

**The Many Directions of Four Stories:
Aboriginal Women's Experiences Living
with Addictions and HIV/AIDS**

by

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**THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF
MASTER OF ARTS**

in the Department

of

Sociology and Anthropology

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August 2000

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ABSTRACT

Stressing the centrality of ordinary human experience by focusing on “what is at stake” for particular participants in particular situations (Kleinman & Kleinman 1991), this exploratory study involved listening, observing, analyzing, documenting and better understanding “things as they are” (Jackson 1996) for four street-involved, HIV-positive Aboriginal women. The particular situation and voices of street-involved Aboriginal women are rarely discussed in reference to policy development in the Downtown Eastside of Vancouver, in BC, in Canada, or within anthropological literature. Accordingly, this thesis contributes to existing knowledge, grounded in the voices and experiences of the four women who discuss ‘what is at stake’ for them as HIV-positive Aboriginal women residing in Canada’s most impoverished neighborhood. The thesis highlights the particular situations and circumstances in which four Aboriginal women live that contribute to their vulnerability not just to HIV/AIDS, but to a number of constraining social factors that affect their overall health, safety and quality of life.

To understand and better appreciate the women’s lived experiences (Jackson 1996), or their positioned knowledge (Kleinman 1995), an ethnographic perspective that placed primary emphasis on narrative was utilized. Through the use of narrative, within a population health framework that takes a more comprehensive view of Aboriginal women’s health to encompass the historical, social, cultural, economic, and physical factors as they interact with race and gender, I examine *some* of the factors that impinge upon the health of Aboriginal women, directed by the four powerful stories/voices of the women themselves.

Acknowledgments

To the four women who helped create this project by sharing their personal stories, experiences and voices, I say thank you. Without your stories, this project would not have been possible.

I also would like to express my gratitude to my senior supervisor Dr. Dara Culhane for the support, time and direction she provided me over the past four years. Thanks as well to my committee members Dr. Noel Dyck and Dr. Suzanne de Castell for their input and interest and the valuable feedback they provided. Many thanks to Mickey Naisby, the graduate secretary for always making me feel welcome when I had yet another question!

Thank you to my mother, Joan Ryan, for sharing her love of books and passion to learn with both myself and my daughter. My father, Pat Ryan, for your unwavering concern and care. Our phone calls will not soon be forgotten! My youngest brother, Patrick, who has been an amazing source of inspiration this past year. To my daughter, Jaimee, thank you for being so patient and understanding while I completed my thesis. Thanks so much to all of my supportive family.

I want to thank Carmelo Miliano for going out of his way to offer computer assistance, cherished friendship and his mother's delicious cookies!

I would like to thank Marcia Guno for her wisdom and friendship. May we continue to learn and grow together.

To Collette Harrington, I extend my deepest thanks. You've been a 'second mother' to my daughter and a first-rate friend to me.

Thank you to Andrea Spencer for reminding me to take care of the physical realm throughout this process. Our long walks together 'cleared my head' and your cooking filled my tummy! Your kindness is unmatched.

To Kristi Olsen (Lundblom) and her family for providing summer sanctuary to my daughter and myself over the past four years. Being 'out at the cabin' means a lot to us both.

Many thanks to Samuel Barudin for reminding me to "do well" and for continuously showing me that "it's all in my head".

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CHAPTER ONE: INTRODUCTION

Purpose of the study

I think we Aboriginal women somehow need to find a way to develop a tighter circle together because I don't reach out to women that often, but I'd like to have healing circles, or talking circles, or Indian medicines, or Indian ceremonies or just anything that collects us together as a group... we need to be together in a circle because right now, we're all so fragmented. I'd like to be involved in that...¹

(Interview with Nadine,² June 1998).

The purpose of this research project was to better understand some of the lived experiences and needs of Aboriginal³ women living with HIV/AIDS (Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome) in the Lower Mainland of British Columbia, Canada. More specifically, this research involved collecting the narratives of four urban Aboriginal women who have past and present histories of intravenous drug use and involvement in the sex trade. The particular situation of inner city, street-involved⁴ Aboriginal women is rarely discussed in reference to HIV/AIDS policy development in the Downtown

¹ The women's voices are identified throughout this paper in *italics* and have been selected from interviews that I conducted beginning in June 1998 and concluded in May 1999.

² All of the names in this thesis have been changed to protect the anonymity of the participants. As well, I have changed or omitted personal identifiers when necessary. In so doing, some interesting and illuminating sections of our conversations had to be excluded in the 'writing up' process. That said, I have tried to maintain the individual expression of participants but it should be noted that the excerpts are edited versions of the raw transcriptions that I selected.

³ This discussion focuses on Aboriginal women in Canada. Therefore, I have used the term *Aboriginal* to refer to Status, non-Status, Metis and Inuit women of Canada, recognizing however that many Aboriginal peoples rightfully describe or identify themselves otherwise. As well, I want to point out that although I recognize the inapplicability of an undifferentiated concept of 'Aboriginal women,' I use this terminology throughout the discussion but I am not implying that *all* Aboriginal women have a similar relationship to HIV/AIDS.

⁴ My use of the phrase 'street-involved' refers to impoverished, marginalised women whose economic and social lives principally revolve around the street-level drug market and street-level sexwork. The phrase is often used by community workers in the Downtown Eastside when referring to, for example, 'street-involved youth' or 'street-involved women' – those individuals whose day-to-day lives and struggles are tied to illegal, street-level activities including prostitution, drug dealing, drug consumption, theft, etc.. However, the phrase is also commonly used by academics and researchers (see Maher 1997; Sterk 1999) as an all encompassing phrase for individuals involved in various forms of street-level, criminal activities.

Eastside of Vancouver, in BC, in Canada, or within anthropological literature. Consequently, this research project contributes to existing knowledge by including the voices of a hitherto silenced group and suggesting policy directions and theoretical questions that arise when the women's experiences become central to analysis.

As I stated above, an important aim of this project is to ground the research in the voices and experiences of the women who agreed to participate, illustrating the importance of 'lived experience' when researching health and illness. Through the women's stories and ethnographic observations made over the past three years researching and working in Vancouver's Downtown Eastside, I have constructed a discussion that not only illuminates the complexity of their day-to-day lives, living with HIV-infection and addiction, but also reveals their strength, humor, courage and active involvement in their communities. In an attempt to keep the women's voices central, I will show what sorts of issues were important to them.

How it's pieced together

In Chapter One, I begin the story by looking at myself in relation to this project, describing the various paths that I followed to get to this particular topic. In Chapter Two, I outline a brief but necessary review of Aboriginal health in this province and here I look back in time at some of the early policies and practices of missionaries, settlers and bureaucrats and how the process of colonization affected/affects the health status of Aboriginal peoples in British Columbia. An historical review is crucial in that it provides context in which to view the

contemporary state of Aboriginal health in this country. Before continuing however, I will outline what I mean by 'Aboriginal health' for I am not simply referring to the absence or reduction of disease/illness amongst Aboriginal peoples. Rather, I am thinking and writing about a much more comprehensive picture of health that encompasses the historical, social, cultural, economic and physical factors that interact with race and gender to impinge upon the health of this country's Aboriginal women.

In Chapter Three, I briefly discuss the setting: Vancouver's Downtown Eastside (DTES), and some of the relevant research that has been conducted in the DTES. In this chapter, I also outline the nature and scope of this particular study and the methods that guided my approach. I highlight the contributions of narrative method, where the women themselves decided "what is at stake" (Kleinman & Kleinman 1991: 277) for them through the stories that *they* decided to tell. In taking an in-depth look at methodology, I also point to the specific challenges faced in conducting the research for this study. Essentially, I show how *my* original research strategies were a world away from the survival strategies of the women who participated in this study.

In Chapter Four, I step aside as author to more fully present the voices, experiences, and insights of the four women. In structuring the discussion, I have deliberately chosen to place the women's stories ahead of the theoretical frames – emphasizing the necessity of their views and their understandings. In this section of the discussion, we will hear the women speak about 'what is at

stake' for them as HIV-positive Aboriginal women who reside in Canada's most impoverished neighborhood.

Chapter Five goes on to discuss the theoretical frameworks that guided the planning, process and eventual analysis of this particular project. I use the term 'frameworks' because no single formula or theoretical approach can account for what I've attempted to do here. Nevertheless, the project was guided by prioritizing lived experience over theoretical knowledge (Jackson 1996). In this chapter, I will look briefly at the population health approach as well as feminist frames, as they relate to this particular study. Mindful of the fundamental question that population health asks which is why some people are healthy and others are not, I call attention to the diverse factors and wider contexts that actually influence and shape Aboriginal women's health today – stressing the importance of gender and race as key variables to health or ill health.

Finally, the discussion section in Chapter Six offers a brief overview of the study and I also take a retrospective look at the study's limitations and suggest processes that I might do differently, were I to undertake similar work in the future. Chapter Six is where I explore some theoretical questions and directions, based on the women's experiences and voices. However, many questions remain unresolved.

I take sole responsibility for this project and I've tried to be as candid as possible about the limitations and contradictions of this particular research, as it actually unfolded. In this way, I offer some explanations for the choices I've made in researching this topic, collecting the data, as well as 'writing up' my

thesis. Furthermore, I want to emphasize that it was never my intention to speak *for women with HIV/AIDS, or for Aboriginal women, or for residents of the Downtown Eastside*. Rather, I've tried to respectfully consider four Aboriginal women's stories and experiences in an effort to raise questions and open the area to further thought and discussion. That said, my claim to speak only for myself does not mean that I have not tried to be responsible and mindful throughout the research and writing process, which includes my goals in attaining academic credentials. Nonetheless, I alone take responsibility for any of the shortcomings found within the pages of this thesis. I've come to accept that this project was about an intense learning process and during that process, I have made some mistakes yet I have tried to work and write from a place of respect. Is this really enough? I now realize that I can only enter into this process from a place that is my own, with the little experience, funds, time and energy that I have as a researcher, writer, and mother and the question above remains open and subject to perpetual reconsideration.

Before going further, I want to acknowledge the important contribution made by the women who participated in this project for they are the 'experts' on the topic of living with HIV/AIDS as street-involved Aboriginal women and without their voices, this project would not have been possible. Thus, I give thanks to the four women who courageously shared their stories with me for it was the women themselves – through the telling of their stories – who helped me to better understand their day-to-day realities and struggles, and the directions that desperately need further attention. That said, policy-makers and individuals in

the helping professions might also find it useful to read (and hear) these stories and form their own opinions about what might be done to improve the overall safety and health of Aboriginal women that call the Downtown Eastside their 'home' and to perhaps reconsider the consequences of their powerful decisions in the everyday lives of these women.

The paths that brought me here...

Before I continue, I want to discuss how I came to this research topic, my involvement in the DTES, and how this ethnographic project has evolved over the past four years. I think it is important to situate myself in relation to the research and to be clear about how things have changed over the past four years. My personal journal⁵ was invaluable here.

I've been interested in past and present issues related to Aboriginal peoples in this country since I began to take seriously my own ancestry – which includes Metis heritage - after the birth of my daughter in 1991. Prior to the birth of my daughter however, I typically avoided the issue altogether. This was often difficult to do because people were/are always asking me, "Are you Native?" or "Do you have Native blood?" Partly because of the often condescending, negative tone of the people asking these questions, and partly because I used to feel ashamed about my Aboriginal ancestry as a young child, I would often answer with "Yah, a bit" and then attempt to re-direct the conversation⁶.

⁵ I have always kept a personal journal and my journal has been an invaluable source of information about relevant dates and happenings but also about how my own views towards this project have shifted and evolved over time.

⁶ While growing up in Prince Rupert and Prince George, I can remember being afraid to talk about my Aboriginal heritage with both my Aboriginal and non-Aboriginal peers. I knew, from a very early age, that a clear division existed between the two communities and having a foot in both worlds was often confusing, to say the least. That said, I also knew that Aboriginal children faced damaging

However, I continue to squirm about various issues related to my identity and the work/research/writing that I do, *not* because I feel ashamed of my ancestry but because now I often feel, "not Native enough" to involve myself in areas perhaps better looked at by "full-blooded" Aboriginal people or by "Status Indians." Realizing that this serves no purpose, I still find myself downplaying my Metis roots (I also have Scottish and Irish ancestry) and in the near future, I plan to treat my identity as "an area requiring further research." However, I know I'll have more to say as my journey along this particular path continues and as I grow and change. For now, suffice it to say that I have actively increased my involvement in Aboriginal issues over the past ten years because I have actively increased my recognition of and respect for my Metis heritage.

My interest and involvement in the area of HIV/AIDS and Aboriginal peoples began in 1996 while I was working on an undergraduate degree in anthropology at Simon Fraser University (SFU). During my last semester, I was hired by the SFU Native Student Centre to assist newly admitted Aboriginal students with their transition to SFU. In this position, I met an individual who was working 'next door' at the Centre for Students with Disabilities. On the wall of his office there was a poster of Buffy Sainte-Marie speaking out about HIV/AIDS in Aboriginal communities which read as follows:

Life is our most sacred gift from the Creator. As the First Peoples of this land, it is our obligation to protect and cherish that life for the sake of our children, our communities and the future of our peoples. One of the most important steps that we must take to preserve our lives and the lives of others is to inform ourselves and our communities about the dangers of HIV and AIDS. This disease is perhaps the greatest threat to our efforts to reclaim our place as sovereign peoples and to make our invaluable contributions to the future of humankind. This is my personal plea to you to be informed

stereotypes/teasing and I actively tried to distance myself from my Aboriginal heritage because I had internalized these images from a very young age. My learning and un-learning continues!

and to protect yourself, your loved ones and your communities from HIV and AIDS. Our future is so bright and ripe with possibilities... let's be there to see it, together (1996 Ontario Aboriginal HIV/AIDS Strategy).

Although this may seem a somewhat awkward beginning, it was this poster that propelled me towards thinking seriously about HIV/AIDS and Aboriginal peoples⁷.

In an effort to better inform myself about HIV/AIDS, I began to have daily discussions with my colleague at the Centre for Students with Disabilities and at my prompting, he would speak about his partner's work at AIDS Vancouver.

Within three weeks, I was being interviewed by the volunteer coordinator at AIDS Vancouver. In this meeting I mentioned that I was interested in working on the Care Team Project⁸ with Aboriginal women living with HIV/AIDS. However, the coordinator explained that there were very few Aboriginal clients and even fewer female Aboriginal clients utilizing AIDS Vancouver but that I could go through with the orientation training and see where things went from there.

After completing the AIDS Vancouver core training seminar in September of 1996, I was placed on a 'Care Team' and my first 'buddy' visit took place at the Surrey Memorial Hospital on October 29, 1996 with a self-described "heroin junkie". During my visits to the hospital, Laura⁹ and I covered a range of topics but what struck me the hardest was the fact that other than medical professionals, I was the *only* person that Laura had had contact with since being admitted to the hospital four weeks prior to my initial visit with her. Sadly, I was

⁷ I want to acknowledge and thank Tony Botello for his gentle encouragement to get involved with AIDS Vancouver and for giving me a copy of the poster I am speaking of here.

⁸ The 'Care Team Project' involves groups of 10-14 volunteers, trained to respond to the on going practical and companionship needs of individuals (or 'buddies') living with HIV or AIDS. Each team is coordinated in its efforts by a Care Team Facilitator, who receives direction from the Program Coordinator of AIDS Vancouver. Some of the services provided by care team volunteers include household tasks; shopping; transportation; hospital visitation and companionship at home.

⁹ 'Laura' is a pseudonym.

still the only visitor to have seen or spoken with Laura when her internal organs failed, causing her death on November 21, 1996. For almost two months, Laura lay in a hospital bed where she would eventually die - alone - at the age of 26, the same age as I was at that time. Reflecting on Laura's fate, I wrote in my journal:

I don't think you can ever really know which way life will take you or how it will take you in the end. I was thinking about Laura's death again today and the call I received from her father and I began to think that maybe I should have talked to him some more about our [Laura's and my] conversations in the hospital... I felt sick to my stomach this morning, thinking about Laura and her family. Addiction really rips things apart and I've been thinking about my own issues and my own family and I've been wondering if this is an area that I should be getting involved in (personal journal entry, November 1996).

I did, however, continue to work on the 'Care Team Project' visiting and assisting HIV-positive clients in their homes and in the hospital. However, in December of 1996 I also began volunteering at Healing Our Spirit: BC First Nations AIDS Society¹⁰ (HOS) and within a few months, I shifted my energy and time to this Aboriginal HIV/AIDS organization. My decision to volunteer at HOS was influenced by conversations I had with the volunteer coordinator at AIDS Vancouver. Understanding my request to assist *Aboriginal* people living with HIV/AIDS, she agreed that I would be better off working with an Aboriginal HIV/AIDS organization since she was unable to place me with any Aboriginal clients of AIDS Vancouver at that time.

Subsequently, I began to volunteer for HOS. At that time they were in need of a receptionist, so for the next few months the majority of my volunteer hours were spent working in the main office in North Vancouver. Over time and

¹⁰ Healing Our Spirit (HOS) provides support and services to Aboriginal people living with HIV/AIDS as well as the promotion of community prevention and awareness strategies. HOS was co-founded in 1992 by Leonard Johnson and Frederick Haineault, who have since died of AIDS.

out of necessity, I was also asked to visit with hospitalized Aboriginal individuals who had little or no support and who were requesting visitors through HOS. I began visiting with some very lonely and isolated HIV-positive Aboriginal women at St. Paul's Hospital and around this time, I began to formulate ideas about how I might research and write about Aboriginal women living with HIV/AIDS. Originally, I applied and was accepted into the MA program with the intention of researching and writing about female-headed, single-parent families. However, I changed my research focus during my first semester in the graduate program, which I entered in September of 1996.

While attending a meeting for HOS volunteers in April of 1997, I began to discuss some of my research ideas with a woman who also volunteered at HOS during a 'smoke-break.' We began to talk about different research methods, specifically interviewing. At the close of this meeting, this individual approached me again and asked if I would be interested in working on a study that involved interviewing HIV-positive First Nations people in the Lower Mainland of Vancouver. When I expressed an interest in this project, she passed me a business card and encouraged me to give the project coordinator a call.

In May of 1997, I was employed by the "First Nations Community Health Resource Project (FN-CHRP)," a 15-month study which looked at the direct and indirect costs of living with HIV for Aboriginal peoples currently residing in Vancouver, British Columbia. FN-CHRP was a joint partnership project between the University of British Columbia, St. Paul's Hospital, and The Assembly of First Nations. More specifically, FN-CHRP was an offshoot, pilot project that

developed out of the initial 'Community Health Resource Project' and upon completion of FN-CHRP, I continued to work at CHRP until the interviewing was complete. In my position as an interviewer, I conducted well over a hundred interviews with individuals living with HIV/AIDS in various spaces including Vancouver Native Health, St. Paul's Hospital, Healing Our Spirit's satellite office on Broadway, the Pacific AIDS Resource Centre, the Dr. Peter Centre, various restaurants in the DTES, and in participants' homes/hotel rooms. However, since I was employed to conduct interviews with HIV-positive *Aboriginal people specifically*, the majority of the interviews that I conducted took place in interviewing rooms located at Vancouver Native Health in the DTES of Vancouver.

During this project, I developed a good rapport with many of the participants in this study. To some degree, these relationships evolved out of the structure of this particular project which involved interviewing individuals every three months, over a 15-month time frame. This got me to thinking that I might actually be in a better position to collect data by interviewing women whom I had come to know through FN-CHRP.¹¹ In January of 1998, I approached my senior supervisor (Dara Culhane) and the principal investigator at FN-CHRP (Robin Hanvelt) about the possibility of conducting interviews for *my* graduate research with Aboriginal women that I had made contact with through my employment at FN-CHRP. At that time, both of these senior researchers supported this decision

¹¹ As a single-mother, full-time graduate student and part-time employee, my decision to interview women who I had already established relationships with was a practical one. However, there were ethical considerations involved in this decision as well and in Chapter Two I discuss my approach and some of the implications of this decision.

but they both strongly expressed the importance of keeping the two projects entirely separate. Keeping participants informed about the distinct aims of the two projects was not all that difficult, however, especially considering that the two projects had very little in common.¹² In fact, from the very beginning of my employment with FN-CHRP I had told everyone (participants, fellow researchers, staff at agencies where I was conducting interviews for FN-CHRP) that I was also an anthropology student doing graduate research on 'Aboriginal Women's Experiences Living with HIV/AIDS'. In brief, this is how I came to know and interview the four women who participated in the research that I conducted for this MA thesis. Undoubtedly, my position at FN-CHRP gave me an advantage in approaching prospective research participants and I think it is important that I make this known here.

