment.

### **3.7 Data Analysis**

I transcribed all interviews shortly after they were conducted, and made further notes during the transcription process. Once the tapes were transcribed I numbered each sentence of the text. I initialled each line to identify the speaker. I further coded each segment using an open coding technique identifying and categorizing general themes and other phenomena arising from the data. I broadly identified organizational categories and then arranged these categories. I used these categories to develop the main themes, beginning with many emergent themes and subthemes and eventually settling on the five themes presented in this paper.

### **3.8 Validity and Reliability**

Maxwell (2005) talks about threats to validity of data by “ the selection of data that fit the researcher’s existing theory or preconception” ( p .108). In order to avoid including any data or themes which may enhance any previous beliefs I held about the lives of women I undertook “member checking” also known as “respondent validation” (Maxwell, 2005, p.111). “Member checking” provided opportunities for the women to give feedback regarding the accuracy of the themes presented. Creswell (1998) suggests that member checking “involves taking data, analyses, interpretation and conclusions back to the participants” (p .203).

For the purposes of member checking I was able to locate three of the 5 women who participated in this research. I spoke to all 3 women face to face. I presented the data to the women and discussed the analysis, themes and conclusions of the research. All 3 women were in agreement about the outcomes and what was presented in the findings. Danni said that the themes were “exactly how she would describe her process of living with HIV”. Sarah said that after hearing the themes she thought that “being diagnosed with HIV was almost like the death of my old self and I been able to recreate a new me”.

Validity of themes was enhanced by grounding each theme in the data and ensuring that sufficient data supported each theme. Credibility was enhanced by accurate verbatim transcription. To further enhance credibility I described the research process results in an audit trail.

### **3.9 Description of participants**

The following is a description of all five women based in the narratives they shared compiled in the order recorded.

#### **3.9.1 Sarah**

Sarah is a petite First Nations woman in her thirties who has been HIV positive for about 5 years. She lives on income assistance in a bachelor suite in an apartment building in the Downtown Eastside. Sarah's HIV diagnosis was unexpected. She had been a "party girl" and finding out she was HIV positive made her more aware of her health and lifestyle.

Like many women, Sarah was initially hesitant to reach out to others due to perceived fear of negative judgement. Sarah now connects with many supports around her, both professional and personal. Her support system has maintained her through periods of poor health as well as maintaining her on methadone and an antiretroviral regime including side effects.

Sarah deals with anxiety, depression, memory loss and other physical symptoms such as weight loss and insomnia and has spent prolonged periods in hospital. Sarah feels the medical system is very accessible to her as she is well supported by a doctor and felt safe and well taken care of during a lengthy stay in hospital.

Sarah volunteers as a peer worker which fills in her time. Many of her relationships, particularly with her parents have greatly improved as she has gotten older and is now appreciative of her life more. As a younger woman she spent a great deal of time away from her parents, travelling the country and into the US. Sarah's children are teenagers and live with their father out of town. She has a difficult time connecting with her children as she feels that her ex husband treats her negatively. Sarah sees a counsellor and says she has decreased her drug use

since finding out her HIV status. She believes one day she will be able to give up drugs altogether. Sarah is sending letters to her children and trying to save money for visits with them.

Sarah pursues many hobbies, particularly Native crafts most of which she keeps for herself. She learned many of these crafts in a special “Native School”, a half Native, half White day school. Sarah also enjoys to cook and has kept a journal for many years. She considers herself spiritual, especially in Native traditions and practices also saying private prayers especially to help her through her illness.

### **3.9.2 Debbie**

Debbie is a First Nations woman in her 30's who has been living with HIV for 14 years. Debbie receives Person's with Disability benefits and lives in supported housing for women. The news that she was HIV positive came after being released from prison where she also learned she had tuberculosis and was pregnant.

Debbie is from Northern British Columbia. She had 1 relationship of 7 years which produced 1 child however the relationship did not work out. She has two children who she talks to on the phone. She witnessed drug and alcohol abuse in her family which was a gateway to her to drug use as a preteen. A repeat runaway she moved between many group and foster homes. Debbie turned to the streets at an early age. While Debbie has phone contact with her family she does not see them.

Debbie describes the impact of having HIV as making life physically more difficult and she gets tired very easily. She sleeps a great deal and describes using sleep as a way of escaping life. Nowadays Debbie says she does not drink and has cut back on her drug use. She is taking antiretroviral medication.

Debbie describes herself as not being very spiritual and having very little to do with her Native culture. She prefers to be a spectator and not participate in ceremony. Her personal relationships are few, most of Debbie's friends have died and she prefers to connect with the staff of the building she lives in for support and describes them as friends.

The housing in which Debbie lives is stable, a home she has had for 4 years. Debbie says she has always reached out to others for support. Her physician is very active in Debbie's life and makes sure Debbie follows up with her medical appointments and routine blood work.

Describing herself as being wiser, Debbie feels HIV does not have the impact in her life that it once had. These days Debbie does not worry about being HIV positive and sees it as a just another illness, like cancer. However Debbie says she has experienced stigma and discrimination and witnessed other being treated poorly because they are HIV positive.

Debbie has been approached to participate in the development in workshops for youth about HIV and drug use and sees this as her way of giving back to the community. Debbie feels that knowledge is ones "best friend".

### **3.9.3 Trish**

Trish is a petite Euro-Canadian woman in her 30's. She lives on Person's with Disability Benefits in the DTES with her boyfriend and "tops up" her income by engaging in street level sex work.

Trish's first drug use beyond marijuana and alcohol was after the birth of her child when she was 18. The news that Trish was HIV positive was no surprise as she had been sharing needles with a partner who was HIV positive. Trish immediately informed her new partner she was positive and she also reached out to a community agency. Trish is a long time sex worker and will not do any dates with anyone who will not use protection. Trish was raised out of province,

a product of a divorced home and raised by a single mother with one brother. Growing up Trish was responsible for the upbringing of her brother while her mother went to school and worked. She was a rebellious teenager who would not go to school and would runaway. Trish considers her role as a young caregiver as one reason she “never got to be a kid”.

Trish is enormously proud of her daughter, a university student, with whom she has regular visits. Trish’s health is stable and she has never had to take antiretroviral medication. She concentrates on staying healthy and keeping her weight up, she is tapering off methadone.