Another recent endeavor that has surely added depth to my thinking and writing was an unexpected offer of employment with the Youth Action Centre (YAC) which is part of the Downtown Eastside Youth Activities Society (DEYAS)¹³. In November of 1998, I received a phone call from a friend of mine who was employed through YAC and he asked if I would be able to help out the centre by cooking meals for approximately 40 – 80 street involved youth that frequented the centre on a daily basis. The previous cook had left unexpectedly and the centre was desperately trying to find someone who could fill in until they

¹² See chapter two for a more detailed account of the selection of participants.

¹³ The Youth Action Centre (YAC) is a drop-in facility for street-involved youth in the DTES. YAC offers a safe environment for young people to hang out and access services which include two hot meals daily, showers, laundry facilities, foodbank access, advocacy, recreational programs/out trips and a job experience program. The Downtown Eastside Youth Activities Society (DEYAS) was created to deliver outreach services to street-involved people, youth and adult, in Vancouver's Downtown Eastside. Programs

had a chance to hire another employee. I knew that the Youth Action Centre was a 'difficult gig' and I knew that I should be focusing specifically on my graduate work, yet I decided to give it a try. At the time, I anticipated filling in for a week or two. However, one week turned into two, then three and eventually I ended up working as front-line staff at the Youth Action Centre for 10 months. Challenging both emotionally and physically, this position became somewhat overwhelming in that I knew I had to get back to work on my degree, but at the same time I began to think that my research and writing was simply not all that important anymore. When I did finally resign from YAC (and my work thus far in the DTES) I felt as though I had betrayed both the youth and the women that I had come to know in this community in favour of a far-removed academic world that I had completely distanced myself from. In what follows, I attempt to re-connect with that academic world, bringing with me a little more experience, a little more knowledge and four powerful stories/voices from the DTES.

include the Health Outreach Vans, the Needle Exchange, and the Alcohol & Drug Counseling Program along with crisis management, advocacy, referrals and risk reduction initiatives and services.

CHAPTER TWO: A BRIEF HISTORY

When the wind blows, that is my medicine
When it rains, that is my medicine
When it hails, that is my medicine
When it becomes clear after a storm,
that is my medicine

- Anonymous

The purpose of this section is to describe the context that Aboriginal health is embedded in, in this country. This is a crucial starting point if one's aim is to better understand contemporary issues and challenges related to and impinging on Aboriginal women's health status. I focus here on some of the policies and practices (past and present) that have shaped Aboriginal health in *British Columbia* specifically. Thus, in an effort to better understand how and why Aboriginal peoples continue to be identified as the most unhealthy population in Canada, I focus on the relationship between public policy (past and present) and Aboriginal health status. I begin by looking specifically at pre-contact Aboriginal health before moving on to review the evolution of early policies and practices developed in relation to Aboriginal peoples in this province including the relentless usurpation of what were, traditionally, Aboriginal lands and resources, the promotion and establishment of the reserve system, as well as the residential school system. Therefore, this chapter offers a *brief* history of Aboriginal health in British Columbia by looking specifically at the relationship between early policy and practice and the decline in Aboriginal health status, but the issues covered here are far from exhaustive¹⁴. That said, my aim here is to

¹⁴ For a more detailed account of Aboriginal health in British Columbia specifically, see Kelm's *Colonizing Bodies: Aboriginal Health and Healing in British Columbia: 1900 – 1950* (1999); and Stephenson, Elliott, Foster and Harris (eds.) *A Persistent Spirit: Towards Understanding Aboriginal Health in British Columbia* (1995).

illustrate some of the more salient historical policies and practices relating to and impinging on contemporary Aboriginal women's health in British Columbia.

The picture of (pre-contact) health

In British Columbia, the end of the pre-contact period is generally marked at a point in the eighteenth century when European explorers or fur traders made contact with various Aboriginal peoples inhabiting this vast area¹⁵. Many investigators of pre-contact health and disease argue that British Columbia's Aboriginal peoples enjoyed relatively healthy lives prior to contact as they concentrated "along the resource rich coast-line and major river systems" (Acheson 1995: 1). Although infectious diseases were not entirely absent in the pre-contact period, Boyd (1992: 249) points out that Old World diseases were introduced much later on the Northwest Coast, but archaeological evidence of diseases amongst the various Aboriginal nations of British Columbia is limited. However, four chronic diseases (viral pneumonia, non-venereal syphilis, tuberculosis and trachoma) were known to pre-contact peoples of the western hemisphere, but as Acheson (1995) points out, "there is no evidence of the kinds of high-mortality density-dependent infectious diseases common to the Old World prior to cultural contact"(9). Moreover, although tuberculosis had been documented among various pre-contact Aboriginal groups in North America, it was not documented in British Columbia until after contact when tuberculosis was first recorded among the Nuu-chah-nulth at Nootka Sound in 1793 (Boyd

¹⁵ I recognize that I am making some fairly broad generalizations regarding Aboriginal peoples and the pre-contact period and I want to point out here that there are, in fact, *many* pre-contact histories in the area we now know as British Columbia.

1990: 137). Even though it is difficult to determine pre-contact population size in British Columbia, a growing body of data argues for a substantially larger pre-contact or pre-epidemic population for Aboriginal peoples in British Columbia. Acheson points to earlier pre-contact estimates for this province, including that of Mooney's 86,000, Hill-Tout's 125,000 and Duff's figure of at least 80,000, "a number which had declined to 28,000 province-wide by 1885, and reached a low of just 22,000 in 1929" (1995: 11).

In the report of The Royal Commission on Aboriginal Peoples (1996) the pre-contact period is described as follows:

...Aboriginal people had adapted well to their home environments: they had developed effective resistance to the micro-organisms living alongside them and had knowledge of herbs and other therapies for treating injury and disease. Of course, some Aboriginal people died prematurely. But more stayed well, or recovered from illness, and thus lived to raise their children and continue the clans and the nations (Vol. 3: 112).

As described above, Aboriginal peoples lived generally healthy lives throughout the pre-contact period but at various times and in various places, Aboriginal peoples' lives and health would have been disrupted by disease, bouts of starvation, and inter-tribal warfare. In their discussion of pre-contact Aboriginal health in Canada, Waldram, Herring and Young (1995) suggest that:

While an idealized, disease-free paradise was unlikely ever to have existed, there is sufficient documentary evidence to suggest that a series of epidemics and famines of varying extent, severity, and duration affected different regions at different times subsequent to contact (65).

By the 18th Century, however, Europeans began to arrive on the coast of what is today British Columbia and with their arrival came new contagions that would eventually prove disastrous to Aboriginal groups who lacked immunity to these foreign pathogens. Discussing the initial period of contact on the Northwest Coast, McMillan (1988: 205) posits that despite the epidemic outbreaks of

disease brought by boat and spread by European explorers/traders, the effects of initial contact were generally positive for Aboriginal groups along the Northwest Coast. Before *sustained* contact and settlement then, McMillan suggests that “traders were only interested in making a profit and had no desire to usurp the land or convert the heathens. Individuals who held such goals, however, were not far behind” (1988: 205).

The post-contact period & the loss of Aboriginal bodies

The devastating impact of European diseases and the subsequent population decline amongst Aboriginal nations after contact is an extremely significant chapter in the history of Aboriginal health in this province. However, the introduction of new diseases would pale in comparison to the destructive impacts of early colonial policy and practice in British Columbia. Before moving on to discuss past policy and practices in this province, I briefly review the Aboriginal population decline that occurred because of newly introduced pathogens brought by Europeans in the 18th Century.

The consistently poorer health¹⁶ of Aboriginal peoples since contact has a complex history but the vast majority of research supports the notion of increased ill health following the post-contact period. Discussing this period, Waldram, Herring and Young (1995) have stated that “as the years passed, however, it became increasingly evident that the poor socio-economic conditions of the

¹⁶ Although there has been a dramatic recovery of the Aboriginal population since the end of the 19th Century, health indicators (infant mortality rates, levels of infectious disease, overall mortality rates, for example), and social indicators (poverty, unemployment, sub-standard housing, substance abuse) have *consistently* shown that the gap separating Aboriginal from non-Aboriginal people with regard to health status and quality of life remains stubbornly wide. Although some communities have made great strides toward the dynamic state of health, “many health and social problems go unchecked and some are getting worse” (RCAP, Vol. 3: 108).

Indians, including sanitation and education, were to a large extent responsible for their relatively poor health" (164). Nevertheless, there is also a substantial body of literature that plots the routes of early diseases after contact and their insidious effects on the biological, social, cultural, and economic well-being of Aboriginal peoples (Meister 1976; Dobyns 1983; Herring 1993; Thornton, Miller, and Warren 1991; Stephenson et al. 1995; Kelm 1999). Warfare and starvation would have continued to contribute to population losses as well but it was the introduction of infectious diseases such as smallpox, measles, polio and influenza that would kill massive numbers of indigenous peoples in the post-contact period.

By the early 1900s, tuberculosis had become a major cause for concern in this province and "of the 38.5 percent of deaths attributable to infectious diseases in 1935, almost 31 percent were due to tuberculosis among British Columbia's First Nations population" (Kelm 1999: 7). Furthermore, it would not take long before certain Aboriginal nations would begin to see their members dying of various infectious diseases at an alarmingly high rate. In fact, Kelm (1999) points out that by the mid-1940s:

Aboriginal people in Canada were seven times as likely to die of pneumonia, thirteen times as likely to die of whooping cough, nine times as likely to die of influenza, and forty-six times as likely to die of measles as their non-Aboriginal counterparts (10 – 11).

The devastating impact of declining populations and the transformation of Aboriginal peoples in British Columbia from a state of good health to one of ill health worsened as Aboriginal peoples' entire lifeways were threatened:

These losses not only posed a threat to the stability and continuity of social institutions through the loss of cultural knowledge, but the occurrence of these diseases also posed a direct challenge to traditional religious beliefs that in itself was a source of distress. Demoralization itself undoubtedly worked to compound the clinical impact of the epidemics (Acheson 1995: 18-19).

Thus, although thousands became sick and died as a result of sustained contact with Europeans, devastating losses would also be felt in terms of long-standing values, social systems, spiritual practices and traditional economies which were gradually undermined or outlawed altogether by the policies and practices of early governing structures (Royal Commission on Aboriginal Peoples, Vol. 3, 1996: 113). However, the usurpation of Aboriginal lands (and resources) would prove extremely significant as well and I turn now to this particular area.

The loss of Aboriginal lands (and health)

The historical trend of controlling "Indians and Indian land," as a basis of government policy, is significant as present day political structures continue to deal with the fundamental errors of policies that were constructed centuries ago. In brief, the control of Indian lands has often led to the direct control of Aboriginal politics, economies, spirituality and virtually every aspect of Aboriginal peoples' lives¹⁷. Thus, although Britain's initial Indian policy aimed to 'protect' the Indian¹⁸ from European exploitation, the imperial government began its 'civilizing' land-based experiments vis-à-vis Indian policy by the 1830s. As Tobias (1976) describes:

Indians were encouraged to gather and settle in large villages on these reserves, where they could be taught to farm and would receive religious instruction and an education. These endeavors became the basis of the reserve system in Canada. The reserve system, which was to be the keystone of Canada's Indian policy, was conceived as a social laboratory, where the Indian could be prepared for coping with the European (41).

¹⁷ For a more thorough review of Canadian policy, see Dyck 1991; Miller 1989; Dickason 1992; and Tobias 1976.

¹⁸ See Tobias (1976) for an outline of Canada's early Aboriginal policies. In outlining the history of Canada's Indian policy since the 1700s, Tobias illustrates how government policy evolved from the notion of protection and then civilization and finally, towards the aim of complete assimilation of Aboriginal peoples.

Essentially, the 'civilizing' regime attempted to re-socialize Aboriginal peoples by encouraging them to abandon their "heathen" ways of life and to instead adopt what the British believed was a more civilized, European standard. Although controlling Aboriginal peoples was typically served by the official practice of treating with the indigenous population for their lands, Brody (1981) suggests that Indian resources and lands were further appropriated because of the treaty-created reserve systems which "came under the administrative control of Whites, a control which created possibilities (not all of them legal)..." (70).

Thus, with the reserve system well on its way by the early 1800s, the government further extended its control over Aboriginal lands and peoples in the late 1800s with the passing of the Indian Act in 1876.

The 1876 Indian Act and subsequent amendments contained provisions which attacked traditional Indian sexual, marriage, and divorce mores and furthered the Christian-European values. Into this category fall the sections relating to illegitimate children, non-band members on the reserve after sundown, non-Indians on reserves and cohabiting with Indians, and Indian women in public houses (Tobias 1976: 45).

It should be noted however, that the Aboriginal population did not passively accept the vast amount of control exercised by these early bureaucrats. However, "resistance on the part of Indians was met almost invariably by amendments to existing legislation or by new acts designed to achieve Indian 'advancement'" (Dyck 1991: 53). Although many of the early policies developed in relation to Aboriginal peoples consistently failed to bring about the anticipated outcomes ('civilization' and assimilation) and were often distrusted by Aboriginal people themselves, the oppression and domination continued with the aim of somehow creating an 'invisible Indian' in an 'invisible land'.

By controlling Indian lands and peoples, both directly and indirectly since the pre-Confederation period, governments have slowly attempted to strip Aboriginal nations of their identity, dignity and cultures while operating under the notion of simply 'doing what's best' for Aboriginal peoples by way of 'managing' their lives. However, Dyck (1991) highlights the downplayed role of the state in creating and sustaining the relationship between governments and Aboriginal peoples in this country:

What Indian administrators and Canadians generally have failed to appreciate, however, is that the Indian 'problem' is not an inherent condition or a 'thing,' but the underlying premise of a relationship. As prominent partners in this relationship, Euro-Canadian attitudes and actions towards Indians are and always have been an essential part of the 'problem'... It is time that Euro-Canadians acquainted themselves with the political and bureaucratic system of Indian administration which has historically governed Indian communities and which continues to manage the Indian 'problem' on their behalf (2-3).

Consequently, it was not just the devastating decline in population due to newly introduced pathogens that would cause concern for the various Aboriginal nations in British Columbia but also the "governmental policy-makers, civil servants, and legislators who consistently sacrificed Aboriginal bodies for 'provincial development'" (Kelm 1999: 177). It must be stressed, however, that the increase and spread of disease and subsequent decline in health conditions experienced by many Aboriginal groups *after* sustained contact was not because of an 'inferior Aboriginal body.' Rather, the rapid decline in health status and the conditions affecting health can be attributed, for the most part, to the individual and collective suffering that has come about from the on-going, colonial practices of controlling Aboriginal lands, notions of solving Aboriginal 'problems,' and relentless attempts to manage Aboriginal people's lives.

Policy & health in BC: the 20th Century

In this section, I describe specific examples of how the ill-health experienced by many Aboriginal peoples - then and now – was not and is not because of a lack of ability to effectively fight disease. Rather, Aboriginal health issues of the past and the present have come about because of colonization – both its discourses and its practices – which have created a multitude of interrelated historical, economic and social issues that continue to impinge on Aboriginal lives and health.

Kelm highlights some of the more notable changes in Aboriginal lifestyles after the arrival of Euro-Canadians in British Columbia (as settlers, missionaries, and bureaucrats), when she explains that:

Restrictions on the food fishery and on the taking of game, along with the alienation of plant-food harvesting sites, threatened indigenous food supplies. At the same time, non-Native employers and further government regulation limited the ability of Native workers to participate fully in the emergent cash economy. Reserve allocations were seldom sufficient either to provide for the subsistence needs of the resident population or, increasingly, even to supply adequate accommodation. Conditions of poverty, possibly for the first time in northwest coast Aboriginal history, became endemic. And with this poverty came undernourishment, poor housing conditions, and greater susceptibility to disease (1999: 174-175).

This process of geographic, social, cultural and economic marginalization worked to further jeopardize the health status of Aboriginal peoples. In fact, the poor reserve conditions Kelm refers to above would eventually provide one of the justifications for uprooting Aboriginal children and placing them in the residential school system “where their bodies were further shaped through malnutrition, overwork, overcrowding, and an alienating curriculum of ‘health education.’ Aboriginal bodies, their reshaping and ‘re-formation,’ then, were central to the processes of colonization” (Kelm 1999: 175). In fact, the residential school

system provides an excellent example of how policy and practice affected the health status of Aboriginal peoples in the province and it is to this early government initiative that I will now turn.

The Residential School System in BC

After the passage of the Indian Act in 1876, the federal government and the Christian churches escalated their campaign to assimilate Aboriginal peoples, languages and values with the founding of the residential school system. Initially, the residential school system was viewed as a pathway from the Aboriginal world into the non-Aboriginal community and this “passage was marked out in clear stages: separation, socialization and, finally, assimilation through enfranchisement” (Royal Commission on Aboriginal Peoples 1996, Vol. 1: 342). Nevertheless, the ‘pathway’ to the non-Aboriginal world often led Aboriginal students, families and communities into deteriorating health. For many pupils, the system actually led to an early grave. Although hundreds of former Residential School students in BC have come forward to have their voices heard regarding mistreatment they experienced while attending this colonial educational system, there are also those who were able to resist and develop creative strategies during and after residential schooling. Here, I will briefly look at both the mistreatment and the resistance movements created by former students. In this section, I also highlight some instances where gender clearly impacted the ways in which Aboriginal girls/women experienced this colonial education system.

Kelm (1999: 59) points out that by 1900 there were eleven residential schools in British Columbia and that in all, eighteen residential schools were operating in this province during the first half of the twentieth century. One of the specific, official, aims of residential schooling was to enhance Aboriginal health. However, a plethora of research and writing has revealed the predominantly negative impacts that the schools have had on the health of both their pupils and subsequent generations¹⁹. In fact, the residential school system has been implicated in undernourishing and overworking its student population as well as creating and maintaining unsanitary and overcrowded living conditions in the schools themselves. These deplorable conditions would eventually be linked to the high death rate among Aboriginal pupils from the rapid spread of infectious illnesses such as tuberculosis. More recently, residential schooling has had an even uglier side revealed as countless narratives continue to be told that speak of sexual, physical and emotional abuse at the hand of school officials. In the report of the Royal Commission on Aboriginal Peoples, this process of radical re-socialization was further compounded by mismanagement, underfunding and the provision of inferior educational services (1996, Vol. 1: 337).

In relation to Aboriginal women, residential schooling held firmly to yet another objective which involved the training of Aboriginal girls and women in a foreign standard of domestic labour. Regardless of Aboriginal peoples extensive and accomplished histories on this continent, the missionaries were convinced that Aboriginal women were incapable of 'proper' parenting and housework.

¹⁹ See, for example, Haig-Brown (1988); Assembly of First Nations (1994); Royal Commission on Aboriginal Peoples (1996), Vol. 1, Ch. 10; Cariboo Tribal Council (1991); and Miller (1996).

Kelm (1999) argues that during the early 1900s, "residential schooling was seen as leading the First Nations to health, both by removing children from the clutches of supposedly negligent and ignorant parents, and by teaching them Euro-Canadian standards of cleanliness and care" (62). Thus, it was the dual discourses of inadequate mothering and inferior cleanliness (or 'whiteness') in the home, that would clearly affect the ways in which Aboriginal girls and women were 'retrained' in the residential schools. For female Aboriginal students, a residential school 'education' went beyond learning about European customs and European history. By focussing on domestic chores such as sewing, knitting, cooking, ironing and cleaning, these church-run schools attempted to 'clean up' brown girls and brown women who would in turn 'clean up' brown men and brown children. However, this 'pathway to civilization' was met with resistance as well, as some Aboriginal students developed creative strategies to cope with being separated from their families and communities while others found ways to make residential schooling work to their advantage upon returning home.

Fiske (1996) describes the aim of both the federal government and missionaries to train Carrier female students to become farm wives and members of a nuclear household unit in the reserve setting. Fiske goes on to explain that "their education included primarily "domestic sciences," reading, arithmetic, and religious instruction. Since the missionaries clearly intended that the girls become "Catholic" wives and mothers, submissive to male authority, all school activities were subordinated to religious instruction and ritual" (167). Fiske goes on to illustrate how some Carrier women selectively utilized the knowledge and

skills they had gained at the Lejac Residential School while resisting Euro-Canadian models of patriarchal authority. She describes the situation as follows:

Although the Indian Act denied women direct participation in their band's affairs before 1951, women utilized their schooling to influence community decision making. In the 1940s, for example, former Lejac students organized local protests against the harsh conditions at Lejac. Carrier women refused to enroll their children and wrote letters to Ottawa demanding changes... Women broadened their community responsibilities. It was they, rather than men, who had the literacy essential to effective political action. Once again they lobbied and petitioned the government, this time struggling for improved housing, health services, and social assistance (1996: 178).

Aside from its harsh routine and patriarchal tendencies then, *some* Carrier women were successfully able to resist and eventually take advantage of their experiences at Lejac by marketing domestic skills and assuming leadership roles in their home communities.

Haig-Brown (1988) also discusses 'pockets of resistance' against injustices at the Kamloops Indian Residential School, noting that maintaining silence, running away, wearing make-up and stealing food to supplement the limited nutrition offered by the school were some of the ways in which Aboriginal students retained a sense of control over their lives. Illustrating the extent and complexity of Aboriginal resistance by collecting the narratives of 13 former students, Haig-Brown concludes that:

The strength of Native culture is evident in the way Native people dealt with the institution of residential school by successfully resisting its interventions in their lives. Repelling its goal of assimilation, Native people adopted aspects that appeared worthwhile while rejecting others. Those who questioned, who refused to accept the authoritarian system perpetuated upon them, survived (1988: 160).

Although the assimilation of "the Indian," by way of reeducating and retraining Aboriginal pupils, would prove to be an unattainable mission - the unfinished business of the church and state continues to wreak havoc on many lives today. Moreover, although *some* students were/are able to resist the negative impacts

of this colonial education system, very few Aboriginal bodies went unaffected by the appalling conditions at the schools.

In fact, even the large number of reports on the “condition of children – hungry, malnourished, ill-clothed, dying of tuberculosis, overworked – failed to move either the churches or successive governments past the point of intention and on to concerted and effective remedial action” (Report of the Royal Commission on Aboriginal Peoples, 1996, Vol. 1: 365). Instead, mistreatment and neglect on behalf of church and government was routinely ignored, resulting in conditions that led to the abuse and death of large numbers of Aboriginal students. As well, the substandard conditions and mistreatment that many Aboriginal children had to endure while attending these church-run institutions have been linked to the dysfunctional conditions found within many contemporary Aboriginal communities today. In fact, the residential school system has been implicated in the dislocation and decreased parenting skills of Aboriginal peoples and increased emotional, mental, and physical health issues as a result of the various forms of abuse that took place. Speaking about being sexually abused as a young boy by his dormitory supervisor for three years, William Blackwater of the Gitksan Nation, linked the higher rates of HIV/AIDS amongst Aboriginal people to the legacy of Indian Residential Schools in British Columbia:

Now anyone who claims that Aboriginal people with HIV/AIDS has a very minimal connection to the legacy of Indian Residential Schools, obviously hasn't spent any time at all in the Residential School System. Visualize the obvious connection – the very fact of our Aboriginal continuous destructive behaviors should be evident enough. The prisons are full of First Nations people who have either gone through the Residential School System themselves or a member of their family has. The loss of connection, being stripped of our dignity and self-respect should be evident enough. We have lost our identity. The skid-rows of every city across Canada are full of our First Nations people who have no other place to call home upon completion of their sentences in various Indian Residential Schools. These survivors are coping with their own traumatic

memories by the only means that is easily accessible – alcohol and drugs. These very survivors share whatever is needed to ease their painful memories, including needles... Ultimately, after all the various abuses endured, it would be absurd that the term "safe sex" would carry a significant prevention meaning to them (BC Aboriginal HIV/AIDS Task Force Report, "The Red Road – Pathways to Wholeness", 1999: 17).

Unfortunately, the residential school system existed in this province up until the 1970s, but the immeasurable damage of this early government initiative continues to weigh heavily on the lives, spirits, and health of individuals, families and entire communities.

In briefly reviewing an historical context in which to view contemporary Aboriginal health issues, I've shown that the clear-cut exploitation of Aboriginal lands, resources and peoples – along with the evolving policies and practices of governments - have all worked together to alter Aboriginal lifeways, thus altering the state of health of Aboriginal peoples. In fact, the historical trend of controlling Indian lands as a basis of government policy in this country has proven to be extremely significant since control of Aboriginal lands has often led to the direct control of virtually every other aspect of Aboriginal people's lives. In this section, I've alluded to some of the disastrous effects that early policy and practices had on the lives of Aboriginal people in British Columbia. I have shown above that the residential school system can be viewed as a prime example of the undeniable relationship between poor government policy and practice and poor Aboriginal health. That said, looking at early policy and practices also points to the resilience and determination of Aboriginal peoples to survive and work towards realizing a vision of healthier individuals, families and communities. Despite disease and increased disruption in their communities, Aboriginal peoples have survived by adapting to and resisting policies and practices that

have attempted to wipe out their distinct cultural identity. In this way, an historical context also reveals the strength, resistance and perseverance of Aboriginal peoples to survive an uninvited and relentless political process that began during sustained European contact. However, I have also shown that this political process worked to break down Aboriginal bodies and spirits, and that past policies undoubtedly contribute to the poorer health of many Aboriginal people and communities today²⁰. Sometimes explicit, sometimes not – the misguided policies that stemmed from a practice of ‘taking care’ of Aboriginal people²¹ over the past two hundred years have clearly contributed to the substandard health of the First Nations of BC. In the following section, I will show how contemporary policy compounds this historical experience in the context of urban Aboriginal peoples today.

Some contemporary issues

Until 1969, assimilation was still the major goal of federal “Indian” policy as evidenced by the White Paper Policy announced during that same year. However, following the Calder case in 1973 (and the Supreme Court of Canada’s recognition of Aboriginal Title), Canada officially adopted a new agenda based on nation-to-nation negotiations, but many believe that the old ideas of assimilation remain intact (Report of the Royal Commission on Aboriginal Peoples 1996, Vol. 1: 314). Regardless, the detrimental impact of colonization on the state of

²⁰ In *An Error in Judgement: The Politics of Medical Care in an Indian/White Community* (1987), Culhane Speck provides a concrete account (through the words of community members in Alert Bay) of the experience of colonialism, Indian policy, and poor Aboriginal health.

²¹ See Dyck (1991) for an in depth look at the past and present relationship between Aboriginal peoples and the governments of Canada. Particular attention is paid to the ways in which the Indian ‘problem’ was created and sustained through the application of ‘coercive tutelage’ to manage Aboriginal affairs.

Aboriginal health continues as research consistently shows that the health status of all Aboriginal peoples is significantly below that of the national average. In fact, the average life expectancy of Aboriginal people is still approximately 12 years shorter than that of average Canadians (British Columbia: Provincial Health Officer 1997: vi). Thus, at the start of the twenty-first century, the majority of British Columbia's Aboriginal population continues to experience poorer health than non-Aboriginal populations of the province. The contemporary picture was described as follows by the Provincial Health Officer for British Columbia in 1995:

In British Columbia today, it is apparent that... Aboriginal communities have substantially poorer health... This is manifested in many health indicators, such as a much higher infant mortality rate and higher rates of suicide, injuries and tuberculosis. This is primarily the result of relatively low incomes, increased unemployment rates, poor housing, low duration of education and insufficient control over living and working conditions (Millar 1993, cited in Foster et. al. 1995: 45).

On average, Aboriginal people have higher levels of violent deaths and suicides, higher rates of incarceration and higher rates of teen pregnancy. Aboriginal people also experience more poverty and higher rates of drug and alcohol consumption and because these rates continue to grossly outstrip those of other Canadians, Aboriginal people also face an increased risk for HIV-infection. A 1998 discussion paper, published by the Canadian HIV/AIDS Legal Network, argues that Aboriginal people are disproportionately represented in groups designated as 'high risk,' including injection drug users and prison populations. The paper also puts forth a number of 'risk factors' that are influencing the rapid spread of HIV amongst Aboriginal people:

- **low rates of safer sex practices (indicated by high rates of teenage pregnancy and high rates of sexually transmitted diseases);**
- **sexual and physical violence;**
- **low self-esteem;**
- **alcohol and drug abuse;**

- poor health in general;
- high mobility among the Aboriginal population; and
- a reluctance to get HIV testing (Matiation 1998: 3).

Besides HIV/AIDS, some of the more pressing Aboriginal health care issues today include addressing child physical, sexual and emotional abuse, home care for Elders, mental health, solvent abuse, parenting, diabetes, nutrition, and appropriate alcohol and drug treatment, to name just a few (RCAP 1993; RCAP, Vol. 3, 1996; Kelm 1999; and Stephenson et al. 1995).

However, in addition to these important areas of concern, there are jurisdictional issues around health transfer policies and the non-insured health benefits program²². A recent report titled "The Red Road: Pathways to Wholeness," published by the BC Aboriginal HIV/AIDS Task Force in 1999, explains how federal health transfer and First Nations health transfer agreements involve the transfer of certain health care services to local, Aboriginal control (registered Indian Bands and Tribal Councils). This results in the delivery of some health care services by Aboriginal governments, rather than service delivery to Status Indians by Health Canada's Medical Service Branch (MSB). The services 'transferred' are negotiated and dependent on the particular Health Transfer Agreement but other than the non-insured health benefits, any of MSB's services could, in theory, be included in a transfer agreement. In this same report, the task force goes on to suggest that:

Reorganizations of the health care system (like "Regionalization" and "Transfer") provide opportunities to create new programs and services, but they also pose challenges to preserve existing services and to maintain program standards. Aboriginal leaders and representatives of Aboriginal HIV/AIDS service organizations must participate

²² See Culhane Speck (1989) for an examination of the 1986 Indian Health Transfer Policy.

meaningfully in the new regional health structures to address long-standing inequities (BC Aboriginal HIV/AIDS Task Force 1999: 44).

Nevertheless, the federal government and the various First Nations have yet to fully work out responsibility for Aboriginal health in this country and this responsibility continues to be shuffled between various departments as well as between federal, provincial, municipal, and Aboriginal governments and band jurisdictions. It is in this context that we must also locate the discussion of urban Aboriginal health.

The Urban Context

In the report titled "Aboriginal Peoples in Urban Centres" which was a product of the Royal Commission on Aboriginal Peoples, it was stated that "there are more Aboriginal people living in urban centres across Canada than there are living in Aboriginal territories and communities" (RCAP report, 1993: 11).

Pushed from their home communities by poor economic conditions, substandard housing, limited education, and social problems – and pulled to urban centres by the potential for education, employment and health care – increasing numbers of Aboriginal people are taking up urban life (ibid: 2).

Approximately two-thirds of Aboriginal people live off-reserve, but debates over jurisdictional issues by both Aboriginal and non-Aboriginal forms of governments result in drastic under-funding of urban Aboriginal organizations.

In most cases, the federal government refers status Indians back to their bands for services but it is inconsistent in providing services to the off-reserve population. It funds some programs but not others... The result is that some Aboriginal people can be served by Aboriginal services while others are not... There is just as much of a jurisdictional void within Aboriginal political organizations as within non-Aboriginal governments (Ibid: 17-18).

The demand for appropriate services in the city is increasing due to the fact that many Aboriginal people do not find a better life in the city because of racial prejudice, discrimination, and denial of culturally appropriate education, job

training, employment and housing (RCAP 1993). However, despite the fact that Canada's Aboriginal population has become increasingly urbanized since the 1960s, very little research has been conducted on the specific needs of urban Aboriginal peoples. Moreover, little attention has been paid to the real differences which exist among and within different groups of urban Aboriginal women as "policy work in the past has tended to treat Aboriginal women as a single monolithic entity, with no regard for their social, economic and cultural distinctiveness" (Stout & Kipling 1998: 3). The urban environment, especially impoverished inner-city areas like Vancouver's DTES, has become a high-risk setting for the spread of HIV for some Aboriginal women who make the difficult transition to urban centres but here as well, research has been almost non-existent. Even though women comprise approximately 30% of residents in the DTES and large numbers of these women are Aboriginal, a review of current literature reveals that the voices of street-involved Aboriginal women in the DTES remain, for the most part, silenced. By listening to and documenting the stories of four urban Aboriginal women, I hope that my research and writing will be a small addition to the literature concerning Aboriginal women in the inner-city. In the following chapter, I outline the setting (the DTES) in which my research project was located before I briefly review some recent research that has been conducted in the DTES. Finally, I explore the methodology utilized during the research process. In so doing I highlight some of the limitations of the project as well as some of the challenges I faced in conducting this particular study.

CHAPTER THREE: ABORIGINAL WOMEN IN THE CITY

The setting:

As a researcher, I've purposely limited the scope of this project in that I have chosen to stay within the 'boundaries' of Canada's most impoverished neighborhood, the Downtown Eastside of Vancouver (DTES). The DTES is located within the Strathcona district of Vancouver, British Columbia and according to the City of Vancouver, this district extends from Main Street to Clarke Drive, and the Great Northern Way to the Burrard Inlet waterfront²³. Nevertheless, the corner of Main Street and Hastings Street is the core point of the neighborhood, extending in four directions from that central point (The Vancouver/Richmond Health Board 1999: 73).

The total population of the DTES was estimated at 16,275 in 1996 and by 1999 there was an average household income of \$11,029 which was significantly less than the City of Vancouver's average household income estimated at \$35,583 (Downtown Eastside Community Monitoring Report, October 1999). A compact, 12-block section of the city, the DTES is a space in which Aboriginal peoples often find themselves when they leave their home communities. The bleak situation in the DTES was summarized in a local paper as follows:

There are more than 200 agencies operating in the Downtown Eastside, spending hundreds of millions of dollars. Result: 6,000 people in slum housing, epidemic disease and widespread crime... Even the most conservative estimate puts Vancouver's addict population at more than 1,500. If you consider the shortage of decent housing, the situation is the same: staggering numbers in need. While it has poured huge amounts of

²³ I think it is important to note here that the boundary set out by the City of Vancouver is based on the zoning and planning that *they* have been working with and as such, this sort of mapping scheme does not necessarily reflect the ways in which residents of the DTES would spatially conceptualize *their* neighborhood.

tax money into the area over the last three decades, the city still lacks a sustained affordable housing program and a continuum of addiction treatment services (reporter Ian Mulgrew, *The Vancouver Sun*, October 22, 1998).

The DTES is an area of run-down single-room occupancy hotels (77.9% of single room occupancy hotel rooms/units (SRO's) are located in this neighborhood), cheap rooming houses, emergency shelters and boarded-up storefronts. Furthermore, many of the residents of this neighborhood are, in many ways, among the most desperate in Canada for this is a community where poverty and addictions prevail. Combined with the highest percentage of IV drug users, HIV/AIDS cases, and street prostitution in Canada, the DTES is a neighborhood struggling with a multitude of complex social and economic concerns. In a 1998 Health Canada news release, Health Minister Allan Rock declared that:

The situation in the Downtown Eastside is serious and highly complex. Not only is there interplay between multiple illnesses such as HIV/AIDS, tuberculosis, alcohol and drug addiction and mental illness, but these conditions are further compounded by broad socioeconomic factors such as poverty and lack of good housing. Therefore it was felt to be important to address some of the immediate needs of the community as well as to develop a longer-term strategy to help solve the problem (Regional news release, Health Canada Home Online, June 25, 1998: 1).

However, it is important to point out that in many ways, the DTES is also a vibrant community and its history is based in not only struggle and deprivation but also in celebration and perseverance. More importantly, the DTES is a community that has shown time and time again that its ready, willing and able to respond to challenge²⁴ (Cameron 1996: 38-39). As John Turvey, the Executive Director of the Downtown Eastside Youth Activities Society (D.E.Y.A.S.), explains:

²⁴ For a detailed history of Vancouver's Downtown Eastside, see Cameron *Fighting for Community: Stories From the Carnegie Centre and the Downtown Eastside* (1996).

If you call this place skid road, you create those (negative) attitudes. But if you call it a community and start perceiving it that way... that it's a community that nurtures... and cares for itself, then all of a sudden you're conveying to the rest of the city and the Province that it (the Downtown Eastside) has all the dimensions of any other community... The ability to respond is here. People are much less far apart than in other areas... and people do care, there's lots of heart (cited in Cameron 1996: 38).

Nevertheless, this community has experienced some fundamental shifts as of late and having worked in this community over the past few years, I think it would be misleading and detrimental to portray the DTES and its residents as healthy, highly-functioning individuals with 'easy,' fulfilling lives. This, in my opinion, negates the realities of substandard, unsafe and unstable housing, violence, poverty, chronic stress and the complex issues around addiction that the women whom I interviewed courageously spoke about. As well, the tendency to highlight 'community spirit' and 'community wellness' in the DTES distorts the very real, day-to-day suffering that I consistently observed amongst the residents of this neighborhood. Kleinman, Das & Lock (1997) look critically at the representation of and responsibility for social suffering in the following manner:

How we "picture" social suffering becomes that experience, for the observers and even for the sufferers/perpetrators. What we represent and how we represent it prefigure what we will, or will not, do to intervene. What is not pictured is not real. Much of routinized misery is invisible; much that is made visible is not ordinary or routine... A major preoccupation in the Western tradition has to do with the incommunicability of pain, its capacity to isolate sufferers and strip them of cultural resources, especially the resource of language (Introduction: xii – xiii).

In describing the DTES, the 'resource of language' is representative in its own right, as the women 'spoke for themselves' about how *they* actually view their community and the spaces and places they currently occupy. Although the women that participated in this project spoke often about suffering, about pain and about enduring hardships, they also talked strongly about feeling accepted and comfortable in this neighborhood and two of the participants stated that they

could not imagine residing anywhere but the DTES. Nevertheless, the women's narratives reveal the push and pull of the DTES. There was much discussion regarding how the neighborhood 'vibe' has shifted and their different perspectives are illustrative of some of the changes that have taken place in their community. Living in the DTES for the past 14 years, supporting her heroin addiction via the sex trade, Shauna explained that:

There's no sticking together anymore. I could really see that a few years ago but not anymore. For instance, when I first started working, the girls really stuck together. It didn't matter who it was. It didn't matter if you knew each other well or not, we all used to stick to a basic fee or price schedule. But now it could be your best friend for years and they would still stab you in the back for five bucks – just to get that half a rock! If anything, the scene is a lot more violent now. The girls towards the dates, the girls towards each other and the dates towards us girls and now I don't even walk down the alleys here and before, it wouldn't have phased me a bit.

(Interview with Shauna, May 1999).

Shauna's comment above is also representative of the changing relationships amongst some women in the DTES, which is often linked to the increased use of crack cocaine. Shauna's 'drug of choice' being heroin, she points to the decreased value of sexual labour and increased tension amongst the girls, because of this current drug trend.

Lisa, a ten year community member, tells a similar story about the changing climate of Vancouver's DTES because of the increased use of crack cocaine:

... and you can forget about the people that are smokin' crack. It's a big issue right now and there's a lot more rip-offs going on here because of it! Before, you could give a friend ten bucks and ask them to go get ya some dope to help you wake up, but now if you give them ten bucks – you won't even see them again! Especially if they're smoking that rock and that's the thing – that's the big difference nowadays and its causing lots more riffs among the people down here. I've seen our people change a ton you know - it just totally changes a lot of people for the worse.

(Interview with Lisa, December 1998).

Lisa's comment above is interesting in light of the fact that she no longer uses intravenous drugs herself, preferring the smokable form of cocaine instead.

Nadine began living on the streets of Vancouver at the age of fourteen. Now 36, Nadine has been in and out of the DTES for over twenty years but at the time of our interview, Nadine and her partner were living in an apartment in South Burnaby. Reflecting back to the time in her life when she tested positive for HIV in 1994, Nadine talked about the DTES as follows:

My ex-husband came and found me downtown, bouncing around in different hotels on Hastings, and he took me to a detox to clean up and that's when I got the HIV test – that's when I tested positive. Now I'm scared to death of down there! I don't know how I ever lived down there. I'm scared to death of everyone and I really don't know how I had it in my system to survive down there. I almost got killed a few times, for trying to learn how to survive on my own, without my husband. You learn the hard way. When I was down there, I got involved with some stupid things, with some stupid people who ripped me off and attacked me and it was fucking scary.