Stable housing has been a challenge to find for Trish. Currently she has a place she likes, though it took Trish and her partner 3 months to find housing. Trish has a few friends and is active in her community as a volunteer and outreach worker. She would one day like to be a counsellor. She is involved in a skills improvement group for sex workers, learning first aid and getting job training. Trish would like to go to schools and talk to youth about the perils of drugs, HIV and sex work.

#### **3.9.4 Danni**

Danni is an Aboriginal woman in her late 30’s who lives in a bachelor apartment in the DTES. She does not work, receiving her income from Person’s with Disability Benefits and her adoptive parents sometimes give her money. She tells me that she has been diagnosed with multiple personalities. Danni is from out province, born to a Native family and adopted into a Euro-Canadian family in British Columbia as a toddler. Danni’s adoptive family raised her as a Christian Scientist. Her upbringing with her adoptive family was full of privilege and religion. A gifted piano player, she began to play at age 3. She attended a private school and vocational school. Danni was interested in sports including ice hockey and competitive swimming.

Eventually Danni went to foster care as she was being molested at home by her adopted father. Danni first had contact with her birth family at 18, however this was brief and she no longer has any connection with them. At around the same time she got pregnant with her only child and got married. She no longer has contact with the father of her son, though she sees her son from time to time.

Danni found out about her HIV diagnosis at a point in her life when she was homeless and very ill. Danni's adoptive family live out of Vancouver and she goes to visit fairly often, however she says she gets paid to leave because her family cannot tolerate her drug addiction and multiple personalities. Today she maintains her mental health and physical health through routine in her life. She no longer drinks giving up around the time of her HIV diagnosis

### **3.9.5 Ann**

Ann is an Aboriginal woman in her fifties who lives in a neat, sparsely furnished bachelor apartment in the heart of the DTES. Ann receives benefits from The Ministry of Housing and Social Development. She found out she was HIV positive approximately 2 years ago. Ann is from a Reserve in Northern British Columbia and she is the second oldest child of 7 siblings. Her parents were alcoholics for much of her life. She is a survivor of the Residential school system being sent there with her brother when she was 13. She was married to a man who introduced her to drugs.

Ann's reaction to learning of her HIV was one of shock. Ann has only told one person she is HIV positive and is scared to tell her children. Ann's health has been "up and down", she described being very stressed and losing weight. Ann is quite isolated and finds it difficult to connect with other women. Ann was a "closet heroin user" for many years. Ann went to trade

school to become a hairdresser and she worked odd jobs. She talks about how she has been a community volunteer.

She thinks about going to drug treatment but is turned off by the rules. She is also on methadone and antiretrovirals. She did not know much about HIV or the significance of her diagnosis. For Ann the stress of hiding her HIV diagnosis weighs heavily.

### **3.10 Summary**

In conclusion this chapter presents brief summaries of the lives of all five women, Sarah, Trish, Debbie, Danni and Ann. They are presented in the order that the women were interviewed. The summaries of the lives of the women were gathered from their narratives during the interviews. As is evident in these summaries during our interviews the women were open and honest and offered insights into their lives prior to HIV diagnosis and the journey they have undertaken to where they are located today.

## Chapter 4

### Themes and Results: Overview of main themes

Emerging from the narratives were five themes which encapsulate the lives of the women and also define their personal experiences. The first theme was “*Life Is Over*” which consisted of feelings of shock, denial and grief. The second theme “*Stigma Management*” included an exploration about decision making regarding disclosure. The third theme that described the process of adjustment was “*Disconnecting From Self And Others*”. This theme described how the women’s lives were “disconnected” from supports, family and positive environments as well as how they further isolated through drug use and depression.

The fourth theme “*Reconnecting With Support Systems*” described how women found the strength to reconnect by reaching out to friends, family and professional support systems. At the time of these interviews most of the women had been able to re-establish fractured relationships and find appropriate health and social support systems to restore physical, mental and emotional health.

Finally as a last theme “*Giving and Sharing Experiences*” described the ways women have given their time, wisdom and expertise to both individuals and community initiatives. It is a theme that demonstrated, despite what else may be happening in their lives , they give back and make contributions to their world around them.

#### 4.1 Life is Over

The women in this study all had similar initial reactions to learning of an HIV diagnosis. Whether or not a positive diagnosis was anticipated, the response was always that of shock and being overwhelmed. Trish states that she “knew” she was going to be positive because of her behaviours with an HIV positive partner, yet she was “scared”. The uncertainty of the future,

especially if one is dealing with other personal life issues can create further challenges in what may be an unstable life.

Both Trish and Sarah thought that they were going to die, that death was imminent. Trish stated that she experienced grief, fear and thoughts of death.

*Cried...I was scared at first, I thought I was going to die right away*

Sarah reacted similarly and expressed feelings of fear of the unknown.

*I was terrified, of course, I thought oh my life's over*

Debbie, in contrast, described suicidal thoughts reacting to the diagnosis by continuing her destructive life which included an excessive use of drugs. During this period Debbie describes herself as being very alone.

*I remember how I acted, how I reacted I just I felt really, I felt just like I wanted to kill myself*

Trish's belief that she was going to die anyway saw her engaging in very self destructive behaviour.

*I went crazy at first, the first couple of years...Yeah, I didn't care, I figured I was going to die anyhow, who cares...?*

Ann's experience was one where she the health care provider who informed her of her diagnosis "blurted it out". There was no preparation for the diagnosis or counselling before or after.

*I was shocked...I was so shocked and it was the way the me that the nurse told me was so hard, she blurted it out, you know and I kind of went into a denial mode*

Ann reported that despite having a great deal of respect for this nurse who gave her the diagnosis she was still resentful of the manner in which the nurse told her. This is certainly one of the ways in which health care providers can contribute to feelings of helplessness and exacerbate the fear of women when delivering such potentially shocking news.

All of the women took the news of their diagnosis very hard. In the early shock of such information several of the women talked about reacting through heavy drug use as they were on a course of self destruction.

Not knowing what the future holds when diagnosed with HIV the women assumed that their lives were over. They were fearful and scared and some had thoughts of suicide while others delved deeper into chronic drug use. These reactions are consistent with literature regarding reactions to HIV diagnosis. Often women are already isolated and have issues of low self esteem due to stigma and marginalization. A diagnosis of HIV intensify these already existing issues and can make the future difficult to face.