(Interview with Nadine, June 1998).

24 years of age, Kelly began 'visiting' Vancouver's streets when she became a Ward of the Court at the age of 13. Prior to residing in the DTES, Kelly stated that she has lived in "so many foster homes, I can't even remember them all" and she had this to say about the DTES:

This place is a never-ending carnival and you can pick any act you want when you live here... Why do you think I like this place so much? Why do you think I stay? I don't need to try and fit in here – I do fit in. Downtown, everyone fits in no matter where you come from or what you do. I was accepted as a kid, when I used to hook and I'm accepted dealing dope on the corner. When I really think about it, my 'careers' have worked out pretty well so far! [laughs]. At least I know I can take care of myself...

(Interview with Kelly, February 1999).

Although many of the residents in the DTES continue to watch out for one another, coming together to support each other over issues relevant to their neighborhood and themselves, "the streets have been taken over by a younger, rougher, meaner crowd attracted by an active drug market" (City planner, Nathan

Edelson cited in *The Vancouver Sun*, Sept. 19, 1998: A20). In the interviews that I conducted, it is clear that the women's diverse perspectives can often be linked to their drug-use patterns and the ways they generate funds to support their addictions, which is presently the unrivaled focus in each of these four women's lives. This is dealt with in more detail in chapter four, when we hear the women speak for themselves about their specific drug-use patterns and the various strategies each of them use to support their consumption of drugs.

As the women alluded to above, the streets of Vancouver have seen some rather significant changes of late, especially since the massive influx of crack cocaine (also called 'rock' or 'up') around 1996 but also because of the expansion of the drug scene, more generally, over the past ten years²⁵. Cocaine is increasingly being injected as well, which requires the user to shoot-up 20 or more times per day. As well, there is a constant supply of fairly pure, low-cost heroin (also called 'smack' or 'down') in this city and a 'point' of heroin (one-tenth of a gram) has recently gone down in price and can now be purchased on the streets for \$10. Crack cocaine (the smokable form of cocaine) currently sells on Vancouver streets for \$10, which buys roughly one-tenth of a gram. Presently in the DTES, there is a trend towards simultaneous, multiple-drug use (cocaine and heroin are often mixed together and taken intravenously - known on the street as

²⁵ Brody (1971) published an ethnographic work titled *Indians on Skid Row: the role of alcohol and community in the adaptive process of Indian urban migrants* and this text offers an interesting comparison to the contemporary context of substance abuse/addictions (especially the widespread use of cocaine and heroin) in the DTES today. Brody's study focused exclusively on alcohol consumption amongst 'skid row,' urban Aboriginal peoples which, at that time, was the 'drug of choice'. However, although alcohol addiction (especially rice alcohol or rice wine) continues amongst Aboriginal people in the DTES, today's 'drugs of choice' are increasingly cocaine and heroin. All four of the women interviewed for this project used cocaine and/or heroin daily but none of the women had consumed alcohol regularly, if ever, since becoming addicted to cocaine and/or heroin.

a 'speedball') and BC's chief coroner relates the increase in overdose deaths this year (which are up 30 percent over last year at this time) to the increased use of multiple-drug cocktails and the surplus of pure heroin that continues to pour into this city. According to chief coroner, Larry Campbell there were 131 overdose deaths in the province from January 2000 until the end of May this year, compared with 96 overdose deaths at the end of May last year (*The Vancouver Sun*, June 7, 2000: B1).

Furthermore, the DTES is a neighborhood in which the virus that causes AIDS spreads quickly, especially among street-involved individuals using intravenous drugs. However, HIV/AIDS is one of a long list of diseases that impacts the health of community members as the Vancouver Native Health Society's²⁶ 1998 Annual Report points out:

The epidemic of HIV/AIDS in this community has been accompanied by outbreaks of many other serious infectious diseases. An epidemic of Syphilis, a genital ulcer disease that facilitates the spread of HIV, began in 1997 and is focused in the Downtown Eastside... Another infectious disease on the rise, particularly amongst individuals with HIV/AIDS is Tuberculosis. The incidence in the Downtown Eastside is several times higher than the National average (8).

One year later, Vancouver Native Health statistics reiterated the reality of the multiple epidemics of HIV/AIDS, Hepatitis B and C, Tuberculosis, and Syphilis weaving their way through the DTES population. Besides disease, the residents of the DTES are often in a state of crisis, struggling to meet their basic needs including shelter, adequate nutrition, or even a place to shower or bath. Their situation is "compounded by the effects of poverty, homelessness, no social

²⁶ The Vancouver Native Health Society (VNHS) offers medical and support services to Aboriginal and non-Aboriginal people in the area. The VNHS walk-in clinic was established in 1991 to improve access to medical services for urban First Nations people. Services available include: HIV/AIDS care, addictions treatment, methadone maintenance, sexually transmitted disease and blood testing, infectious disease

supports, and drug and alcohol abuse” (Vancouver Native Health Society 1999: 10). As is revealed in the narratives, these four street-involved, drug addicted Aboriginal women do not view their HIV-infection as a primary concern on a day-to-day basis. Rather, HIV/AIDS tends to be looked at by these women as just another ‘hard’ reality that must be dealt with and this perspective needs to be placed in the larger context of multiple, constant constraints and crisis that women contend with daily.

Some current research in the DTES

In October 1999, the Vancouver/Richmond Health Board released a report entitled “Healing Ways: Aboriginal Health and Service Review”. Based on the findings of this study, the board had voted to spend \$471,000 in the fiscal year to improve the health, well-being and social status of Aboriginal peoples under their jurisdiction. The report illustrates the magnitude of the problems facing the approximately 28,000 Aboriginal people living in Vancouver and the report’s introduction highlights some of the areas of particular concern:

- alcohol-related deaths and drug-induced deaths are both eight times higher for Status Indians than the National average.
- the average life expectancy of Aboriginal people (63 years) was 16 years lower than the average life expectancy of others in the Region.
- three times more Status Indian women die from HIV-infection than other women.

This report also describes debates and concerns related to jurisdiction, stating that “jurisdictional ambiguity has led to a fragmented, uncoordinated system that leaves many First Nations people, especially those that live in urban centres,

screening, and immunizations. Drop-in staff also dispense and monitor antiretroviral medications for HIV-

unclear about what services exist, what they are entitled to, and how to access the services" (1999: 76).

In 1995, a research report titled *The Place to Start: Women's Health Care Priorities in Vancouver's Downtown Eastside* (1995) was released by Core Women Care. Interviewing a total of one hundred and forty-two (142) women living in the DTES, the Core Women Care advocacy group (made up of women of the Downtown Eastside) asked the women who participated in the study to prioritize their health care needs. Of the 24 health issues reported, the areas of critical concern *to the women themselves* were: (1) more/better/safer transitional and long-term housing; (2) more/better services for street-involved women with alcohol/drug issues, with an emphasis on flexibility and diversity; (3) more/better services around violence against women; and (4) more female, street outreach workers who have "been there" themselves (Core Women Care 1995: 10). Moreover, the report clearly states that the long-overdue and crucial commitment to improving women's health in Vancouver's Downtown Eastside stems from the fact that this is the area "where positive change is most desperately needed" (ibid: 1).

In 1998, the Vancouver Native Health Society observed that First Nations people are over represented in the HIV/AIDS category and they go on to point out that "this pattern was most evident with Aboriginal women. They accounted for 65% of females with HIV/AIDS while making up only 53% of all female patients" (Vancouver Native Health Society: Annual Report, 1998: 11). In a 1995 study titled *Assessing the Violence Against Street-Involved Women in the*

positive patients.

***Downtown Eastside/Strathcona Community*, 85 community women currently involved in the sex trade were interviewed in the DTES and this study found that almost 70% of its respondents were Aboriginal women (Currie et al. 1995: 13). In a more recent draft report prepared by the 'First Nations Communities Health Resources Project' (FN-CHRP) it was noted that of the Aboriginal female participants with AIDS, the proportion who stated IV drug use as the mode of infection (54%) was significantly higher than that of the female non-Aboriginal participants (17.1%) involved in this particular study (First Nations Communities Health Resources Project 1999: 20).**

Thus, the interrelated issues of HIV/AIDS and intravenous drug use among Aboriginal women in the DTES are demanding to be noticed, within the larger frames of poverty, racism, sexism, inadequate housing and treatment, violence and abuse and a lack of commitment to affecting real change in the lives of street-involved, Aboriginal women. From the research and statistics that have been conducted to date, it is clear that the impact of HIV/AIDS on urban Aboriginal women that reside in the DTES is increasing. However, this is an area that will require future research, attention, funds and creative strategies which are developed from the ground up, where the women themselves assist in research design and direct the areas that most desperately require further attention. As quality of life continues to decline for Aboriginal women in the DTES, concrete solutions that mesh with the realities of these women's lives need serious consideration if any significant change is to occur.

Methodology

"Study the patient rather than the disease..."

**- Hippocrates' advice to physicians
more than 20 centuries ago.**

This project followed an exploratory process in that I made no attempt to test a hypothesis. Rather, I have interacted with the data/peoples/spaces in an effort to better understand the impact of HIV/AIDS - from the actual experiences, voices and lives of Aboriginal women themselves. In this way, the project was guided by prioritizing lived experiences over theoretical knowledge, or what William James called "the world experienced" (cited in Jackson 1996: 8). The women themselves decided "what is at stake" (Kleinman & Kleinman 1991: 277) for them through the stories that *they* decided to tell. In this thesis then, the reader will hear excerpts from the stories told by the four women that participated in this project. Subsequently, this research project is not only about 'Aboriginal women' and 'HIV/AIDS,' as the women's stories and lives necessarily expanded this project to include issues of violence, addiction and treatment, mothering, unstable housing, involvement in the sex trade and drug economy, etc..

Nonetheless, what I am concerned with in this section of my thesis is providing an account of the methods utilized in the construction of this research project. As such, this next section outlines how I conducted the research but it also looks at the 'writing up' process, how the project was actually put together. In looking at both of these areas, however, I try to be clear about how and why I made the decisions that I did and what the implications of my decisions were for the project, for participants and for the researcher.

In this research project, I placed primary emphasis on the life-stories of 4 HIV-positive Aboriginal women who have both past and present connections with the Downtown Eastside of Vancouver, British Columbia. Each of the four women interviewed for this project have past and present histories of IV drug use and 1 of the 4 women currently works in the sex trade. The participants in this study were 38, 36, 33 and 24 years of age. Moreover, there was one Metis, one non-Status, and two Status women involved in this project. As I mentioned earlier, the four women that participated in this project were women that I had had previous contact with through past employment in the DTES²⁷. Haig-Brown (1988) talks about the methods that guided her research on residential schooling and she suggests that interviews *may* be richer/fuller because of established relationships between an interviewer and participants. She writes:

Because of the intense emotions involved in sharing pieces of life with an interviewer, one must have established a warm relationship before the interview, or be capable of establishing rapport quickly... I do not mean to imply in any way that this relationship should be developed in an exploitive way, in order to interview, but rather the converse. The accounts reproduced here were generally fuller and more open than is often the case with one-time interviews, for the most part because of a long term relationship between the interviewer and the participant (153).

In regard to this study, my decision to ask women who had come to know me and who I had come to know – where a relationship had already been established prior to the interviews – was made because of practical and ethical considerations. At the time, I felt that I would likely be more 'successful' in asking women who knew me to participate in this project but I also suspected that the interviews would be much more in depth, that there would be more disclosure

²⁷ As I discussed in the initial chapter, I developed a relationship with many individuals residing in the DTES through my employment on the 'First Nations Communities Health Resource Project' (FN-CHRP), which began in May of 1997. In this research project, I was responsible for interviewing people living with

because of the fact that the women knew me *and* my research intentions. As well, because the women that I was interested in talking with are also involved in various illegal activities, it would have been naïve to expect women to come forward and disclose information to a stranger, or worse a researcher, that they had never met before. However, I did not pre-plan this approach and I certainly never intended to exploit or bring harm to the women that I had come to know in the DTES. In fact, when I first thought about this approach, I didn't know if it would even be possible, but I followed this direction because I felt that doing so would be a less invasive method of collecting data. Furthermore, this decision was made because the topic itself was not only personal but also potentially emotional, and because of this I did not feel that it was an appropriate area to approach with strangers. However, I also recognize that the interviews were undoubtedly affected by the fact that 'rapport' had already been established and that participation on behalf of these four women must be seen in the context of our established relationships. Thus, selection of participants was anything but random. Rather, in conversing with women in the DTES I spent hundreds of hours listening as women spoke about their lives. After several months, I found that I had developed more intense relationships with certain women that I had come to know while working as an interviewer at Vancouver Native Health. On my breaks, I began spending more time with the women I had come to know which at times simply involved 'hanging out' at Vancouver Native Health, going for 'smoke breaks,' helping prepare meals, 'cruising' the neighborhood or going

HIV/AIDS and the project operated mainly out of the Vancouver Native Health Society interviewing rooms.

for coffee or a meal at the Ovaltine restaurant. The relationships I developed were not one-sided as I too shared stories with the women who took an interest in my life (my daughter, my family, my relationship, work, and my studies were areas I often spoke about) and in this way, many of the women whom I had come to know in the DTES knew about my research/thesis as well. Eventually, I interviewed women who I had developed relationships with and who expressed an interest in taking part in an interview when I approached the subject with them. However, by the time I actually conducted the first interview, my employment with FN-CHRP was complete.

Research participants in the DTES are typically given small sums of cash when they participate in an interview and the women that participated in this project would have likely had this in mind from the outset. In her study of female heroin addicts, Rosenbaum (1981) discusses the paid interview as follows:

The paid interview made the women feel important; they were being paid to share some of their knowledge and expertise rather than being "therapized" and they appreciated this... most of the women interviewed were poor; all other reasons aside, they came to be interviewed because they needed the money (144).

In fact, two of the women who I interviewed asked if they would receive a cash payment before they formally agreed to conduct an interview with me. Prior to their inquiry, I knew as well that I wanted to offer something in return to participants at the close of the interviews but I knew that a 'gift' would likely be sold, food would likely go uneaten and being 'realistic,' I knew that either cigarettes or cash would be most appropriate. Further, I was leaning towards a paid interview because I knew that in taking up these women's time, I was also removing them from possible opportunities to generate income. Before I

conducted the interviews then, I had decided to give each participant \$20.00 for their time, energy and involvement in this project and as I mentioned above, the paid interview is an established research practice in the DTES. As I already mentioned, before agreeing to an interview, two women had inquired about whether or not they would receive any monies and two of the women did not, but all four participants were given a \$20.00 cash honorarium upon completion of the interview. I realize that my decision to give \$20.00 to the women will likely be criticized by some as 'buying' the data. Personally, I think that research participants/residents in the DTES should be compensated for their time, their participation, and their knowledge that has made this project (and many others) possible. Saying that, I also recognize that there are many ways that researchers and research projects can attempt to 'give something back' to participants and payment is certainly not the only method here. In fact, this is an area that could have been given more time and attention on my part.

Nevertheless, it was clear that some of the women who shared their stories with me, both informally and during the 'formal' interview setting, also seemed to find the conversational process 'semi-therapeutic' and one of the women put it this way:

I don't talk about this kind of shit with very many people. I know that I should, I know that you have to talk about things so you can move on but it's hard you know. People down here all have the same story and most people don't give a shit about what I'm going through - cause they're going through the same thing... Sometimes I wish I had someone to talk with but I've tried the counseling thing, I've tried lots of shit but I'm still an addict to the core... Then there's the people who won't talk to you cause you have HIV. Everyone knows each other's business down here and sometimes that really gets to me.

(Interview with Kelly, February 1999).

Having asked another participant why she agreed to participate in an interview with me, she talked about wanting to make a difference in the lives of HIV-infected individuals. However, she also makes reference to the lack of meaningful changes despite the increase in research projects in the DTES.

Nadine explained that:

I really feel for people who are HIV-positive and I've always tried to help other people that I know are positive. It's just the way I am I guess, taking care of our own. I don't mind getting involved in projects about HIV and AIDS 'cause I plan on being around for a while yet and who knows, maybe I will... Since I tested positive, I've always hoped that my involvement and participation might make things better - for all of us. I'm always hoping that something might come of these studies but so far, I've haven't seen much change, but I'm always hoping.

(Interview with Nadine, June 1998).

Before conducting the interviews, I went over the details and implications of participation in this study, explaining to each participant again that the interview would be taped, that they could withdraw from the interview at any point, that they could turn the tape-recorder off or ask me to do so at any point, that they could refuse any of my questions, that excerpts from the interview would appear in my published thesis, and where and how they could register any complaints they might have about the project, the researcher or the interview process itself (see Appendix Two and Appendix Four²⁸). At that point, I also asked the women if they would be interested in reviewing a transcript of the interview but only one of the participants expressed an interest in doing so. Finally, I asked each of the women if they had any questions about the interview process before continuing on. All four of the women then read, agreed to, and signed an informed consent form and each of the four women were provided with a signed copy of the

consent form and a participant feedback form (see Appendix Two and Appendix Four). After the consent forms had been signed, the tape recorder was then turned on.

Each interview was taped and lasted between 2 and 4 hours. In negotiating the interviews, I asked participants to choose a location where they would feel most comfortable. The first woman I interviewed (Nadine) suggested "either my place or your place". I offered to make lunch for us at my home before conducting the interview. This suggestion was met with enthusiasm. After discussing possible interview locations, the second participant (Lisa) agreed to an interview in my home as well, stating that she was curious and interested in seeing "life in the burbs." When I then inquired as to when she had last left the DTES, this participant's response was "about five or six years ago". Subsequently, the first two interviews were conducted in my home, which worked out well, but I admit that I was a bit apprehensive about bringing participants to my home. Our interactions, up until the interviews, were conducted in 'public spaces' (on the streets, in various community organizations, restaurants, etc.) and the 'move' to a private, personal space (my home) seemed suggestive of a possible shift in our current relationship. Although I was pleased that the women were interested in conducting the interviews in my home, I was also mindful about the importance of being clear and up front with the women, for I knew that some boundaries had to be erected and respected. Calling feminist methodology into the debate, Stacey (1988: 24) questions the notion of feminist ethnography's

²⁸ Each participant was given a "Participant Feedback Form" (see Appendix Four) and a stamped envelope with the address of the Chair, University Ethics Review Committee at Simon Fraser University.

superior ability to safeguard and therefore better represent the interests of informants:

The irony I now perceive is that [feminist] ethnographic method exposes subjects to far greater danger and exploitation than do more positivist, abstract, and "masculinist" research methods. The greater the intimacy, the apparent mutuality of the researcher/researched relationship, the greater is the danger (cited in Kirby 1993: 130).

That said, I had known both of these women for over a year at the time of the interviews and I made a judgment call here that proved unproblematic for both the participants and myself. I picked both of the women up in my vehicle at an agreed upon location and time and after the interviews, I dropped off the participants at a location of their choice. My fieldnotes from the second interview that I conducted in my home read as follows:

Other than forgetting to turn my ringer off, I think this interview went okay. I could tell right away that our interactions were 'different' than usual and I suspect this was mostly due to the setting (Lisa's comment about my place, 'in the middle of nowhere') rather than conducting the actual interview... I know I felt a bit strange/nervous about having Lisa come to my place and I could tell that she felt a bit awkward being here. I wish I would have thought to ask her about how she felt being here at my place during the interview and I'll have to remember to bring this up next time I see her. Anyway, the dynamic was awkward at first but we both relaxed after I made tea and she seemed to enjoy looking through my photos and books. After the interview, I gave her my copy of "Don't Sweat the Small Stuff" to take back to her place and we both had a good laugh while she read some of the passages aloud, relating them back to her life. Lisa definitely isn't lacking a sense of humor! (fieldnotes December 1998).