#### **4.2 Stigma management**

Women reported that they managed the stigma of their diagnosis by making careful decisions about whom to disclose the information. All but one of the women in the study were quick to disclose their HIV status, particularly to intimate partners and friends. They reported that telling partners, particularly intimate partners or people in drug using networks was necessary in order to maintain the health and wellbeing of all involved.

Disclosure can come in several forms from telling people directly, by associating with professionals who work with HIV/AIDS agencies and by attending facilities and medical clinics that work only with people who are HIV positive. Some clinics and agencies are solely available for the purposes of providing services to HIV positive people. Anyone who attends such a facility or connects with an HIV professional runs the risk of having their status known by association.

Danni explains the reality of knowing she was HIV positive but not wanting to attend a drop in that she refers to as “that place” because it was specifically for people living with HIV. To go to the drop in meant outing herself as being HIV positive.

*...it was a harsh it was a harsh, I mean being down in the Eastend I knew I did not want to be here... I didn't even want to go to that place because you know for that specific thing and a lot of the people that know me*

Women know from experience how people will respond if they know someone has HIV. They have been around others and heard the judgement about people who live with HIV/AIDS .

Sarah discusses her experiences when associating with others who are critical of people living with HIV. These situations inform her decision making process around disclosure.

*...people just categorise other people a lot, ... don't hang around here kind of thing...*

Debbie also describes previous personal experiences with disclosure. These moments are unfortunate for several reasons. They isolate women from sharing and connecting with others based on unknown reactions. They also perpetuate stigma and negative discourse which also, as Debbie explains, alienates women further.

*People did think, it was very, how would you say alienating, alienated back in those day, it was... if you had it they wouldn't even touch you, you know*

Knowing when to tell people can lead to all sorts of questions and concerns for women. Physical violence is most certainly not unheard of as well as blame for bringing HIV upon themselves and placing others at risk.

Telling the “wrong” person or people can cause public shunning and ridicule, making the experience of living with HIV even worse. Fear of the reaction is very real and keeps women silent. For instance as Ann explains:

*I do but I don't know how to go about it [disclosure] ....I am afraid of what their reaction is going to be, you know*

Trust is a big factor for Ann when getting involved in women's groups in the community as there is a great deal of judgement of women who are HIV positive in such groups. This is often an approach women will use to deflect from their own situations. Lack of trusting friendships makes it difficult for women to open up and find others to connect with.

*No, I have talked to women, I haven't told them that I am HIV but I bring the subject up and then they are saying, oh did you know that so and so has HIV and they go down a whole list of names so I don't really trust them to talk to...*

Ann was also ashamed of her status and lifestyle to the point that she did not want to tell her children

*I have 3[children], 2 boys and a girl and I want to tell them, like I said I don't know how...if I ever pass away, I wanted them to tell them that I just died of cancer or something*

Telling family members is always a challenge because the response is unknown. Ironically by revealing status there is a fear of rejection yet by not disclosing status women also risk isolation and loneliness. Another consideration in disclosure is the risks taken by women engaging in sex work. Trish was an active sex worker and she had made definite decisions about revealing her status to her dates. To tell dates you have HIV puts the women at risk for violence or loss of income. On the other hand saying they are "clean" usually ensures the date.

*I tell people I get high with and that I am positive, I don't tell my dates*

My conversation with Trish goes on to discuss her experience when engaging in sex work.

*Just curious about the dates thing, do they ever ask?*

*Yeah, a lot of them ask "are you clean?"*

*I just tell them yeah but it doesn't matter you have got to wear a condom anyhow"*

*So you always use a condom?*

*Yeah*

Sarah had also put thought into who she told, based her previous experiences and also described situations when she would disclose her HIV status, putting the health and welfare of others first.

*In what situations would people ask about HIV do you think?  
When you are fixing  
So, like they might be at risk  
Yeah*

Clearly Sarah feels that being open about her HIV status is more important than the stigma that may come from revealing that she is HIV positive. Several times she referred to thinking about HIV everyday and reasons why she would share this information.

*So that they don't get it or...they're just aware of it...so they're more at ease  
Because it is like it something that I live with and it is so important that people know*

Disclosure is not just about telling people. It is about who to tell and when, making choices about why one would tell and not feeling pressured to reveal HIV status if not necessary. Based on level of risk, such as drug using networks and engaging in sex work, women in this research have extra considerations when it comes to disclosure.

#### **4.3 Disconnecting from self and others**

Even before contracting HIV, a pattern emerged that consisted of women's disconnection from many of the people in their lives. Prior to diagnosis three of the women were estranged from their children or had very little contact with them primarily due to their drug addictions and poor health. There was also disconnection from self given that their lives were destructive and chaotic. The majority of the women were outside of the realms of conventional health care before being diagnosed with HIV and were not receiving any type of medical support. This disconnection continued for most of the women immediately after they were diagnosed.

While disconnection from significant support systems prior to diagnosis with HIV is not the focus of this research it is important to acknowledge that disconnection “before” HIV diagnosis certainly plays a role in keeping women further isolated. When not disconnected from families and friends, women will engage in risky behaviours and tend to associate with others who had a similar background. Many of the coping mechanisms and behaviours that women employ when they are diagnosed with HIV were learned prior to sero-conversion as a means of survival and adaptation.

Early on, prior to diagnosis, Debbie disconnected from family and ran away to the street as a young woman developing a tough streetwise side to her. This is an example of “disconnection from self” when one reverts to a survival mode to get by. Women display a “hard” outside exterior given their fear of violence, they are not able to show their true selves for safety reasons.

*It was pretty scary but I was the type I was the type of kid who would do something and I wouldn't care , I show myself that I was really strong and tough, show people I was tough to them I look like ...how would you say, I looked like I was able to handle it because I always showed that toughness side of me*

Trish also became a street kid very early on, following a tumultuous and difficult early adolescence.

*I left home when I was 15 with consent from my mother but I have been on the street off and on since I was about 12*

This pre-diagnosis disconnection from family was consistent for all of the women in the research. This period of estrangement from family and supports remained for some of the women even when they learned they were HIV positive.

Once she contracted HIV, Debbie remained estranged from her family.

*I talk to my family but I don't have a anything to do with them because I just don't they are too negative towards me right now*

Trish experienced discrimination by her step father when he first found out she was HIV positive.

*My step dad, when I first told him when I was kicking my heroin habit in 96 I went home he's a hick cowboy hey and he doesn't know much about it and when I told him [I had HIV] I had to have and I had my own cupboard, my own knife and fork, my own cup*

Fear keeps women from connecting with others, when asked about reaching out for support in the early days of her diagnosis Sarah said she did not know where to turn.