At the participant's request, the third interview (with Kelly) took place at the Ovaltine restaurant in a booth. This proved to be a rather awkward setting considering the interruptions, lack of privacy, and the intoxicated group of men that were seated in the booth behind us just as we were finishing up the interview. Upon transcribing the third interview, I discovered that the last five minutes of this interview were barely audible because of the background noise, which points to the influence and importance of the interview setting. The final interview I conducted (with Shauna) took place in one of the SRO units in a hotel

located in the DTES, which has been this woman's home for the past two years. This also proved to be a satisfactory setting for an interview as the participant was visibly relaxed and other than a bit of yelling in the hallway, her actual hotel room was fairly quiet. Although I felt comfortable once I got up to and in this woman's home, I found the atmosphere in the lobby and ride up in the dilapidated elevator with two men who suddenly 'forgot something upstairs' and who began interrogating me in the cramped space of the rickety elevator somewhat intimidating.

Nevertheless, at the end of the interviews participants were also given a "Resource List" (see Appendix Three), that noted some relevant resource information and services. However, in presenting each of the women with a resource list, I was also hoping to minimize emotional harm or damage to participants – for I had anticipated that sensitive subjects and emotions could come up during the interview process. This is an area worthy of further consideration and I call attention to it here because I believe that I could have thought this through more carefully. In retrospect, offering a 'resource list' in an attempt to cope with the possibility of painful human emotions seems rather 'green,' rather naïve, and altogether inadequate.

Although I witnessed countless violent altercations while researching and working in the DTES, I was never physically assaulted myself. Constant verbal insults and physical threats did not escape me, however, and there were many situations where I did feel threatened, by both men and women. For the most part, however, my position as a researcher and worker in the DTES provided me

with a bit of a 'safety barrier' while I made my way in the community. In this sense, being an 'outsider' was significant in that it decreased my chances of being a victim of physical assaults. In Maher's ethnographic study of women and the drug market in Brooklyn, she claims that "I think the fact that I was a researcher was salient in affording me a degree of protection from the men that was not extended to women drug users" (1997: 220). I would add to this that threats to personal safety in an inner-city setting such as the DTES come from both men and women. In taking precautionary steps to avoid victimization, researchers would be naïve to think exclusively in terms of victimization at the hands of men.

Maintaining a sense of balance can be challenging when working or researching in the DTES and this is another important consideration for researchers interested in better understanding the lives of inner-city, drug-using individuals. Keeping my sanity as a community worker, academic and mother has been difficult in an area where addiction, poverty and abuse are rooted so deep that a sense of futility and frustration has also seeped into my own life over the past few years. Further, keeping a sense of balance working within a community with its own rules and its own version of justice and, at time, circus-like atmosphere can prove challenging in itself.

Although it was my original intention to follow an interview schedule made up of reasonably open-ended questions (see Appendix One), all four of the interviews played out a lot more like conversations and I found the interview schedule somewhat 'unnatural'. In fact, the interviews and the project itself

evolved in ways that were not always apparent to me at the outset and the shifting, flexible nature of ethnographic research has been described by Wiebe in the following manner:

Often, emergent topics of investigation are identified that shift the focus of inquiry in unanticipated directions. Thus, a major strength of ethnographic research stems from its exploratory, flexible, and descriptive capabilities... it is furthermore important to note that other types of methodologies do not lend themselves to the types of findings that are the mainstay of ethnographic research (1996: 197).

In spite of the fact that the original aim of this project was to explore the impact of HIV/AIDS through Aboriginal women's experiences and stories, I found that the project shifted in focus towards the multiple constraints and day-to-day realities that these four street-involved, drug-using women spoke about. Furthermore, even though each of the interviews began by my asking each participant the first question on the interview schedule, which asked if they could please tell me about themselves - the women's stories did not simply proceed to follow *my* pre-determined questions. Moreover, because I was interested in finding out what *the women* had to say, the interviews were directed largely by the stories that the women decided to tell. I did make some minor attempts during the interviews to 'fit' the schedule questions in when they seemed relevant to what was being said, but again, I was careful not to re-direct the conversation away from the stories that were naturally unfolding during the interview process²⁹.

Data obtained from interviews (and field notes) were read repeatedly in an effort to identify and compare the ideas and experiences of this small group of HIV-infected Aboriginal women. In so doing, I was looking not only for

²⁹ Stacey Pigg stressed this approach to me suggesting that I be cautious about imposing identification on research participants because of the ways in which I had framed this research project. In attempting to

commonalties in the data but also points of diversity, contradiction, etc., for it was not my aim to present 'typical' inner-city, HIV-positive Aboriginal women. In the first reading of the transcripts, I began to highlight the most obvious themes that were running throughout the stories that I collected. During the second reading of the transcripts, I was looking for any unusual or contradictory points that stood out and these comments were highlighted and then moved to a separate list. In the third reading of the transcripts, I began to think about piecing this project together and at this point, I began to link and select the excerpts from the four interviews that I thought best portrayed what the women themselves were telling me about their lives.

In conducting this research, I better understand that participants' involvement may or may not follow the intentions of the researcher. Although I remained open and flexible throughout the research process, being mindful not to 'push' participants towards activities aimed at meeting my own research agenda, I wasn't always successful here. For example, at the end of each of the interviews that I conducted, I asked the women if they would be interested in reviewing the transcripts of the interviews (presuming that some of the women would), but only one participant expressed an interest in doing so. Within the same week, I returned the transcript to this woman, asking her to call me at home in the next couple of weeks, once she had a chance to look it over. However, I never heard back from her and after leaving several messages at a community organization frequented by this woman and two trips to the DTES, I

obtain *the women's analysis*, she suggested that I show the participants that I would be just as happy if they didn't talk about their 'disease'.

finally found this participant. When I asked her if she wanted to discuss the transcript or interview, she explained that she had been kicked out of her hotel and that she had left all of her 'stuff' with a friend. I then asked the participant if she wanted another copy to review but she stated that she didn't think she would get to it because things had really gone 'down-hill' for her lately, which I could see for myself. At that point I decided that it would be best not to pursue the matter further. In fact, I felt rather awkward about the situation and in driving home later that day, I realized that *my* interest in obtaining feedback was clearly unimportant to this woman, especially considering her predicament at the time. Even though I was mindful of not being 'pushy' or aggressive as a researcher, I realize that in this situation I was attempting to direct this woman's participation (rather than the other way around) because of my intent to 'share' this project. Maher discusses the burdens that can be placed on participants through well-intentioned efforts to 'assist' the trend of participatory methods and studies in the following manner:

Another way of framing this apparent dilemma is to ask whether it is appropriate to expect that women who have a difficult time just surviving—who face so many problems, risks, and dangers in their everyday lives—should be as involved and invested in this project as one whose future academic career rests on it. Certainly, they were interested—but to a point. To expect anything more would amount too little more than the imposition of my own needs for reinforcement and affirmation on my informants. This is a burden that the women who agreed to participate in my study did not undertake to carry (1997: 230).

With my limited experience as a graduate student and researcher, I believe that I was attempting to "impose my own needs for reinforcement and affirmation on my informants" (Maher 1997) in the situation described above and even though my intentions were not malicious, they were intentions not shared by this particular participant, at this particular point in time.

That said, doing follow up research with individuals with long-term, intense drug addictions can be difficult for various reasons and from my experience, I found it challenging to actually find the women because they are often moving, due to unstable housing situations and because they face new crises almost daily. As well, when I did find participants, they were often too high or too tired to bother with the project and usually, I'd end up just "shooting the shit," giving them a few smokes, and the odd few dollars that I could spare.

I had originally developed respondent 'profiles' for each of the four women who I had interviewed but after writing and re-writing participant profiles, I realized that profiles do not lend themselves well to guaranteeing confidentiality. The informed consent form that each of these four women signed stated that the researcher would "guarantee confidentiality of both identity and information provided by using pseudonyms and omitting all identifying characteristics in the data... this pseudonym will also be utilized in the written report (MA Thesis) and again, the written report will not include any other identifying characteristics" (see Appendix Two). As such, I provide only minimal details about each of the women that agreed to participate in this project and where necessary, I've avoided identifying information and in this way, certain sections of the transcripts were not included in the writing up of this report.

I have highlighted various themes related to the methods utilized in the collection of data and the writing up of the final report for this project and in so doing I have shown that I directed the project much more than I originally intended. What I mean to say here is that I had originally hoped that the

participants and myself would get together to discuss the transcriptions, to discuss how their stories might best be presented, and what might have been done differently. I believe we have to take the lead from those who agree to participate in our projects and in this way, it was never my intention to 'push' women to engage in the research process but as I illustrated above, my pre-set research agenda proved to be significant and it did lead me to make some poor decisions. Although we can and should attempt to make our methods more participatory and more collaborative - whereby knowledge is produced reflexively by subjects and ethnographers – intending and attempting to do so does not guarantee increased participant 'involvement'. I presumed that the women whom I interviewed would, in fact, be interested in staying involved in various stages of the research project but this was not the case. Although I was open to the notion of reflexive knowledge production and I offered and encouraged participants to get and stay involved (beyond participating in the interview), the women that I interviewed were not at all interested in reviewing transcripts, reading drafts, or offering feedback. As a researcher, I tried to respect those decisions but I wasn't always successful and, at times, I let my own agenda get in the way.

Although we can never really measure 'how much' we (as researchers) influence our participants' stories, we play a large part in the construction (and re-construction) of their stories by the ways in which we frame our projects, by interviewing experience (or lack thereof), and by 'being' our individual selves in

the field which refers to our age, sex, race, class, and all of the multiple weaves of our identities. In fact, I've thought often about these sorts of issues:

I feel a bit obsessive lately, wondering how things "could have been" with this project. Really, things are what they are and I can't keep worrying about looking too 'rich,' which seems kind of funny right now, all things considered! The same with my thinking about not being "Indian enough" or thinking people will take me more serious when I'm "old enough"! Why do I do it? It's too much...I am what I am and I have to stop making apologies for "being me"... So what's the bottom line??? Being up front, being respectful and non-judgmental, but "being me" in that process and being okay with that.

(personal journal entry, May 1999).

Although I've tried to maintain the centrality of the women's voices in this project, my voice took precedence throughout the research project in that I chose the topic and the participants, I framed the questions, and I've chosen what to include in the writing up of this report which obviously re-shapes the women's narratives. Despite the women's desire for others to hear them and to understand their (hard!) lives, it is my voice that is at the forefront. However, in the following section, we will hear from the Aboriginal women who participated in this project and look at some of the practical and theoretical issues that come out of their stories.

CHAPTER FOUR: THE NARRATIVES

Positive beginnings

Before I go further, I wish to point out here that I have re-arranged the women's narratives, beginning with their diverse views about testing positive for HIV. As mentioned previously, the women's narratives did not follow *my* pre-determined interview schedule and in this way, topics emerged in some of the interviews and not others, or they were more pronounced in certain stories, depending on the storyteller. My point here is that I have re-arranged their stories into themes that were obviously significant to the women themselves, but I was not attempting to present their words in 'order of importance' or as evidence of their collective 'agreement' on issues of import to each of the participants. Rather, I have arranged the narratives, beginning with their stories about living with HIV, recognizing that my decision to do so re-shapes the stories told to me by the women themselves, resulting in the construction and creation of the narrative (re)presented here.

Testing positive for HIV-infection was painfully difficult, in different personal ways, for each of the four women interviewed for this study. Nonetheless, some of the women's stories are also representative of the strength and perseverance of drug-using, Aboriginal women infected by a virus that poses yet another challenge to their daily survival. Each of the four women who I interviewed spoke about this time in her life and what the diagnosis meant to her and to those around her, as Lisa explains below:

I knew it [HIV-infection] was through sharing rigs and when I got tested in '91 at the clinic on Main street, I didn't even need to see the results because I already knew the results. For me, it was just like hearing the final confirmation and that's another day I remember

really, really good. I sat there and I felt really dirty and I didn't want to be near anybody. My friend tried to hug me and I remember just pushing him away cause I was scared and I didn't even know that much about it [HIV] then. Yah, I knew a few people that had it but I didn't have to deal with it cause it wasn't me. When my friend tried to hug me that day I actually thought I could pass some germs or something! I went downhill fast after that. I remember looking at all these Spanish dealers, probably about twenty of them and I sold for every one of them that day! I would sell and then be back in the alley doing my dope. Even the dealers kept asking me what was the matter but I didn't care. I knew who had good dope, who had bad dope and I just kept going back in the alley.

(Interview with Lisa, December 1998).

Lisa's comment above also reveals her erroneous perceptions about HIV

transmission back in 1991 and points to the inadequate knowledge surrounding

HIV transmission during that time. Despite the increased presence of HIV/AIDS

in the late 1980s and early 1990s, many of the women who I spoke with made

reference to their own misperceptions regarding HIV transmission - before they

themselves tested positive. Lisa's initial concern (in 1991) that casual contact

might pass 'something' to her friend might also be suggestive of her continued

engagement with high-risk activities at that time. Although education about HIV-

transmission is undoubtedly better understood (especially amongst IV drug-

users) in the year 2000, misconceptions and outright denial about HIV-infection

continue.

At another point in the interview, Lisa spoke about both the rejection and

acceptance that she felt from various members of her family, because of testing

positive for HIV. Lisa explained:

She [Lisa's mother] blamed herself for me getting it [HIV]. She started making up all of these reasons why it was her fault! She thought if we wouldn't have argued, it wouldn't have happened and she thought if she wouldn't have given me money, it wouldn't have happened - but it would have... My aunts were different though! They didn't even recognize me. Someone told them I was sick you know and when they saw me, they said, 'You should come back home cause we can't afford to come back out here and get your body'. I thought, 'Holy Shit! Nobody is taking my body anywhere anyway! I don't know, they probably know what I've got but I choose not to discuss it with my aunts. My main concern was with my mom and daughters - that was my concern... Even my mom kind of got over it, you know, me having it but she could never say it. She could never

say the word. I could have had any kind of disease, I could have even had herpes and she would have just loved me! But she couldn't say HIV. She never did say it.

(Interview with Lisa, December 1998).

Although Lisa's comment above is representative of the intense stigma, fear and condemnation associated with HIV-infection, this is only one side of her story as she also described her HIV-infection as a 'positive' turning-point in her life, that she explained in the following way:

This woman asked me once, 'If you were granted one wish to change anything at all in your life, what would you wish for?' It took me two seconds to answer that one and I said "To have my mom back." The woman then asked me, "but don't you wish that your illness would go away?" and I said, "NO WAY!" I told her that this [HIV-infection] has really helped me to take a better look at my life. Yah, it's taken me quite a while you know, to actually open my eyes... For the first five years I was down here, you couldn't get me to go a block past Main and Hastings – I just couldn't do it! It was like there was an imaginary wall and I couldn't go any further. Then, I branched out by delivering papers for the Women's Centre to all these other places and that was okay. Same with the Positive Women's Network. At first, I wasn't ready to talk to them much but eventually, I got involved with them and so it kind of evolved that way. It's kind of neat really, 'cause I've met a lot of good women through there.

(Interview with Lisa, December 1998).

In time, Lisa's seroconversion³⁰ became an important part of her identity as she slowly began to increase her involvement with various agencies in and around the DTES and this 'shift' in Lisa's life is looked at in more detail below.

Nadine also talked about the day she tested positive, in 1994, from sharing needles with her then husband - who was already HIV-positive. Nadine described that time in her life as follows:

When my husband and I were married, he was already HIV-positive and we were careful about using safe sex. It wasn't until I began whacking [injecting drugs intravenously] coke and heroin for days on end that things got bad. Then my husband started whacking with me, we got a hotel room and just kept going. My rigs were all fucked up and I told him that they were plugged and barbed and that I needed one of his rigs. I didn't care because I thought I was going to be dead by the end of the weekend anyways and when

³⁰ 'Seroconversion' refers to the development of detectable antibodies to HIV in the blood as a result of HIV-infection. It normally takes several months for antibodies to the virus to develop after HIV transmission has occurred. An individual may have either a positive or negative 'serostatus,' dependent on whether or not they have detectable antibodies in their blood.

he went to the bathroom, I took one of his rigs. At that point, I knew that if I lived through the weekend, I was gonna be infected a few months later and I was... I was told by a nurse at the detox that I was positive. I wasn't surprised at all. I was in shock yet I wasn't in shock. I remember being alone then and I hated it and I went out on another suicide mission right away.

(Interview with Nadine, June 1998).

Nadine's story is an important one that needs to be heard and acted upon, especially when one considers that a "growing epidemic of passive suicide is happening in Vancouver's Downtown Eastside" (Core Women Care 1995: 35). Many of the girls and women who I came to know in the DTES made frequent comments about having "nothing to live for" or they believed that their current lifestyle would likely cut their lives short, as Lisa explained when she used to constantly tell herself, "Nope, you're not going to see 30, no way!" Lisa went on to explain to me:

I couldn't even 'OD' properly when I tried! I'd get all these stupid thoughts running through my head. You know, I tried but always in the back of my head, I'd think, "walk it off woman, walk it off." So Christ! [Participant laughs] I couldn't even kill myself properly!

(Interview with Lisa, December 1998).

Speaking about passive suicide amongst women in the DTES, the Core Women Care report suggests that "they are deliberately putting themselves in one high risk situation after another. Death is seen as a release, rather than something to be feared" (1995: 35). Lisa also made reference to the increasing numbers of addicts who deliberately attempt to share needles with someone they know who has HIV/AIDS in the hopes of speeding up their own death or increasing their monthly government assistance cheque by acquiring 'disability' status by way of HIV-infection. As Lisa explained:

With the HIV, I let people know beforehand, especially before fixing 'cause fine, I fucked up my life but I don't need to fuck up anyone else's life! I just say I can't, I'm positive and

I can't get my blood mixed up with yours – and that's that! I've had a lot of people tell me they really respected that. But then there's the really fuckin' stupid ones who knew I was positive and I'm sittin' there doing my hit in the back alley and they're like, "oh come on." But I'd tell them to just get the fuck away from me, don't talk to me, don't even come near me! Ya, some people just don't care about the consequences, I guess they don't care about dying 'cause they're too fucked up in their living!

(Interview with Lisa, December 1998).

Kelly, the youngest participant interviewed for this study, was much more matter-of-fact about testing positive two years prior to the interview, at the age of 22.

During the interview, Kelly spoke about being infected with HIV as follows:

HIV is no big deal to me. I was angry at first but I don't worry about it too much anymore. We're all gonna die somehow, right? I'm always sick with something so why not HIV?...

(Interview with Kelly, February 1999).

At the time of the interview, Kelly didn't view HIV-infection as a major issue in her life and this may have been due, in part, to the fact that she had not experienced any opportunistic infections³¹ at that point. More likely, however, Kelly's lack of interest in her positive serostatus stems from the centrality of heroin and cocaine addiction in her life, combined with low self-esteem, unresolved and painful issues of past and present, and her own observation that her health status was largely beyond her control. Again, speaking about the issue of passive suicide amongst women in the DTES, Core Women Care states that:

The women are trapped into living and hanging out in this volatile and depressing environment. They are continually bombarded with mainstream attitudes, stereotypes, and myths held about themselves: that they are expendable, subhuman low life's that lack intelligence, morals, motivation, intrinsic self-worth, or any redeeming quality; that the world would be a better place if they weren't in it, that the situation is their fault, and that they're unwilling to help themselves. The trouble is that the women also believe these things about themselves (1995: 35-36).

³¹ 'Opportunistic infections' or 'opportunistic conditions' refer to an infection or cancer that occurs especially or exclusively in persons with weak immune stems due to HIV/AIDS or cancer. For example, Pneumocystis Carinii Pneumonia (PCP) is a lung infection that grows rapidly in the lungs of people with AIDS and was formerly the leading AIDS-related cause of death.

Kelly's outlook on testing positive was further described to me in her response to my asking her if she currently received any help or support. Kelly replied:

Nope, 'cause I still don't get enough dope to dull the pain! [Participant laughs]. To tell you the truth though, I don't spend a lot of time thinkin' about HIV or AIDS. You know, I never thought much about it before having an HIV test and I don't think much about it now. I'm young, I'm strong! So far, I guess I've been pretty lucky cause I haven't had any bouts of sickness yet. It's not like I don't know what can happen to me or something. It's not that, it's that I can't do much about it now so I try not to worry about it. Nobody can change that. I get a hell of a lot more sick from the dope than HIV but I can't change that either!

(Interview with Kelly, February 1999).