*Well, because I was reluctant to think that...in the early part everyone's going to think badly*

For social workers it is important to pay attention to disconnection whenever it occurs for people infected or affected by HIV. Without significant stable support systems places women on the margins at risk for isolation. When in need it is imperative that women are not forced to cope alone. If social workers take heed of when families are fractured and when children are lost to the street early intervention can take place. Early support and trust building is part of practice as social workers and allows to work with families and try and keep them strong and together.

After diagnosis the fear and shame of being HIV keeps some women apart from their families. This is evident in the early days of HIV diagnosis for the women in this study. Disconnection that is evident prior is maintained when women are diagnosed with HIV because they feel further guilt and shame. Understanding disconnection is important as recognizing when women are not receiving adequate support can mean the difference between connecting them with appropriate services or keeping them out on the margins.

#### **4.4 Reconnecting with support systems**

The strength and resilience shown by the women was their ability to “reconnect” with many people in their lives particularly upon and around diagnosis. Most of the women were able to re-

establish relationships with their families and themselves after a period of estrangement from these parts of their lives. For most of the women families became vital. In order to maintain good health and despite whatever else was happening most of them were able to rely on their families for support.

Ann who experienced Residential school explained about her reconnection with people who were able to bring her closer to her culture, how she gets together with people who spoke her language and of cooking traditional foods together.

Furthermore she is continuing the circle with her grandchildren by speaking her Mother tongue at every opportunity.

*My brother and there is a bunch of other people that went to residential school  
Here [in the DTES] and every chance I get I talk in my language and um my little great  
granddaughter I talk to her and sing to her*

Trish described her life including drug use and sex work as a major part also found the opportunity to reconnect with her mother.

*Yeah, [my mom] she's my best friend now , I can talk to her about everything...I  
call her every weekend"*

Sarah also has strong ties to her family after a long period of being estranged from them for many years as a younger woman.

*Yeah actually with my mom and dad they have, we have moved closer because we value  
our time now*

In addition to re-establishing ties to family they also developed important connections with community agencies and health care providers. In this research the vital role of caregivers and professionals was an integral part of physical, emotional and spiritual growth. All of the women who participated in this study now have a strong professional presence and community support who assist in maintaining their physical health. This professional support continues to provide

ongoing care and nurturing and several of the participants in this study referred to the professionals in their lives as “family” and “friends”.

The belief that “*life is over*” subsided for most of the women and they utilised this renewed health network to overcome major illnesses and to find a medication regime that worked. Health and social care providers were a major part in supporting women and giving them hope in the belief that life is not over.

Trish and her partner would like to get pregnant and is consulting with her doctor on how to do this safely. She cooks at home with her partner and has tried to reduce her drug use. She follows up with blood work as required.

*I have got a great doctor... yeah she is awesome... Very supportive, really on me about making sure I do my blood work...*

Given that Ann was very private about her HIV status, connecting with her health networks was especially important. She spoke about her doctors and nurses being the people she can talk to.

*“Cathy” (a home care nurse) is the only that I can talk to, and Dr “Brown” that I am comfortable talking with, oh and “Kim” (a clinic nurse)*

Danni lives a very quiet life, remaining mostly in her home. Her support system is small but she refers to her health care and support workers as family members.

*What friends? Friends are my nurses, my support worker, they’re my family....*

Debbie who had found the streets to be a place where she found her community lives in a supportive housing environment which has been a place for her to connect with staff who she refers to as “friends”

*The staff here, the staff that work here at the XXX I can talk to them, I can talk to them whenever I want ...whatever time of the day I want to talk I ask them if I can talk and they say yeah, I can say that they are friends*

While there was some discussion in these interviews about women having negative health care experiences and witness ill treatment of other women with HIV/AIDS by health care providers it is notable that all of the women had very positive professional support networks. This is due to the accessibility of services in a community in the DTES who specialise in treatment of women with HIV. Given the large number of women who are HIV positive or at risk for becoming so, the DTES has highly skilled professionals who for the most part accept the women “where they are at” and will go to great lengths to see that they receive the care they need. The present research, therefore, presents a contrast to the existing literature in that it cites positive experiences with health care for women with HIV. Most of the research illustrates negative medical experiences and discrimination from initial diagnosis through the stages of HIV. Often this treatment is based on stigma against women who are drug users or who engage in sex work.

#### **4.5 Giving and sharing experiences**

The notion of women giving back to their community in a variety of ways emerged as a final theme in the process of adjustment. The isolation and the daily physical and mental burden of living with HIV was overcome time and time again women realised that one way to beat these debilitating situations was to become active in the community.

Sarah told of participating in a public education video for school children about the effects of drug use.

*I've done things like I did a video thing of myself sick and then not sick”*

Trish and Sarah had also participated in a video to catch a serial killer operating in the DTES targeting women who were working on the street, and who was later charged and convicted with multiple murders.

*I've been in one they did, you know they did for the Pickton thing*

*I went on America`s Most Wanted to help catch Pickton too*

All of the women reported that they saw themselves as role models, as someone that others might regard with respect.

Sarah described how she assisted a friend who had been diagnosed with HIV.

*My girlfriend of mine she was positive and I was there for her and it was the day she was diagnosed.... and she was going through the same things as I went through and I able to talk to her about my past experience and I think it helped her a lot”*

Sarah also spoke about how her volunteerism had helped her self esteem. As indicated in the literature feelings of low self esteem perpetuate stigma. Clearly one of the ways in which woman can counteract feelings of stigmatization is to be further involved in their community.

*Plus I feel positive about helping others when I volunteer*

Ann talked about her volunteering activities, which were at times frustrating. Despite this she did offer her time engaging with others. Again community involvement and not being isolated are ways in which women with HIV can overcome feelings of low self worth and stigma.

*I used to do a lot of volunteering before but that is another thing , I get pissed at people don`t appreciate what you are doing and they always want something better, or they want more and they scream at you...*

*I worked at the Women`s Centre and I worked with the diabetic thing*

Trish sees herself as a role model and talks about the ways she provides assistance to others. This is a more “informal” contribution, a way of giving back to others. As a woman who has been out on the street for a long period of time she is able to mentor younger women who may be falling into the same patterns.

*But more, I am always helping girls out on the street, if they have got not clothes, or they need somewhere to shower I bring them home and shower and clothes and stuff*

Debbie also spoke about public speaking, working with a staff member from the building where she lived. The theme of public service and public speaking resonated throughout most of the women's narratives. Telling their stories as a way of trying to convince others not to take the same path of addiction was of great importance to the women.

*... "Ashley" she asked me to do a talk, a workshop with her and I agreed to , she (asked me to) help her with this workshop on HIV*

The women in this research were not "out" politically or involved directly in HIV/AIDS advocacy and activism. This means that the women are not speaking publicly at forums related to HIV/AIDS such as rallies or conferences. They are not volunteering on the front lines at agencies or support groups for people who are HIV. They all chose to be more private about their HIV status,. However they all of the women are involved in one way or another in providing support to others who require it.

The women in this research were involved in some of the ways a woman may give back to the DTES community. There are numerous other ways in which women who learn they are HIV positive give back to this community beyond the ones presented here. Some women choose to become politically active, speaking in public and being very open about their health status. Many engage in research, though the numbers of women in HIV research continues to be low in proportion to that of the study of HIV and men. Some women volunteer their time with agencies providing support for people living with HIV. Volunteering and being active in community allows people who are HIV positive to connect with similar others in order to reduce stigma.

#### **4.6 Summary of the themes**

The themes in this research represent several steps in the lives of the women when they are diagnosed with HIV. The first theme, "*Life Is Over*" introduces immediate feelings of loss of

their previous self, uncertainty for the future and suicidal ideation which play a role in women's reactions to the news of having HIV. Faced with who to tell, the second theme of "*Stigma Management*" plays a role in the beginning of diagnosis when decisions need to be made about disclosure to intimate partners and people who may have been or continue to be at risk for contracting HIV. Who to disclose information to about HIV status remains a consideration for women living with HIV for the rest of their lives.

"*Disconnection From Self And Others*" describes isolation from personal and professional supports as well as a feeling of not being balanced in oneself is another finding in this research. Engaging women living with HIV in their community and supporting their physical and emotional wellbeing plays a huge part in the health outcomes for women. If women are able to receive adequate supports in a timely fashion they may be able to get the treatment and care they require to deal with any health issues they may have related to their HIV as well as other aspects of their lives. "*Reconnecting With Support Systems*" the fourth theme in this study, provides discussion about the ability of women to engage with supports at crucial times. It also illustrates the importance of social workers and other health professionals building trust and the ability to offer women the tools they need to reach out when they require support.

Finally the last theme is about the process of "*Giving And Sharing Experiences*" which is a way in which women living with HIV move forward in their lives and offer themselves and their time in building community. This theme represents women's abilities to be able to find a balance with their own needs as well as offering their experience and wisdom to others as a way of a contribution to those around them.

## Chapter 5

### Discussion of the themes and findings

The process of adjustment was emotionally and physically overwhelming for the women. As indicated by the narratives, the social position of the women in this research creates huge barriers in overcoming stigmatization and in easily achieving the basic necessities of life. The intersections of poverty, gender and race place women at a disadvantage as they constantly negotiate the world around them and the people they come into contact with on a daily basis. It takes a huge amount of courage and wisdom to know when to accept the support as it is being offered. In addition it is evident that women eventually come to a place where they realise that they have something to offer and they are not restrained by feelings that their lives will have an early demise. Clearly for some women they are able to find more confidence and support in coming to terms with a diagnosis of HIV. Certain feelings of despair and anguish about living with a chronic illness never completely go away, often increased by a change in health which may require hospitalisation or medical intervention. Life with HIV can be a waiting game and when health may take a downturn

The first theme of *Life is Over* incorporates emotions of fear and grief which arise from hearing the diagnosis of HIV. Women in this study fear mortality and for the most part their unknown health status created uncertainty. For some women diagnosed with HIV, suicide is an option and for others drug use increases as they consider that they will die young anyway. Having witnessed early deaths in the beginning of the HIV epidemic, women feel it is a matter of time before they too die. Early on, treatment was not as advanced as it is today. Nowadays research on medications for HIV have heralded a “shift in the conceptualization of HIV infection from ‘death sentence’ to ‘chronic illness’ (Jarman, Walsh & DeLacey, 2005 p. 534). Despite this

shift, research indicates that HIV diagnosis, stigma and suicidal ideation do occur and “ [B]ecause social isolation is recognized as a risk factor for suicide, perceived stigmatization may increase the risk of suicide” (Demi, Bakeman, Sowell, Moneyham & Seals, 1998, p. 345) .

The fear of stigma and judgement was also evident in the theme *Stigma Management* a concept developed by Sandelowski et al. (2004) which involved decisions about who to tell and who needs to know about HIV status. This was of great consideration to the women when they discovered they were HIV positive. Managing HIV stigma was a very difficult issue for the women to deal with. As Lather and Smithies (1997) explain “living in fear and secrecy is highly stressful, though some women find it safer than disclosure” (p. 68). Women must constantly weigh up the risks of whether or not to tell. Disclosure can come in different forms . Some women tell intimate partners immediately. This is consistent with research by Falkin and Strauss (2000) who state that “[D]isclosure of HIV infection to sexual partners often takes place out of concern for their partners health” (p. 803). If they are drug users they may also share the information with these networks.

The other side to disclosure is caution about whom to tell. Trish spoke about not telling dates she had HIV when she was working on the streets because to disclose HIV is business suicide for a woman who works in the sex trade. This is an ethical dilemma for social workers and those who engage professionally with sex workers, knowing that women who are HIV positive are working on the street. Engaging women in harm reduction practices is important when working with women who are sex workers and HIV positive.

Frequently there is little analysis about men and their responsibility as those who seek sexual services from women, who may be HIV positive, to ensure safety for themselves and also others with whom they may have sex. There are assumptions made about women who engage in sex

work primarily that they are irresponsible and spread the disease deliberately. Yet when reading Trish's comments it is worth considering these accusations. Trish states she uses condoms at every date. Berger (2004) talks about how sex workers "shoulder most of the burden in dealing with HIV" and "[W]hile the clients that they are engaged in sex for money are not stigmatized" (p.127)

While research about the realities of sex work for women is more prevalent over recent years, there remains a general misunderstanding of the women who engage in sex work that they are "vectors of disease". Recent studies regarding sex workers in the DTES show "an observed relationship between living on the street and the enhanced likelihood of both rape and physical violence" and "an extremely high prevalence of both sexual and physical violence against female sex workers that persists because of large scale structural inequities. (Shannon, Kerr, Strathdee, Shovellar, Montaner and Tyndall, 2009, p.8). The issue of sex work and HIV responsibility is a complex and highly charged debate.