Kelly's statement above about not getting "enough dope to dull the pain" highlights the tension that exists between re-presenting 'their' story (participants) and 'my' story (as a researcher) in that narrative analysis necessarily involves points of departure. What I mean to say here is that these four narratives of experience diverge from my own voice, from my own analysis at particular points. Kelly's comment above points to the need for a better understanding of the unique care and support needs of street-involved, drug-addicted Aboriginal women living with HIV. Her story supports my own observation that many Aboriginal women remain untreated for their HIV disease, their addictions, their lack of self-esteem, coping skills and anger – often directly related to their painful, violent pasts and their poverty. This results in an increased risk for early progression to AIDS for street-involved Aboriginal women. Further, it shows that current strategies are failing to reach all street-involved Aboriginal women and that a more comprehensive approach that looks at the *whole* woman, which might also include children and larger family and community networks, is desperately needed to improve health and quality of life. If we hope to enhance the support of *all* HIV-positive women, we should start by validating Aboriginal

women's voices and experiences, where realistic and relevant solutions and strategies stem from the women who need them the most.

Shauna explained to me that she learned of her HIV-positive status two years prior to the interview from her involvement with the VIDUS project³².

Shauna said:

It was a shock to hear it, 'cause I guess you always keep that glimmer of hope you know, that they were gonna say, "No, you're okay". I never shared my rigs with anybody except my girlfriend back then so when she came and told me, "Guess what, I'm positive," I knew. She didn't tell me for quite a while and she knew already when we were sharing needles, but she didn't say anything. Yah, her theory was "Hey, you already got it" but that's not exactly a positive way to think because that's not necessarily true. I think that misery loves company and that's what she was probably thinking. But hey, I made the choice myself when I chose to share the rigs so I can't blame it on her 'cause it's both of our faults. She was sharing with somebody else behind my back and I shouldn't have been sharing in the first place. So, I can't blame it on anybody but myself.

(Interview with Shauna, May 1999).

However, later in the interview, Shauna had this to say about her health and her life since testing positive for HIV:

I think I have this part, where it's like denial. You know, if you don't really deal with it, then it's not really there. Yah, especially with something like HIV, 'cause you don't feel sick... I've actually been healthier since I tested positive than I've ever been. Just the little things that I've changed, but they make such an extreme difference! Like I used to go for three or four day benders without sleeping but now I make myself go to sleep everyday and if I can't sleep, I still make myself lie down for awhile.

(Interview with Shauna, May 1999).

Testing positive for HIV-infection and actually living with this disease means different things to each of the four women who I interviewed. As is seen in their stories above, HIV-infection is not necessarily *the* central concern in their lives – lives that revolve around day-to-day survival – but again, it depended on the particular storyteller and where the story was 'at' for shifts in focus were common. Nevertheless, in various contexts this disease is woven throughout

each of their stories but from my observations and listening to the women themselves, HIV-infection plays out as yet another constraint on these women's difficult lives. Although this virus has devastating implications, especially for female, IV drug-using Aboriginal women who are seroconverting at an alarmingly high rate, the women's narratives are illustrative of the multiple, complex and brutal constraints they face on a day-to-day basis, as well as their strength and perseverance to survive.

Addictions & treatments

By far the most central, shared theme that ran through the four women's stories was that of their past and present drug addictions. From my observations and the data I collected, generating income to attain and consume drugs is presently the unrivaled focus in each of these four women's lives. Each of the women I interviewed spoke candidly about their addictions and some women discussed previous treatment experiences. Although their stories of addiction are found within this particular section, I wish to again point out that I have placed the women's stories here - I have decided which excerpts to include and where to include them. Subsequently, I call attention to my editorial decisions, recognizing that this story could have been put together differently.

Nevertheless, Shauna's comment below highlights the relationship between the drug economy, current drug trends, and the decreased value of her sexual labour:

Well, the working girls prices have always gone by the price of dope. If dope prices go up, then our price goes up. But now, it's so fuckin' cheap! Before the 'skanky' looking things, you know the older, uglier girls, would charge way less, you know twenty bucks or

³² The Vancouver Injection Drug User Survey (VIDUS).

somethin' but we'd all just let that slide because they couldn't really make that much money anyway. But now, you've got good lookin' women who could be charging lots more, but they're doing ten dollar dates 'cause they want to do that rock so damn bad.

(Interview with Shauna, May 1999).

Supporting her heroin addiction through sexual labour, Shauna questioned how much longer she would be able to support herself via the sex-trade. After 14 years of generating income through the sex-trade, Shauna talked about her predicament in the following way:

When I started doing heroin it was 35 bucks a cap and I'd usually do about two caps for a fix, so say 70 bucks and if I did a speedball, it would be about 90 bucks. So, I'd go out and do one date and maybe if it was a bad date, I'd have to do two to get a hit. But now I can't even imagine making 90 bucks for one date – it would probably fuckin' kill me!... Lately, I've been out on a payday, you know Friday night and I've still only made 100 bucks – all fucking night! I mean I could make more if I wanted to sit there and do twenty dollar dates all night but I'm not gonna do 20 bloody dates in one night. And why should I? I mean Christ, you're already degrading yourself enough as it is, so why push it? I know everyone cracks to a certain extent. When you're 'jones'n' [also commonly referred to as being 'dopesick' - when a drug-user is physically dependent from the on-going and intense use of drugs such as cocaine and/or heroin. When their use is withdrawn, the body responds with a set of withdrawal symptoms including cold sweats, aching bones and muscles, nausea, sleeplessness, and diarrhea] or whatever, all of us, and nobody can say they don't, will go under what they believe in and what they think the rates should be. But still, I maintain you should stick to a fee schedule cause once these guys pay twenty bucks, they're never gonna pay the regular rate again. I mean why would ya? If I go pay one dollar for a piece of chocolate cake, then why would I pay five dollars some place else? It's just common sense - it's economics and it sucks. It's gotten to the point now where I can't even make a living and that's really sad. That's part of the reason why I want to get more involved in other stuff and lately I've been thinking about the 'meth.' [methadone]³³ program 'cause I just can't make it out there anymore.

(Interview with Shauna, May 1999).

Nadine spoke about her heroin and cocaine use as a daily battle – sometimes won, sometimes lost – in the following way:

I relapse, sometimes fuckin' up, doing the coke or heroin. Other times it's fighting the compulsions and obsessions and my days might start off the same, you know getting up, eating, cleaning up, fighting those things and setting goals and plans and following through

³³ Shauna is referring to Methadone Maintenance Programs which offer one form of treatment for individuals addicted to heroin (or other opiate drugs). Taking methadone prevents withdrawal and there are approximately 3,600 people in Canada on methadone maintenance which is thought to reduce the incentive to inject. Methadone maintenance cannot be utilized with people addicted to cocaine or other non-opiate drugs. For a more detailed examination of methadone maintenance programs in Canada, see the report titled "HIV, AIDS and Injection Drug Use: A National Action Plan (May 1997).

with them so I can spend time with my daughter. I try skipping past all those other things and plan schedules, trying to maintain a healthy life with a balance of eating, resting, doing positive things. Other times my day will be upside down, if I go the other way, if I choose drugs, and then my 'one day' might turn into seven days before I finally go to sleep. My one day will turn into scoring drugs from someone, and then piecing me off and getting me going and on and on it goes.

(Interview with Nadine, June 1998).

Miss-treatments

Discussing a previous attempt to get off heroin in 1991, Shauna criticized the limited availability of treatment options and facilities available to women with addictions in the DTES. She stated:

People always assume that because you're an addict, you're an idiot or something. Some dates treat you like shit just 'cause they know you need cash to fix. Yah, I'm sick of workin' but the detoxes here don't do shit for ya. I've gone through all the detoxes here and they were just fucking useless. They're in the most terribly situated places that they could possibly be but no-one thinks about that. You know, in the summer time you've got your window open and you can hear everyone in the alley fixin' - and I'm sorry, but you just can't do that when you're an addict! You're at your lowest point, your weakest state and this [the DTES] is just the last place you should be. I went up to a detox in Kamloops once and that place was really great. It's situated in a great spot, we'd go for long walks and see the odd deer and it was just really good. That program was great 'cause it kept ya busy but here you just sit on your ass and maybe have a group meeting once a day and then you have all this spare time to think about how shitty you feel. Well everyone eventually thinks, 'gee, I could feel better in 10 minutes' and they're back workin' and usin'.

(Interview with Shauna, May 1999).

Nadine spoke at length about healing and the time in her life when she was "clean and sober," working for an Aboriginal organization that assists urban Aboriginal individuals and families with addictions.

When I was about 19, I stopped drinking and drugs and started self-healing. I was looking for my identity and I started training and taking courses at college. I really wanted to make something of my life and so I started trying to heal and I became clean and sober. I started going out with this guy who took me on a spiritual journey for a couple of years and that really taught me a lot and helped me to get strong. I trained in Alberta as a drug and alcohol counselor. I really wanted to help anybody to not have to suffer or go through the shit I did. I met an older guy and we tried to get a treatment centre together and the funding almost went through but we had a change in Chief and Council and that screwed everything up. I got really disappointed and I said fuck it and I started doing the drugs and drinking again... When I first tried it [intravenous drugs], I was still working there. I took a medical leave but I phoned my work and I told them I could no longer work there anymore because I was no longer walking my talk and I begged them to let me go. Yah, I told them that I crossed the line and I could no longer work... I was doing family and individual counseling for drugs and alcohol but I was burnt out and I needed to leave

to get help myself... but when I went into recovery, my husband always kept hounding me and obsessing and manipulating me and I'd always say fuck it, and I'd come back out. Every time I wasn't using, he'd come back around 'cause he didn't like where I was at and he wanted us to be together.

(Interview with Nadine, June 1998).

Nadine's narrative made frequent references to the role of men in her life as a steady source of violence (see below) but also as key players in her introduction to drugs and the maintenance of her habit. Nadine's experience corresponds with Taylor's ethnographic study of female intravenous drug users in Glasgow, where she discovered that male partners were often significant facilitators, teaching girls and women the "skills involved in becoming a successful drug user: knowledge of where to purchase drugs; who to buy from; what to say; what to do with them" (Taylor 1993: 36).

There are many complex barriers to treatment for Aboriginal women in the DTES. Currently, there are just 59 detoxification beds operating and available (if you can wait) to residents of Vancouver's DTES. In the DTES then, 29 beds operate at the **Cordova/Harbour Light Detox**. Of these 29 beds, 6 were set aside as 'female-specific' but these 6 beds have recently been transferred out of the community to the BC Women's Hospital. Additionally, there are 24 detox beds operating in the **Vancouver Detox** and finally, there are 6 detox beds available to youth 21 years of age and under at the **DEYAS Youth Detox**. What this adds up to is a critical shortage of detoxification facilities, and the governments' inaction and neglect results in large numbers of individuals going untreated with the disease of alcohol and/or drug addiction. Further, when you combine the large number of individuals with addictions in the DTES with the

limited detoxification services available, the result is long wait-lists and missed opportunities. Moreover, considering that the facilities remain full to capacity on a day-to-day basis it is safe to say that current demand for treatment cannot possibly be met by the current supply of detoxification facilities in the DTES.

As well as an acute shortage of detoxification beds, there are also many other barriers to existing services. For example, the 'window of opportunity' for intervention is narrow and this means that when individuals do seek treatment, they must be able to access services without delay, otherwise, that 'opportunity' might be lost. Another barrier to efficient treatment involves the limited hours of detoxification services which means that individuals must currently decide and be ready to go into detox between the hours of 10 a.m. and 6 p.m. Finally, there are the female-specific barriers to seeking adequate and appropriate treatment for addiction considering that few centres offer services for pregnant women or have provisions for women with children in their care or take into account the fact that many women simply don't feel safe in the presence of men. A women's detox centre in the DTES could address these issues, offering a safe space for street-involved women going through the painful process of detoxification.

In the Core Women Care study completed in 1995, 52% of female respondents cited further alcohol addiction and drug treatment services as a top priority in the DTES (Core Women Care 1995: 26). Furthermore, the Vancouver/Richmond Health Board suggests that individuals most at risk for contracting HIV are those who are, or are likely to become, injection drug users and within this group, Aboriginal peoples, women, people with mental illness,

youth and those with unstable housing were identified as being most at risk for contracting HIV (Regional news release, Health Canada Home Online, June 25, 1998: 2). However, the narratives reveal that further research and creative strategies regarding treatment options and facilities are best conceptualized by the actual residents in this neighborhood, for drug-using women are diverse and in this way, their needs do not necessarily converge. In fact, the women I interviewed were quick to point this out, as will be seen in the next section.

The harm reduction approach

The 'Harm Reduction' approach, with respect to HIV/AIDS, is often associated with injection drug users and this approach, grounded in the theory of behavioral change, is followed by many of the centres (staff) offering services in the DTES and it is put into practice by some of the IV drug users that reside in the DTES. Harm reduction holds different meanings to different people and organizations, but essentially the harm reduction approach focuses on reducing the harmful effects of behaviors without asking people to abstain or stop those behaviors. Thus, the central aim of the harm reduction approach is to *lessen* the negative consequences of IV drug use. However, this approach is not restricted to IV drug users alone. In fact, the harm reduction discourse runs through much of the prevention literature relating to gay men and HIV/AIDS, but it is now being applied to various 'populations' such as women, youth, and IV drug users. Nonetheless, what I am going to briefly outline here is the harm reduction approach as it is used with regard to injection drug use and in so doing, I will

outline some of the principles of harm reduction, as set out by the Canadian AIDS Society.

The first principle holds to the idea that no drug is inherently 'bad' and following from this, complete abstinence is not always necessary. Secondly, this approach suggests that the non-medical use of drugs is inevitable in any society that has access to drugs. Subsequently, the realities of drug use must be dealt with in an effort to lessen individual and social harm. Thirdly, the harm reduction approach looks at drug use as a public health issue rather than a criminal justice issue and in this way, addiction is viewed as a chronic process that may even require life-long treatment strategies. Next, the harm reduction approach recognizes that drug users are an integral part of large communities and with this recognition, the harm reduction approach works to enable drug users to effectively integrate within their communities, rather than to segregate and marginalize them. Finally, harm reduction recognizes that drug users are not a homogenous group and that the actual practice of harm reduction works best when various supportive strategies and resources are made available and then left to the individual drug user to decide how to put them into action (Canadian AIDS Society, 1997).

Examples of strategies that follow a harm reduction approach in Vancouver's DTES include the methadone maintenance program, the needle exchange programs (which have operated lawfully in Canada since 1989), and the availability of free condoms. These initiatives attempt to attract IV drug users with a non-judgmental approach in an effort to reduce the harm, individually and

socially, of IV drug use and 'unsafe' sexual activities in the DTES. Further, proponents of harm reduction hold to the notion that it is a more 'realistic' framework especially considering that attempts at drug prohibition consistently fail and they do absolutely nothing for those who actually live (and use) in this neighborhood.

Talking about her participation in the making of a documentary film about living with HIV, injection drug use and harm reduction,³⁴ Lisa discussed her understanding of the harm reduction approach as follows:

Basically, it's just like if you're gonna use, well we're not condoning it but if you are gonna use, be safe! We put the street nurses in this movie, DEYAS, VIDUS, all these places and then they asked me to work with them for one day and I ended up working with them a whole week! So, if you're gonna use, well this is what could happen to you and if it does happen to you, there is help.

(Interview with Lisa, December 1998).

However, Lisa's comment below shows how current promotion of safe injecting sites for intravenous drug addicts does little to address the needs of large numbers of urban crack users like herself in the DTES.

Everyone has their own ideas about how to 'fix' this place but to me, safe fixing sites are just not something that I really believe in. Well, it's just not going to deal with all the issues. What about this big issue that's coming up and that's that people are smokin' a lot of crack. They need as much help as the people that fix but nobody wants to talk about it. For one thing, when people come down after three or four days of smokin', and they don't have a hoot and they're telling ya they want to die or else their lungs are going on them – it's really hard you know! Sometimes, you don't even know if what you're smokin' is rock or not. So ya, right now it's only looking at part of the problem.

(Interview with Lisa, December 1998).

³⁴ Visiting the Youth Action Centre (YAC) in May 2000, I viewed YAC's copy of this video which is titled *IV positive: an educational documentary about living positive*. The video was produced by "Crossroads Productions" and it was funded by the AIDS Community Action Program, Health Canada and the pharmaceutical company Merck Frosst Canada & Co.

Although much more can and should be done regarding treatment/detox facilities and harm reducing options for drug-addicted Aboriginal women living with HIV/AIDS, I wish to point out that this approach alone will not make any significant changes in these women's lives. I call attention to the systematic inequalities that constrain the lives of poor, drug-using Aboriginal women and safe injecting sites and more treatment beds do nothing about the larger issues of racism, sexism, poverty and classism which all interact to constrain the women from controlling certain aspects of their lives and therefore their health.

Furthermore, we need to think about better organization and expansion of services towards a more comprehensive, long-term approach, which might increase access and decrease the frustration and stress that marginalized peoples often talk about as they get shuffled around or diverted to various agencies. This sometimes results in some people giving up on their healing and recovery because the system is simply too fragmented and inflexible to make any real impact on their lives.

Street-involved women care

Although female crack users have often been portrayed as being cutthroat, irrational, desperate and self-serving, my observations of Lisa's 'networking' capabilities and relations in the DTES strongly challenge these narrow images. Lisa's presence in the DTES is warmly welcomed by other addicts (both IV-drug using and non-IV-drug-using men and women) as well as by agency staff that I often observed her interacting with. Further, Lisa's outgoing personality makes her well known in the DTES and, as I stated above,

she is well liked. She frequently goes out of her way to inquire about how others are making out and her tendency towards caring for others, especially other women, is easily appreciated when one spends time with Lisa. Working in the DTES, listening to women's stories and day-to-day realities, I better understand the 'insider' knowledge and street survival skills that are necessary to reside in this community, openly shared amongst some of the women themselves.

For women involved in the sex trade, this type of insider knowledge and intuition is even more important. In fact, peer support is critical to some women's day-to-day survival in the DTES and the women I interviewed spoke about the support or help they receive from friends and peers. In the DTES one example of how peer education can be a successful strategy in reducing the inherent harm of sex trade involvement is the use of the 'bad date list'³⁵. However, this is an area that requires more attention to both the possible benefits of and obstacles to increased peer education but again, direction from street-involved women is crucial to these sorts of strategies.

The reality of women as formal and informal caregivers, responsible for managing the majority of family and community health directions on a day-to-day basis was apparent in each of the stories told by the women that I interviewed. In fact, many of the women who reside in the DTES continue to carry out the gender-inscribed role of 'caring for others' despite their addictions and day-to-day survival strategies. Drug-addicted, HIV-positive Aboriginal women may re-work

³⁵ The 'Bad Date List' is published every two or three weeks by DEYAS and WISH and this list alerts sex-trade workers to dangerous individuals/situations to be aware of (violent johns, johns that refused payment, johns that have recently raped workers, etc.). Information for the 'bad date list' is reported by women involved in the sex trade in an effort to keep each other safe.

this role to fit their current lifestyles, but they do continue to play out the caregiving role inscribed on women. In the interview, Lisa spoke often about the various individuals she was attempting to care for, and in her comment below

Lisa talks about visiting her cousin, who was dying at St. Paul's Hospital:

Yah, one of my cousins is in St. Paul's [Hospital] but I don't think he's gonna make it out this time... he's gone full-blown now and... he's just so happy to see me when I'm there but, then it's so hard! I know I can't turn my back on him but I also know I'm seeing what will eventually happen to me. I mean, I hope it's not for a long time but – it's still just hard to go and see him but I will. The last time I went, he couldn't even hold his balance anymore. It's just hard to watch, that's all.

(Interview with Lisa, December 1998).

Lisa's comment above is also representative of the large family and generational networks that exist in the DTES, especially amongst Aboriginal residents of this neighborhood. Speaking with Lisa, I heard many stories about her family members who also lived in or visited the DTES, struggling with their own issues and their own addictions. Many are no longer living today.

Nadine described her earlier attempts to manage the 'juggling act' of caregiving as a young Aboriginal women with addictions, living between Vancouver's streets and her reserve community.

Slowly, I started thinking about the teachings my father told me when I was younger and I tried to go back to school. I tried to stay in school even though I partied, drank and did dope. I tried to graduate and I made it as far as completing grade 11. I never did fit in there because I was already grown up, living on my own and doing, you know - adult things and stuff. Yah, I did all of that shit and while I was partying, I was taking care of an old man, and I was going to school. I was taking care of other people too. Other runaways (long pause)... ya, I was taking care of a whole family of people, like I was their mother...