The further side of the disclosure issue was apparent with Ann's inability or fear of telling anyone she had contracted HIV. The stress and worry about her health appeared to be making her sicker and she seemed immobilised to seek assistance through counselling. Women may eventually have to tell family or other people when they begin to show signs of being HIV positive. "According to the disease progression theory, individuals disclose their HIV diagnoses as they become symptomatic" (Serovich, Lim & Mason, 2008, p.24). At this stage the choice of disclosure is taken away. As the illness progresses it can become harder and harder to "hide" symptoms, especially if hospitalisation is required. Health professionals, who may assume that the HIV status has been shared with family members, may disclose this information without permission.

In our interview Ann cried many times and the distress in her voice was obvious. Ann was the woman who had been HIV positive the shortest amount of time and over time she may be able to progress to a stage where reaching out was easier for her. The theme regarding disclosure was clearly a natural progression from the initial feelings of the shock of finding out that one had HIV.

The choice of whether or not tell someone whether one has HIV is highly complex and there are many mitigating factors playing into this decision following diagnosis. While women were making decisions and coming to terms with the realities of being a woman with HIV, there was a period of adjustment which translates into the third theme in this research.

Following these thoughts of who to tell and when, most of the women had experienced *Disconnecting from Self and Others*. The diagnosis of HIV removed the women further from their family and loved ones. There was a period of adjustment for women where they had to deal with emotions of dealing with their new status of having HIV. Some of the women had already disconnected or removed themselves from family a long time before the HIV diagnosis and the changes in their health status upon diagnosis initially kept them from reaching out to the people from whom they were already estranged. Many of the women were entrenched in drug use which is an isolating experience mentally and socially. Most of the women were not connected to health care services at the time of diagnosis in any significant way.

Upon finding out about being HIV positive, Danni was homeless and did not have a doctor and Debbie was in jail, pregnant and ill with tuberculosis. Possibly if these women were in a position of being engaged with a supportive and caring network their circumstance might have been different. It seems that the use of drugs and life on the street maybe one of the reasons why they needed an escape to cope with the disconnection from family and support systems.

Theme four then leads to a progression for most of the women of *Reconnecting with Support Systems*. This occurred regardless of whether some of their behaviours of drug use or involvement in sex work were still present. Many of the women found supportive and caring medical practitioners and counsellors who cared. Some of the women found housing which provided more stability and an ability to be able to take care of health. Several of the women reconnected positively with family, while others like Danni found a “happy medium” with her family. It seems that reconnection is a natural progression through periods of grief and uncertainty. Lather and Smithies (1997) speak of how “with the gift of time, many families are remarkable in their capacity to change and adapt to the situation “( p 6.5). Women for the most part seemed more sure of themselves and it appeared that they were clearer about their future and where they were heading.

The fifth theme *Giving and Sharing Experiences* described women sharing their expertise as well as a desire to give back to others in variety of ways. Giving back and being involved in community also provides women with an opportunity to stay busy and stay connected to others therefore warding off isolation. Trish and Sarah were already part of the community, particularly with women on the street, and supporting them in practical ways, such as use of their room, clothing and showers or with advice and encouragement to contact family and loved ones. This type of support is consistent with the street culture and lifestyle of the DTES. Based on years experience on the street both of these women had participated in videos related to sex work and predators. Sarah had also featured in a video on the risks of drug use and Debbie was also in the process of going and giving presentations with staff in her building about life living with HIV.

Danni had volunteered time in her community playing piano at agencies and for seniors, while Ann had volunteered her time with a diabetes support group. This theme is positive given

the amount of stigma, judgement and scrutiny women endure in their lives. Many women who are poor and addicted are regarded as not having anything to offer. This theme shows that women have the ability to overcome and transcend any negative stereotypes they may face. By “giving back” women are doing a service to not only others, they are giving back to themselves. They are enhancing their sense of self worth and self esteem and engaging in their community. It is encouraging that women find a way to share their wisdom, expertise and knowledge which helps them through the initial shock of diagnosis and figuring out to whom to turn.

In the book “Workable Sisterhood” Berger (2004) speaks about activism and advocacy among HIV positive women stating that “most women do not identify the work they do in “traditional political terms. The majority of the women do not call themselves activist or political people” (p .144). Yet women with HIV are becoming involved, whether it be in research or providing expertise in other ways in the community. Women do not want their children recreating the same patterns as them. Essentially by becoming involved in community and engaging with others to share their stories they are giving to younger women something that they would have benefited from when they were younger.

## Chapter 6

### Conclusion: Findings in relation to theory

The first theme *Life Is Over* mirrors the responses in the literature of other women who are diagnosed with HIV. Thoughts of mortality and suicide are common for women who are diagnosed. In a study of 241 women living with HIV by Demi et al (1998) it was found “that suicidal thoughts and suicide attempts are relatively common among women with HIV infection” ( p.350). 44% of respondents answered yes to having suicidal thoughts during one of the two interviews conducted for the research and 31% of respondents stated they had attempted suicide since finding out they were HIV positive ( Demi et.al, 2008, p. 353).

*Stigma Management* and disclosure pertains to the way in which women “ ‘psychologically’ protect themselves, and also others, by restricting the boundaries around their relationships, and keeping their HIV-positive status, or their feelings about being positive, concealed” ( Jarman et al., 2005, p. 546).

The women in this study experience multiple oppressions every day. The intersections of race, class and gender combined with the stigma of being HIV positive while engaging in sex work and drug addiction combine to place women on the edge of the margins of society. The DTES is unique in many ways. Poverty and addiction is entrenched and visible. The people in the community have to contend with a lack of affordable resources such as housing and adequate nutrition. There is a “culture of survival” in the DTES. Women often participate in activities particularly sex work not by choice because their options are limited. Women are in this place because of the intersections of oppression and stigma where they do what they can to get by. As Berger (2004) states “[S]tigma has the potential to affect reseources” (p.23) . Women who have

few choices and lack social and political power embark on daily survival as best as they can. The women in this research are no different.

This study highlights women's positive experiences with health and social work professionals. It also shows women's abilities to reconnect with family members who at other times in their lives had been estranged from them. It is highly unusual for women who also engage in sex work and use drugs to engage so readily with professionals, due to perceived stigma and discrimination. This is also the case for family where many women are disowned due to their choice of lifestyle.

Yet as the research indicated women became more than positive about their professional network and their families and in fact credited these people in helping shed some of their fears about having HIV. It was obvious the professional networks motivated the women and in many case were thought of as friends and family. According to the literature "[S]tudies indicate that individuals who are more satisfied with their social support are less likely to show signs of psychological distress (Schmitz & Crystal, 2000 cited in Jarman et al. 2005). It is a tribute to the women in this research that they had the ability to connect so readily. A large portion of the literature talks about negative experiences of women who are HIV positive when it comes to dealing with health and social work professionals. Negative interactions with health professionals are in fact a huge part of women's oppression and perpetuation of stigma. Berger (2004) describes how "challenging it can be for women to get the services she needs if she suspects that a provider is discriminating against her..." (p.102).

Overall there are many consistencies with other research related to women with HIV and their reactions and coping mechanisms when making decisions about disclosure and ways in which they engage with others. However as illustrated, there are also some differences and new

understanding stemming from this research, primarily the women's abilities to work with and build trust health and social work professionals. Research in relation to these unique relationships would certainly enhance understanding of these relationships and ways in which they contribute to minimizing stigma, further.

### **6.1 Implications for social work**

Previously in this paper it was suggested that there is a unique aspect to the way in which social work is carried out with women living with HIV in the DTES community. Trust building with clients, while a central requirement social work, is of great significance in this community given the high level of marginalization and inter-secting oppressions women endure.

In the findings of this research several of the women discuss their early beginnings on the street and the ways in which they adapted by becoming "hard" in order to survive. Social workers in the DTES have to learn to cater to women who have been disconnected from mainstream services and have developed coping mechanisms of survival amidst chaos and violence.

One of the implications of this research for social workers is recognising when intervention is needed. Careful attention needs to be paid to women who exist outside of the margins and social work practice should to be adapted to meet the needs of women. In the findings of this research the women responded very positively to the ways in which their support teams encouraged them to follow up on health care and appreciated home visits by several different kinds of supporters.

When working with women who are newly diagnosed with HIV or at risk for contracting the virus "health care providers need to consider the high frequency of suicidal thoughts among women with HTV infection, to be able to assess the severity of these thoughts, and to make appropriate referrals for mental health services" (Demi et al, 1998, p 351). One of the best

interventions a social worker can undertake is to be constantly alert and recognising when clients may be falling outside of the view of mainstream support services. It is clear from this research that stigmatized women living with HIV isolate and disconnect from support systems and it is up to us as social workers to recognise when this is happening and take action.

When dealing with stigmatized clients social workers are required to “begin with a self searching of our biases and our own fears of clients ‘otherness’ ” (Bunting, 1996, p.70). This is consistent with the findings in the literature that encourage health professionals to analyse these positions of power if we are to mitigate the effects of stigma. Further to interacting with stigmatized clients it is suggested that “[P]sychosocial interventions should be identified that offer stigma afflicted patients additional social support and resiliency training to mitigate the negative treatment impact of stigma” (Rintamaki, Davis, Skripkauscus, Bennett & Wolf, 2006, p .365) .

The findings in this research offer insights into the actions and reactions of women who are diagnosed with HIV as well as experiencing other areas of oppression and stigma in their lives. In conjunction with the existing literature these findings support social workers in developing innovative approaches to working with women as unique as the women who participated in this study.

## **6.2 Implications for future research**

This research provides insight into the complexities and realities of the lives of women with HIV in this community. By using narrative methodology the stories and experiences women related increased the depth of understanding of their situations. Research offers understanding for social workers and other community professionals about the day to day lives of women in the DTES. Important for application to social work practice are the themes from the feelings and

emotions of initial diagnosis and the ongoing journey of HIV in women's lives as they adjust. As professionals we hear stories about women's lives and may witness health outcomes first hand. Research reinforces the reality.

The focus of this research is narrow in scope. The women are all from a community which experiences a high levels of poverty, addiction and mental and physical health issues. The women all had experienced receiving a diagnosis of HIV. Therefore the women had similar concerns. Drawing upon the discussion of inter-sectionality and stigma the women face some considerable barriers. Through their narratives it is clear that the women have all employed various means, some different and some similar, in coping with the challenges in their lives.

Future research about women living with HIV might be expanded to a greater demographic area which would offer more depth in regard to the experience of HIV and the adjustment that comes with this diagnosis. Research might include women in Vancouver who live with HIV but not only in the DTES. Given that the women in this research have multiple barriers including addiction further enquiry as to whether women experience depression and grief based on their drug using experience or because they are HIV positive is warranted.

An inquiry into women's own views on inter-sectionality and stigma expanding on how women themselves think the two concepts impact their lives would also be useful. Deserving more attention is research investigating the type of support women require when first diagnosed with HIV and ways in which they can receive services which meet their needs in an appropriate way. The first three themes in this study discuss women's isolation and disconnection. Investigation into the ways in which women can feel supported early on would be useful for social workers and health professionals to incorporate in their practice.

### **6.3 Limitations of this research**

There are several limitations in this research. As stated previously this is a small sample with specific characteristics. I recruited from one subsidized housing facility, thus providing me with women who were all living in adequate housing environments. I also recruited from one geographic location. While I was familiar with all of the women in this research I view this not as a limitation but an asset. It is possible that this research may have been enhanced if the researcher and the participants were not familiar with each other. It is possible that the women answered as they thought I might want them to in order to “do the right thing”. This is questionable and I maintained the familiarity enhanced the narratives, however it is worth considering.

This research is concentrated solely on the lives of women with HIV. The respondents are women who also have multiple areas of oppression and marginalization in their lives. This research is limited by a full understanding of how the diagnosis of HIV in conjunction with other stressors in women lives such as drug addiction and violence. It is possible that women had difficulty discerning what was related to being HIV positive and other areas of oppression. While inter-sectionality prescribes that there are many locations of marginalization, it would be worth expanding research enquiry to the various areas of intersection and whether women feel they are affected in different ways by the various overlapping oppressions in their lives.