(Interview with Nadine, June 1998).

The notion of 'street families' is important to this discussion since it was often referred to in the interviews. 'Street families' take various forms, but essentially one's 'role' typically stems from being a veteran of life on the street and

subsequently, women often end up spending much time and energy with those with less experience, especially youth, and this can be draining for HIV-positive women with compromised immune systems. That said, taking on the role of street 'mom' is obviously a central aspect of Lisa's identity.

I usually hang out at Native Health and at night I drop by the WISH³⁶ program from six 'till ten at night. A couple of days ago, it made my day when I was on the bus and this woman says to me, 'you know if it wasn't for people like you or Sandra, I probably wouldn't be around anymore'. She said that I make the girls feel accepted and cared about and I was just sitting there on the bus thinking, that's cool!

(Interview with Lisa, December 1998).

Having spent a fair bit of time with Lisa over the past few years and observing her interactions in the DTES, I've come to better appreciate the ways in which 'street mothers' attempt to make life more comfortable for those individuals that they are especially close to. Furthermore, I've seen how these 'mothers' provide protection and instruction to each other, sort of like 'Survival 101' where the most crucial lessons are often learned from long-time community members who instruct the younger, less experienced girls/women about the skills necessary to stay alive in the DTES. However, what also needs to be pointed out is that the multiple responsibilities and demands placed on women in the name of 'caring' may result in lower health status among these women, and this is especially marked in women that have compromised immune systems from HIV-infection and chronic addictions. Nonetheless, the caregiving role typically taken on by many Aboriginal women plays out in a similar manner in the DTES and this is an area where more research is needed.

³⁶ 'WISH Drop-In Centre Society' operates out of the First United Church located at 320 East Hastings and it is a drop-in centre for sex trade workers in the DTES.

Mothering was also talked about at length by some of the women involved in this project and as the narratives reveal, their stories of motherhood shifted during the interviews, sometimes cheerful and sometimes somber. Nadine talked about her relationship with her then eight year old daughter as follows:

I know the drugs have affected my daughter because she's had to grow up really fast. She's had to learn about alcohol and drugs, and needles – things that she really shouldn't have to know about. Because of me, she's had to be without her mother at times, to learn how to have losses and stuff and put her feelings aside. I guess, you know, for her to learn to be smart, so she's like a little adult... Sometimes I'm like a kid, just fucked right up and crying and she's there telling me 'it's okay mom', you know... So, she's been really resilient and our bond is just as strong as ever, it's never separated us. And throughout all these years, I've tried to be there for her, as fucked up as I've been, I've taken time out and I've tried to clean up and I go spend time with her... I've been trying to fight it ever since I got hooked! But ya, she's had to suffer losses but not a complete loss because we're still together.

(Interview with Nadine, June 1998).

At a later point in the interview, Nadine came back to the challenges and the joys she experiences parenting, which she does with her family's assistance.

However, Nadine's narrative also illustrates the ongoing tension between her role as a mother and her role as an IV drug user. Nadine stated:

If I end up being involved with other crack heads or heroin addicts, I have to fight the drugs even stronger if I plan on being with my daughter and that's the hardest thing for me to try and do. You know, to say I can't do this because my daughter is here or because I'm going to see my daughter and then I have to walk away from what I might normally do. So I have to fight it all the time. It's not difficult once I walk away. When my daughter and me are together, nobody can burst that bubble. It's like my daughter has such a power and strength and when we're together and somebody walks in and says, "Hey Nadine, can you do this for me?" It's like "Hey, fuck off right now!" Mostly my daughter affects a lot of people. She can affect six people to not do dope and play with her instead and get responsible and stuff. The common thing about me and other addicts I hang around with is that they have a child too, that they are out of touch with. I don't know if they're pretending that they're with their own kid or what but they're glowing just as much as me after our weekend together is over! Yah, sometimes me and a half a dozen other people will all be devoted to my kid!

(Interview with Nadine, June 1998).

Besides relationships with their children, the women involved in this study also spoke about their past and present relationships with men and women.

During the interviews, three of the four women made reference to same-sex relationships but none of the women identified themselves as lesbians. Shauna's comment below shows how she views her same-sex relationships as a direct result of her negative and abusive experiences with men. However, Shauna's story also suggests that in seeking same-sex relationships, she is better able to receive the kinds of support and respect she needs because of her involvement in the sex trade. Explaining her preference for women as steady partners, Shauna stated:

I think my attraction to women came with the constant bullshit that I got from a man, every single fucking time from a man, no matter who it was! With guys, I couldn't seem to seek out anything real, mentally, physically, emotionally – whatever it was, my expectations were never met no matter how much I lowered them, they were never met. I know this is a terrible thing to say but with women it's 80 % mental and 20% physical. It's not so much of a physical relationship and I don't end up feeling like I have to have sex. And that's a big pressure for me. Men just don't seem to understand that when you go stand on a corner all night, the last thing you want is anybody touching you. And men seem to think you can turn your feelings on and off like a light switch but you just can't! When I'm working, I set my mind in motion to go out there and when I come back in, it's hard to wind down and act like yourself again because you're not really 'you' when you're out there – you can't be yourself of you'd go fuckin' crazy!

(Interview with Shauna, May 1999).

Although Kelly and Lisa also made reference to their involvement with temporary, same-sex relationships, neither of them spoke in much detail about their relationships and as I mentioned above, none of the women actually identified themselves to me as 'lesbians'.

Violent views: past & present

Another factor that clearly impinges upon Aboriginal women's health in the DTES is the impact of violence and this is another area that clearly requires further attention by the health research community. As the narratives reveal below, violence and abuse are on-going constraints for these four women and

their experiences of violence are cast in many forms, including childhood sexual abuse, partner violence, and for women involved in the sex-trade, work-related sexual violence/assaults. Moreover, each of the participants who I interviewed spoke of being violated, violently, by family, by partners and by the individuals that they work and reside with and the women's stories illustrate the centrality of violence and abuse in their day-to-day activities and decisions:

There's just too many working girls now and I'm passin' up a lot of money out there these days 'cause I'm so over-cautious, but I'd rather be cautious than stupid or dead! I almost died two summers ago when this date tried to kill me... so yah, I'm really cautious now but I'd rather turn down money and think that I may have saved my ass than take it and think maybe I'll get this money or maybe I'll end up in a ditch somewhere. It's just all too fucked up out there now, and I've been working here since I was eighteen!!

(Interview with Shauna, May 1999).

All four of the women interviewed for this study referred to childhood abuse, again, cast in many forms. Other research studies have shown that women who use illicit drugs frequently have histories of childhood abuse (Bourgois and Dunlap, 1993; Boyd, 1993; Sacks, 1993). Although impossible to 'measure,' the women's histories of abuse and violence (and low self-esteem) played a significant part in their decisions to engage in activities that increased their risk for HIV infection.

Discussing her painful childhood, Nadine's comment below illustrates the extent that violence and abuse featured throughout her 'developing years' and she goes on to draw a link between early childhood traumas, running from abusive situations at home, and her early involvement with drugs and alcohol in the following manner:

There was always lots of beatings and sexual abuse and shit, from parents, from baby-sitters and that. So, we tried to run away and then my father phoned my mom on Vancouver Island and said, "come and get your kids," so she came and got us. After

that, my stepfather was beating me on a regular basis and the teenagers on that reserve were trying to sexually abuse my sister and I... The drunken in-laws were always trying to sexually abuse us too so I ran away, my mom actually helped me run away and I tried living with my father again. I stayed for awhile but I kept running away, living down on Granville Street at the time. Yah, that's when I really got into the drugs and alcohol. When I was a kid, everybody stayed up on Granville. All the heroin addicts, cocaine addicts, acid freaks, pot-heads, alcoholics – everybody stayed up on Granville. Everybody sold their dope and drugs up on Granville, everybody got together after the bars closed and we'd all be in the same room, whether we were fourteen year olds or thirty year olds! We'd be crammed into the same hotel room, drinking and doing drugs all night. Yup, it was like one big family back then and none of it really scared me. No, I was actually a lot safer down on Granville than I ever was at home.

(Interview with Nadine, June 1998).

Linking early childhood traumatic events to her involvement in the sex trade, Shauna described her feelings concerning past abuse experiences in the following manner:

I'm not really one of those types of people that blames others. You know, 'My parents raised me badly and that's why I'm all fucked up' type of thing. But I will say that a lot of the things that happened to me when I was a kid all put this in motion. Still, I mean some of the choices I made myself along the way, but I don't really believe I would have made those same choices under different circumstances. I was abused constantly – I don't even remember the beginning. My uncles abused me, my grandfather, my baby sitter, and then my dad was the last in line of all the people! So, I just don't think I would have made some of the decisions I have and I might not have been here. I know I never would have started working down here except for the fact that I obviously view sex in a different sort of light than most people. Well, I have yet to have had any fun doing it! I suppose if I actually worked out all my little things in therapy, it might be a different story. But the only way I view sex is something to exchange. That's the way it was when I was a kid, something to be exchanged for something else – that's just the way it worked out to be. It's just always been a role play and I've never been thoroughly interested in sex. But even in the relationships I've had, it's always been phony, it's always been fake, and it's always been like this is what they expect so this is what they get. But if I just dealt with sex the way I wanted to, I'd never even have it! It doesn't hold anything for me.

(Interview with Shauna, May 1999).

Shauna's comment above about being uninterested and dissociated from sexual acts was an outlook that was expressed to me by many of the girls and women involved in the sex trade in the DTES. Moreover, early childhood sexual, physical and emotional traumas were often cited as reasons for and the ability to 'disconnect' during sexual activities as well as being related to their move and

adjustment to surviving, as Aboriginal women, in the DTES. Thus, despite their diversity, the narratives reveal that the women held many issues in common as well and past and present abuse/violence was an area referred to often in each of these women's stories. Some of their stories showed how in attempting to escape abuse and violence in their early lives, they eventually made the move to Vancouver's streets. However, instead of escaping or finding relief from violence, many Aboriginal women continue to experience grim violence in their day-to-day struggles to survive.

On the move...

Another common theme revealed in the interviews was the lack of secure and stable housing available to street-involved Aboriginal women and all four of these women talked about how often they had to move and/or why they were always moving. Moreover, decent housing is almost non-existent within the DTES and since the federal government stepped away from social housing in 1993, the city has taken the stance that they cannot afford to do it alone.

This means that large numbers of street-involved Aboriginal women must reside in SRO's and this living situation involves sharing a washroom with men, which often places women in vulnerable situations. As well, there are usually no cooking facilities and most of the SRO units do not come anywhere near meeting basic health and safety standards. Furthermore, because there are so few affordable options for women in the DTES with regard to safe housing, women may find themselves locked into abusive relationships, where they again sacrifice their bodies in order to house themselves. The housing situation is even worse if

you have HIV/AIDS because then the physical conditions of current housing (damp, roach infested, rat/mouse droppings, inadequate heating, little/no cooking facilities, no fridge to keep prescription drug treatments in, etc.) inevitably impact one's health status. In identifying and prioritizing the current health needs of women living in the DTES, the Core Women Care study revealed that 72% of female respondents felt that an increase in transitional facilities were a top priority which included recovery homes, detoxification spaces, homeless shelters, and battered women's shelters (Core Women Care 1995: 18). Frustrations regarding housing came up again and again in the narratives I collected and during my work with women in the DTES, housing crises were common.

Discussing the unsafe situation of her current housing arrangement (a SRO unit in the DTES), Shauna stated:

I have a lot of trouble sleeping, it's just always been like that. I think a lot of it has to do with being down here. I'm always constantly worried. Anybody could break into my room but they [hotel landlords] don't give a shit! When I moved out to Abbotsford, I slept a whole lot better!

(Interview with Shauna, May 1999).

Kelly also made reference to the run-down state of available housing options that currently exist for drug-addicted, street-involved women in the DTES when she explained:

I'm always in-between things you know, I'm here and there and everywhere! Ya, and I don't plan on staying put - what for? On the streets, nothing holds you down and when you do try and settle, there's always someone or something that gets in your face and puts you out. I really don't know how these women can do it! I mean I'd rather live outside than live in these shit-holes down here anyway and I know a lot of people that feel the same way.

(Interview with Kelly, February 1999).

At the time of the interview, Kelly had been homeless for just over a month and she explained to me that she was currently staying 'wherever' possible.

Essentially then, what is desperately needed to address women's specific housing needs is *more* housing, but also *safe, flexible* and *relevant* housing options that allow drug-addicted women to take further control over their lives, thus improving their overall health status. In the meantime, however, the city must stop destroying the only affordable housing options that DTES residents have unless governments are going to offer alternative housing for community residents.

Another recent study also revealed that the unstable housing situation in the DTES was most evident amongst female injection drug users. In the data collected for the 'Community Health Research Project' (CHRP) it was found that 75% of female IV drug users live in non-stable housing (Information Request Report, Community Health Resource Project, March 1999: 5). Moreover, the research findings from the CHRP study correspond with the findings in this study, in that non-stable housing was a common theme in both the narratives and my direct observations in the DTES. Infected with HIV, trying to take care of her daughter, her partner, her dysfunctional family - and then having to cope with moving – yet again – was a self-described 'breaking point' for Nadine. Further, the actual impact of inflexible housing on the health of women in the DTES was observed over and over again. After being evicted from the Mavis-McMullen housing project for women, which had been her home for years, I noticed a marked difference in Lisa's appearance and overall health. Since then, Lisa has

moved three more times and she continues to struggle to find safe, affordable and relevant housing in her community. In the meantime, her health continues to deteriorate.

Active community members

Importantly, the narratives point to the fact that street-involved women are active community members, but to some extent these women are also defined and constrained by the spaces where they live. As was discussed above, Lisa's life changed rather significantly since testing positive for HIV in that she had never involved herself in community agency activities prior to seroconverting. Lisa's comment below points to the reshaping of her identity and her increased community work since testing positive for HIV in 1991:

I just got sick of always taking and taking and after awhile, I just wanted to give back to the community. Ya, right now I'm working on a committee to put something together to help keep track of the working girls because so many of the girls are missing from the Downtown Eastside. And recently I was asked to sit on another committee - a hiring committee for a new HIV Outreach Worker at the Women's Centre... staying involved keeps me out of trouble. If I get bored, I'm back 'downtown' using [drugs] again so it's an added bonus!

(Interview with Lisa, December 1998).

Street-involved Aboriginal women continue to create and re-create their own identities and livelihoods within the Downtown Eastside community. For Lisa, testing positive for HIV has also opened up many opportunities (including some income generating opportunities) and she spoke often about her increased involvement in the DTES. That said, Lisa's goal to keep herself busy and involved in community work stems from multiple factors that she made reference to throughout her story including: staying away from drugs, a desire to help

others, generating income from community agencies, and keeping her mind off painful and unresolved personal issues.

I try to do lots of other things so I don't have to think about things I'm not ready to deal with. That's why I go help out but there are some things I'm just not ready for you know. I feel happy when I help people out, but still I know there are some things that I just can't do. But I try to be happy with the things I do... Like when I was a lot younger I used to tell myself, 'Nope, you're not going to see 30, no way' but now I see myself wanting to live bad, like 'till I'm 60 'cause there's a lot of things I want to do now. I have a lot of 'gung ho' in my life now! Now when people ask me if I want to fix, I can say no. I found it weird at first 'cause I was so paranoid when I was straight but I can say no... Now I do special events, I speak at conferences, and I work at the information booths. I just started doing that recently. I spoke at a conference at Carnegie and one at Healing Our Spirit. Right now I'm doing a talk for the speaker's bureau at Crabtree. I used to volunteer there a lot too. I also volunteer at the Women's Centre, you know mostly I just help out. I do the same at Native Health and WISH.

(Interview with Lisa, December 1998).

Lisa's story above is also important in that it challenges the narrow images of drug-addicted women in the DTES, revealing a more accurate picture which reflects the hard work and commitment of many street-involved women to take care of each other and their community. In fact, throughout each of their narratives, the women talked about making the most of the spaces they currently occupy. Shauna's comment below reveals how she approaches her life in the DTES:

You can play this place either way. You can totally alienate yourself down here but if you know the resources or at least get off your ass and try to get involved, there's a definite sense of community. But, you have to involve yourself in it because it's not going to just take you in – you have to get off your butt and take care of yourself. I mean there's lots of Outreach Workers who try to get you involved but unless you're going to put the effort in yourself, there's nothing there.

(Interview with Shauna, May 1999).

Thus, although the women's stories show that they are, in some ways, able to actively negotiate their involvement in their communities, the women's lives and activities are also defined and directed by the spaces they occupy and their day-to-day struggles as poor, drug-addicted women residing within those spaces.

Speaking about the large numbers of Aboriginal people that live on or near

Vancouver's streets, including herself, Lisa explained:

It's hard to live by traditional teachings downtown. Natives keep talking about that too, like going back to our teachings, which is really neat, if it helps. I live by my own teachings because that's what you have to do, it's the only way to get by downtown... Most of us never make it out of here. I don't dwell on it or anything, I mean I have a lot of things going for me right now. If I start thinking about it I get this 'I give up' attitude. I look at things differently, you know... Actually, I really enjoy the times when I just sit and have a coffee with somebody 'cause then instead of going for a toke or something it's, well, it's a big difference.

(Interview with Lisa, December 1998).

As an active community member, Lisa also discussed the politics of her increased community involvement by way of both her drug-using peers and certain staff members at the various community agencies she has been involved with in and around the DTES. With regard to her street-involved, drug-using peers, Lisa had this to say:

A lot of addicts just totally give up down here but for me I just think, well yah I'm an addict, but I don't give up because of it. I've had my share of harsh words though, for volunteering at these places down here. Some people think I'm too good or they're like, "Oh, you think you're too good for us now" ~ you know, shit like that. But I try and just let it go 'cause it's not worth it.

(Interview with Lisa, December 1998).

Negotiating her own role in the DTES, Kelly made reference to the importance she placed on maintaining a 'tough' image, drawing a link between her image and current income generating strategies that she is involved in (selling drugs on the street-level market). Moreover, the daily work that Kelly must do to support her addictions, and the image she portrays during and after work, do not seem to lend themselves well to active involvement in her community. Kelly explains:

With my job [selling drugs], you don't fuck around too much. Ya, I have to keep my own shit together so people know I'm not gonna put up with their crap. You know it's mostly an image thing but I don't give a fuck if people like me or not. Actually, I go out of my way sometimes to make people NOT like me! I have to! I mind my own, take care of my own and that's the way she goes. You know, I keep to my self and my corner of the world and that's just the way I like it!

(Interview with Kelly, February 1999).

In fact, when I first met Kelly she went out of her way to show me that 'tough' side of herself but in time, I came to understand the importance of creating and maintaining an image in the DTES, and how image also plays a significant role in many of the women's day-to-day negotiations and strategies to survive.

Later in the interview, Lisa again made reference to negotiating her role in community activities. Describing some of the more difficult aspects of her involvement with various agencies in the DTES, Lisa gave this view of her situation in relation to the work she does:

All of these organizations, as far as I'm concerned, have got to stop fighting with each other. They should pull together and instead of fighting for grants, they should be fighting together to share grants and stuff - not trying to tear each other apart, because they're all down here for a purpose. Another thing that really gets to me down here are the people that try and manipulate me. I know a lot of people in the different organizations down here so I always seem to have people asking me, "Is so and so doing their work?" or "Do you know what so and so is up to?" I turn around and say; "Well do I look like an information booth to you?" Or I say to them, "You're the one that hired her so you figure it out!" I've even told the person that sometimes too!

(Interview with Lisa, December 1998).

As the narratives illustrate, community involvement is neither simple or predictable amongst street-involved women who reside in the DTES. However, I believe that this is an important area, worthy of more attention and action in that many of the women that I came to know were willing and able to 'help out,' get involved, participate in various activities and decision-making opportunities within their community. In this way, more attention could be placed on providing paid opportunities for drug-using, street-involved women who are willing and able to work and gain new skills while living in their community. In so doing, interested

women could generate income, gains skills and take a break from their work in the sex trade or drug economy.