Future research might also explore women’s coping mechanisms towards stigma in this community. Given the incredible resilience and “survivor’s spirit” women in the DTES show this would be a topic deserved of attention for future researchers in relation to women living with HIV and stigma.

## 6.4 Summary

The five themes emerging from this research represent the voices of five different women. It would be very easy to reflect solely on the difficulty of their positions as women on the margins of society, oppressed and stigmatised by the social locations they occupy. This research is consistent with findings from other studies and literature which discusses women living with HIV and the challenges they face when faced with a chronic illness.

Using a narrative methodology within the theoretical framework of inter-sectionality combined with stigma I have presented a study which outlines some of the experiences of women diagnosed with HIV. As social workers in this community it is imperative that we continue the discussions about oppression and areas of marginalization especially for women living with HIV. By opening up and engaging in dialogue we move people from the margins and provide a voice to those who are challenged by the burdens of stigma and social dislocation.

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## Appendix A

## THE UNIVERSITY OF BRITISH COLUMBIA

**School of Social Work and Family Studies**

2080 West Mall

Vancouver, B.C. Canada V6T 1Z2

Tel: (604) 822-2255 Fax: (604) 822-8656

www.swfs.ubc.ca

**Are you a woman living with HIV/AIDS?**

I am a UBC student conducting research for my Masters of Social Work thesis.

Study Title: Lived experiences of women with HIV/AIDS

I am interested in conducting interviews about the impact of HIV/AIDS on your life.

The purpose of this study is to further examine the realities and experiences in the lives of women living with HIV/AIDS in order to aid in the development of improved services.

**I am seeking study participants who :**

- self identify as a women
- are HIV+
- speak fluent English.
- are willing to participate in 1 interview of maximum 2 hours, and a follow-up interview (1 hour maximum).

This study is supervised by Dr. Mary Russell (phone: 604-822-2795 ).

**Interested? Please contact:**

**Vicki Bright-Tel: (604)216-4255**

*Study participants will receive a \$20 honorarium.*

## Appendix B

**THE UNIVERSITY OF BRITISH COLUMBIA**

School of Social Work and Family Studies  
2080 West Mall  
Vancouver, B.C. Canada V6T 1Z2  
Tel :604-822-2255 Fax 604-822-8656  
www.swfs.ubc.ca

**Consent Form****Lived experiences of women with HIV/AIDS**

**Principal Investigator:** Dr. Mary Russell, Professor  
(604) 822- 2795  
mrussell@interchange.ubc.ca

**Co-Investigator:** Vicki Bright, BSW, MSW (student)

**Purpose of the study:**

This study aims to examine the realities and experiences of HIV/AIDS in the lives of women . The results of this study will provide useful information to service providers in their quest to provide relevant and improved services to women with HIV/AIDS.

**Objectives of the inquiry are to:**

Increase understanding of women's experiences of living with HIV/AIDS.  
Identify supportive and problematic aspects of the lives of women who are HIV positive. Uncover ways in which women utilise skills of resistance and resilience in order to negotiate their lives with the HIV virus.

**Study Procedures:**

Participation in the study will take 1-2 hours, including:

A one-hour interview in a private place, either your home or my private social work office.

Tape recording of interviews and transcription by the interviewer.

Receipt of a copy of the transcript of your interview and an further one-hour interview to discuss the transcript.

Receipt of a draft of the report if you wish.

**Confidentiality:**

Documents will be identified only by a code and kept in a locked filing cabinet; computer data will be password protected

Your identity will be kept strictly confidential

The researcher will have access to the tape of the interview for the purpose of transcribing, and will substitute a code for your name if it occurs during the interview; your name will not be in the transcript.

**Contact for information about the study:**

If you have any questions or desire further information with respect to this study, you may contact Vicki Bright at (604)216-4255.

**Contact for information about the rights of research subjects:**

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

**Consent:**

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to any services that you are or may be receiving.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

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Participant Signature Date

---

Printed Name of Participant Date

## Appendix C

## THE UNIVERSITY OF BRITISH COLUMBIA


**School of Social Work and Family  
Studies**

2080 West Mall

Vancouver, B.C. Canada V6T 1Z2

Tel: (604) 822-2255 Fax: (604) 822-  
8656[www.swfs.ubc.ca](http://www.swfs.ubc.ca)

## Question guide

## Purpose of the study

The purpose of this study is to further examine the realities and experiences of HIV/AIDS in the lives of women in order to aid in the development of improved services.

How has your life changed since finding out you have HIV?

**Probes:** Do you remember what your first reaction was when you first found out you were HIV positive?

What emotions did you feel when you first heard this news?

Did you think of anyone you could turn to for support when you first found out you were HIV positive?

What impact has having HIV had on your life in general ?

**Probes:** On your physical health?

On your mental health ?

On your spiritual health ?

On your relationships?

On how you deal with things?

What ,if any, are the positive things about having HIV?

**Probes:** Have any relationships in your life improved or become more supportive since finding out you are positive?

Have you decreased or stopped any activities which might have been considered unhealthy ?

Have you increased or started activities which might be considered healthy?

## Appendix D



The University of British Columbia  
Office of Research Services  
**Behavioural Research Ethics Board**  
Suite 102, 6190 Agronomy Road, Vancouver,  
B.C. V6T 1Z3

## CERTIFICATE OF APPROVAL- MINIMAL RISK RENEWAL

<b>PRINCIPAL INVESTIGATOR:</b> Mary Russell	<b>DEPARTMENT:</b> UBC/Arts/Social Work	<b>UBC BREB NUMBER:</b> H08-00076
<b>INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:</b>		
<b>Institution</b>	<b>Site</b>	
N/A		
<b>Other locations where the research will be conducted:</b> The research will take place in the participants private residence or a private social work office.		
<b>CO-INVESTIGATOR(S):</b> Brian O'Neill Vicki Bright		
<b>SPONSORING AGENCIES:</b> N/A		
<b>PROJECT TITLE:</b> Experiences of women living with HIV/AIDS.		

**EXPIRY DATE OF THIS APPROVAL: January 5, 2011**

**APPROVAL DATE: January 5, 2010**

The Annual Renewal for Study have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

*Approval is issued on behalf of the Behavioural Research Ethics Board*

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Dr. M. Judith Lynam, Chair  
Dr. Ken Craig, Chair  
Dr. Jim Rupert, Associate Chair  
Dr. Laurie Ford, Associate Chair  
Dr. Anita Ho, Associate Chair