In the chapter that follows, I look at some of the theoretical links that contributed to, and at times challenged my research, analysis and writing throughout this particular study.

CHAPTER FIVE: THEORETICAL LINKS

"It takes a great deal of work to erase
people from theoretical discussion."
- Lee Maracle

In Chapter Three, I talked about how this research project was conducted by looking closely at the methods utilized in carrying out the research process. In Chapter Four, we heard the women's narratives, which were unavoidably partial and incomplete - yet not insignificant - for collecting their 'theories' was largely what this project aimed to do. In this chapter, I link the methods and voices with the theoretical frameworks that have guided my thinking and writing and in so doing, I grapple with certain aspects of narrative method, feminist ethnography, and population health, their contributions and unresolved contradictions, as played out and related to this study.

Documenting silenced stories

Essentially, this project was about documenting the experiences and stories of four street-involved Aboriginal women living with HIV/AIDS. My starting point was that their voices, their stories and their knowledge were virtually unheard, beyond their own circle, and that they deserve further attention. Personal narratives and illness accounts are increasingly used as research data in anthropology and health related research more specifically. Narrative method focuses especially on an individual's subjective experience and understanding of an illness, "pointing to the crucial importance of social and cultural factors for the interpretation of symptoms" (Steffen 1997: 99). This approach has been elaborated by Arthur Kleinman in his book *The Illness Narratives* (1988) and was

expanded upon in Kleinman and Kleinman's article, "Suffering and Its Professional Transformation: Toward an Ethnography of Interpersonal Experience" (1991). Stressing the centrality of ordinary human experience by focusing on what is at stake for particular participants in particular situations, Kleinman and Kleinman suggest that:

Anthropological analyses (of pain and passion and power), when they are experience-distant, are at risk of delegitimizing their subject matter's human conditions. The anthropologist thereby constitutes a false subject; she can engage in a professional discourse every bit as dehumanizing as that of colleagues who unreflexively draw upon the tropes of biomedicine or behaviorism to create their subject matter (1991: 170).

In a more recent work, Kleinman called for the inclusion of positioned knowledge for when it is rejected, "say through the sole use of HIV sero-status and AIDS fatality rates to measure the AIDS pandemic, something fundamental to the human experience of suffering may be lost: namely, its grounding in greatly different local worlds and lives" (1995: 82). Following Kleinman then, I was interested in looking at the social course of HIV/AIDS with particular participants, in particular situations - namely, street-involved, Aboriginal women living with HIV-infection. To understand and better appreciate the women's lived experiences - their positioned knowledge - an ethnographic perspective that placed primary emphasis on narrative provided the framework for this research.

Although street-involved Aboriginal women in the DTES have told and continue to tell their stories amongst themselves, their voices do not typically go beyond Vancouver's streets - to the far removed places and spaces of academe. However, in thinking seriously about the methods and the voices that guided and informed this study, I better appreciate how I too moved the women's stories from their original form and context and placed them somewhere else (to

academe and this MA thesis), which beyond documentation does very little for those that actually told their stories to me. I have to point out here as well the damage done to the women's stories, in that academic research and writing involves a process and that process goes well beyond the collection of women's stories. It involves the selection, arrangement and presentation of women's stories and knowledge, but then whose knowledge is really being presented here? And equally important, who benefits? Although not my original aim, I alone selected and arranged the women's stories and in this way, I have largely directed this text. My original intent, however, was to seek out ways to 'share' the project with the women who agreed to participate but what I found instead was that my intentions were not 'shared' by the women themselves. I had been submerged in academic (feminist, postcolonial, postmodern) trends which demanded that I be accountable, reflexive, and non-exploitive (Hervik 1994; Hastrup 1994; and Weeks & Schensul 1993). Further, my research had to be collaborative, polyphonic, participatory and quick to expose any and all power relations (Okely & Callaway 1992; Moore 1988; and Mascia-Lees et al.). However, as I explained in Chapter Three, these sorts of 'intentions' were not followed by the participants of this study.

In theory, I agree with these sorts of research and writing strategies and frameworks but in actually conducting this study, I found that the women themselves had very little interest in the research strategies discussed above. In retrospect, this seems rather obvious considering our respective locations. Put more simply, these four women were interested in survival strategies, not

research strategies. However, I had not given sufficient attention or thought to the actual position of the participants of this study because most of my attention had been focused on *my* position as a researcher interested in conducting 'respectful' research, directed by 'respectable' theories, utilizing 'respectful' methods. Ultimately, the project was shared – not in some of the ways that I had originally hoped and planned for – but by way of the women's involvement, their experiences, their expertise, and their stories which made this project possible.

Going back, then, to the notion of prioritizing lived experience over theoretical knowledge, Jackson (1996) has pointed out that for the most part "human beings live their lives independently of the intellectual schemes dreamed up in academe" (4). Jackson goes on to suggest that:

In prioritizing the knowledge with which people live rather than the knowledge with which Western intellectuals make sense of life, ethnography helps us place practical and social imperatives on par with scholastic rules and abstract understanding. It helps us recover a sense of those critical contexts of existence where knowledge is not a matter of how to know but a matter of life or death, when something is hazarded and risked in the process of coming to know... (1996: 4).

Discussing her outlook on research studies in the DTES, Lisa made reference to the disappearance of researchers and the apparent inapplicability of our academic projects to affect real change in her everyday life. Lisa offered the following thoughts:

Well, it [research] ain't so bad if it can actually be used in this area. The Eastside is just one of those areas that is always in an epidemic state because of one thing or another... With all good intentions, the research starts but then it just goes away and a lot of these people I see are just terrified of this area, it's like they don't fit in down here. Others do so I guess it really depends... it's just, you know, nobody seems to be doing a whole hell of a lot right now!

(Interview with Lisa, December 1998).

For myself, I've had to accept the fact that this project will likely not do, as Lisa stated above, "a whole hell of a lot right now" but I still think it is an important step

in that four HIV-positive, street-involved Aboriginal women's voices have been documented here, but more stories must be told and heard if meaningful, grounded changes are to occur for these women.

It goes without saying that globally, within most countries, and then within more localized settings (such as the DTES), women have different relations to HIV/AIDS because of poverty, race, geography, sexual orientation or age. What this means is that the day-to-day realities of, for example, an HIV-positive Aboriginal woman living in the DTES are going to be a world away from the day-to-day realities of an HIV-positive Caucasian woman who returns to a nice house from a well-paying job. In the same way, women with HIV/AIDS that care for children, partners and/or family or community members will have different experiences than, for example, women living with HIV/AIDS in the prison system. What I am suggesting here is the need for the inclusion of *many* more voices. Further, I maintain that the narrative model, as utilized in ethnographic, health-related research, provides for the inclusion of marginalized voices and unvalorized knowledge and experience. In this way, marginalized women's perspectives, on their lives or illnesses, can become a resource to direct change. Discussing the striking silence on the topic of women in AIDS discourse and questioning why women's voices were virtually unheard during the first decade of the pandemic, Farmer (1996) observed that:

One explanation for this partiality is that the majority of women with AIDS had been robbed of their voices long before HIV appeared to further complicate their lives. In settings of entrenched elitism, they have been poor. In settings of entrenched racism, they have been women of color. In settings of entrenched sexism, they have been, of course, women (8).

In conducting this study, a space was created where four HIV-positive Aboriginal women could speak about what is at stake for them. The results are not neat and tidy, the study is incomplete and fragmented, but in hearing these women speak, this project accurately reflects some of the constraints and struggles, hopes and fears, and strength and resistance of four street-involved Aboriginal women. In this way, I have shown how an ethnographic perspective, with an emphasis on narrative, can offer a platform for marginalized knowledge and theorizing about health and well-being.

The population health approach

The narrative model utilized in this study provided the means to illustrate how four, street-involved Aboriginal women actually experience the unequal distribution of health status in this country. Guided by a population health perspective, I have also called attention to the larger contexts which, as the stories revealed, undoubtedly shape and direct these four women's experiences. In fact, their important stories highlight the need for fundamental changes to occur – changes that address the poverty, social exclusion and devaluation of many Aboriginal women today.

The diverse factors that actually influence and shape our health then – the physical, mental, emotional, spiritual, cultural, historical, economic, and environmental are all interrelated and must be taken into account when looking at a population's health status. Moreover, gender and race are intricately connected with the factors outlined above, for they too shape, determine, and/or heavily influence our experience with health or ill health. That said, the literature

and many population health-based research projects seem to have ignored or downplayed gender and race as variables to health and my point here is to emphasize the limitations of a population health framework that downplays race and gender simply because it is already taking multiple variables into consideration.

Nonetheless, the most significant contribution of population health has been its ability to move researchers and policy makers away from a narrow concern with the causes and cures of specific diseases. Instead, researchers and policy makers are recognizing the validity of focusing in on the wider picture – which has included a more serious look at the historical or colonial linkages to health and ill health, as related to this country's Aboriginal population. In fact, more and more interested parties are beginning to utilize a population health perspective in this country. Recently, the population health model was promoted in a report on Aboriginal health status by the Assembly of First Nations (AFN), where it was noted that:

Many interrelated factors come into play, and population-health researchers are beginning to think of health more broadly, as a relationship between the person and his/her physical and social environment. In this respect, the population-health approach is becoming more congruent with traditional First Nation and Inuit views of health as a state of balance within the individual, and with the family, the community, the environment and the spiritual world (AFN 1999: 12).

As the most advanced thinkers in health policy circles today have begun to reach some major conclusions about what makes people well – why some people are healthy while others are not (Evans et al. 1994; Wilkinson 1996), we can see that these 'determinants of health' converge with some Aboriginal perspectives on health and healing through several key ideas: health comes from the interconnectedness of human systems - body, mind, emotions, spirit – not their

separate dynamics; economic inequality (personal and community poverty) plays a central role in determining health; the health of the environment affects the health of the people; and that health and well-being in childhood affect lifelong health status.

Nevertheless, population health is really a set of interrelated ideas rather than an actual model and as such, the population health approach often shifts depending upon the researcher utilizing its framework. However, the same can be said for each and every theoretical framework and paradigm and after having looked closely at the population health approach, I find it both applicable and useful towards extending our dominant paradigms of health to include areas previously not considered in how we view health, illness and healing.

Considering how slippery the population health approach is, I think it is helpful to keep in mind the fundamental question the analysis is concerned with, which asks why some people are healthy and others are not? With the recognition that social, political and economic structures and processes have a powerful influence on health, Wilkinson (1996) points out that:

The development of effective forms of prevention means understanding how social and economic structures impinge on people and what kinds of policies might be beneficial. It means understanding the implications of different institutional structures at work; of different forms of insecurity in relation to housing, income, and jobs; of social and community development; it means understanding the determinants of the subjective quality of life; finding ways of strengthening the social fabric of society; above all, it means understanding the psychosocial effects of hierarchy and social position (14).

Adding to this, researchers who follow a population health perspective must also put race and gender at the core of all analysis if inequalities and their relationship to health are to be worked out, both theoretically and practically.

Women involved in health-related research have expanded upon the population health framework to ask why poor women of color experience less quality of life and health and what we might do as a society to promote meaningful change. In this way, advocates for research in women's health are focusing more consistently on the interaction of gender, race and many other factors on the creation of health and well-being for all women.

HIV/AIDS, women and health research

Over the past ten years, the literature relating to women living with HIV/AIDS has grown rapidly in response to the neglect and lack of awareness that existed throughout the first decade of this disease. In fact, during the early 1980s, HIV/AIDS was erroneously labeled a 'gay men's disease,' that could be virtually ignored by the 'general population'. In fact, the homophobia, racism, sexism, and classism that directed the early response to this virus ensured that the topic and subsequent research of women living with HIV/AIDS would receive scant attention for some time to come. In reality however, women have lived with and died from HIV/AIDS since the early 1980s when the virus was first recognized. Yet many of the women who died of HIV-related infections never did receive an AIDS diagnosis, proper treatment, care or support. This is because HIV (which causes a syndrome of illnesses known as AIDS) affects women differently than men³⁷ and the hegemonic medical definitions of the disease had been based on illnesses more common to men. Subsequently,

women were rarely enrolled in research cohorts, especially those from poor communities. Furthermore, the lack of women in experimental drug studies meant that the effects on women, positive and negative, of these drugs had often remained unknown until women were prescribed these treatments after licensing. When women are permitted to take part in experimental drug trials, the study sites do not generally consider women's unique needs for childcare, appropriate transportation, and appointments that match their need for caring for children and other well and ill family/community members. Apart from the lack of enrollment of women in research trials, the "research agenda itself for HIV/AIDS has some glaring omissions that have a direct impact on the health care of HIV-infected women" (Rodriguez-Trias & Marte 1994: 309). In fact, Rodriguez-Trias and Marte (1994) go on to suggest that because of a lack of funding and commitment to women's health research, we still do not know how to evaluate or effectively treat a large number of health-related problems experienced by women with HIV/AIDS:

Menstrual irregularities are experienced by many HIV-infected women, but we still know nothing about the hormonal consequences of HIV or how (and whether) to treat them. Conversely, virtually nothing is known about the effects of hormonal interventions, for instance, oral contraceptives, on the course of HIV infection despite the widespread use and the importance of HIV-infected women of being able to choose safe and effective contraception. Research on abnormal Pap smears in HIV-infected women is the first and still the only gender-related issue to be investigated in any depth (310).

Six years later, very little has been done to balance the research agenda.

However, advocates for research in women's health are taking into account the diverse variables that interact to create health conditions (including many of the

³⁷ There are many AIDS-related opportunistic infections that affect only women including increased vaginal infections (especially vaginal candidiasis, also known as yeast infections), higher incidences of cervical dysplasia, cervical cancer, pelvic inflammatory disease (PID), as well as menstrual changes.

variables found within a population health approach), but women's health research focuses much more *consistently* on race, ethnicity, sexual orientation, and disability.

In a recent publication advocating the establishment of a **Women's Health Research Institute** within the already existing Canadian Institutes of Health Research (CIHR), members of the 'Working Group on the CIHR: Gender and Women's Health Research' called for the inclusion of sex and gender as critical variables in *all* health research in Canada. Moreover, this working group suggests that a women's health research agenda would work to address the glaring absence of data on, for example, Aboriginal women, women with disabilities, lesbians, and immigrant women, providing for a more comprehensive approach to women's health research. In this report, the working group states that in order to guarantee a climate of comprehensive health research, "two key variables: *sex* (the biological differences between men and women) and *gender* (the different social and cultural experiences of women and men)" must be integrated into all health research (Grant & Ballem, Jan. 2000: 4). The report goes on to highlight some of the specific areas that might be better addressed by a women's health research agenda which are summarized as follows:

- (1) identifying gaps in existing research through consultation with a range of stakeholders to form the basis of the research agenda;
- (2) recognizes that one cannot generalize to women what has been learned from researching men. Doing so may lead to improper diagnoses and damaging treatment. The quality of science suffers from this omission as well;
- (3) uses multiple methodologies, including qualitative, quantitative, interdisciplinary and cross-cultural approaches and;

- (4) involves paying attention to the interactions between gender and other determinants of health including income, race, education, sexual orientation, and environment (Ibid: 4).

Recognizing the importance of the above strategies, we can no longer delay health research and innovative strategies related to improving street-involved women's overall health, especially Aboriginal women, who are over-represented in Vancouver's DTES. However, we need to do more than simply 'pay attention' to those 'other' determinants of health. This is particularly crucial with regards to stigmatized and stereotyped women who, because they use drugs or sell sex are often judged as 'immoral' or 'unworthy' of our attention, research, or funds.

Stigmas & Stereotypes

According to Sontag (1989), societies need to have an illness identified with evil, where society can lay blame on its "victims" through stigmatization and the creation of a 'spoiled identity' or shameful existence. Sontag goes on to explain how societies have created myths, often through metaphors (Sontag calls them metaphoric trappings), and that these sorts of metaphoric descriptions can be found in an analysis surrounding myths about tuberculosis, cancer and more recently, HIV/AIDS. In fact, Sontag goes on to explain that the advent of HIV/AIDS "has provided a large-scale occasion for the metaphoring of illness" (1989: 104). As such, HIV/AIDS has been conceptualized and perceived as a viral 'assault,' 'attack,' or 'plague' that often guarantees one's membership in a particular "risk group" worthy of societies condemnation, criticism and judgement.

Sontag suggests that:

The illness flushes out an identity that might have remained hidden from neighbors, job-mates, family, friends. It also confirms an identity and, among the risk group in the

United States most severely affected in the beginning, homosexual men, has been a creator of community as well as an experience that isolates the ill and exposes them to harassment and persecution... The unsafe behavior that produces AIDS is judged to be more than just weakness. It is indulgence, delinquency – addictions to chemicals that are illegal and to sex regarded as deviant (1989: 113).

Certainly, one need not look far to see how invasive and insidious our descriptions surrounding women, HIV/AIDS, Aboriginal peoples, and women involved in the sex trade can be. Moreover, how we've conceptualized the health and justice issues in the DTES and what we as a society are prepared to do about the pressing health concerns says a lot about how the public feels about who is worthy and/or not-worthy of assistance and improved quality of life. The time to start a dialogue about street-involved women and HIV/AIDS is long overdue. For example, in the literature that I was able to cover there were no studies that have looked at how cocaine/crack and heroin interact with prescription medications taken by some women living with HIV/AIDS. In fact, we know very little about the affects of street drugs on the human body (especially the immune system) and this is a research area that may be side-stepped because governments are afraid that research in this area might be viewed as approving of IV drug use. As a society, we should seriously think through our attitudes toward addiction, HIV/AIDS, Aboriginal women residing in the DTES - and toward all people who occupy the bottom of the social ladder – for we need to look at inequality but more importantly, we need to address inequality with research and preventative strategies that are based in reality. Thus far, the overwhelming efforts by governmental policies to date have been ones of containment and separation - between one group of people from another – the sick from the well, the brown from the white, or the undeserving from the

deserving. By containing and segregating 'dirty Indian' women in the DTES, we have created a system that turns a blind eye to some women's suffering in the name of moralism, racism, and classism and in so doing the powerful, multi-layered discourses that have created and sustained such injustices remain, for the most part, obscure.

Many writers have expanded upon Foucault's recognition of the production and reproduction of certain *kinds of sexuality, of certain kinds of bodies, and of certain kinds of power*. Thus, although Foucault (1977; 1984) treated the body as if it were not differentiated by gender, feminist research on HIV/AIDS has highlighted the themes of bodily self-control and self-discipline that run through much of the AIDS discourse, and they have directed attention to the mainstream interpretation that those women living with HIV/AIDS are not only responsible but somehow deserving of their illness. More specifically, women depicted in HIV/AIDS discourses are almost always mothers, pregnant women, women of color or women involved in the sex trade, thus depicting a particular 'kind' of woman that is polluting to men and children and categorically different from 'normal' women.

HIV/AIDS discourses, which are about disease but which are equally about sexuality, power, and race, "reflect this diffusion of power relations in their reproduction of already existing mechanisms and patterns of social control" (Sacks 1996: 61). With their preoccupation with 'perversions' and irregularities in sexual behavior, HIV/AIDS discourses often place 'deviant' bodies in sharp contrast with the 'general population' or 'normal' bodies, which allows for the

stigmatization, policing and control of these 'deviant' bodies. In "Women & AIDS" (1996), Sacks explains that:

Discourses help these behavioral norms to become internalized, and in so doing to reinforce existing social, political, and economic hierarchies. They are patterned in systematic ways, ways which perpetuate perceptions of certain 'kinds' of behavior, and – because, according to Foucault, sexual behavior is perceived as isomorphous with identity – certain *kinds* of people as deviant, less valuable, more prone to and deserving of disease, and inexplicably intriguing in their apparent perversity (60).

For Aboriginal women in the DTES, this means that too often they are perceived as agents of transmission who infect men. Regarding research on HIV/AIDS among women in the sex trade this means that in almost every instance the emphasis is on the potential for sex workers to spread the disease to male customers who might then spread the disease to less-deserving (or less 'dirty') women, like their wives, who live in communities around the Lower Mainland. Moreover, substance-using women, like those 're-presented' here, have been viewed as self-destructive, insecure and immoral. They have been stigmatized in countless ways because women who use drugs are viewed as having deviated from a woman's expected gender role³⁸. According to some researchers, even a limited number of drug-use episodes severely affects "a woman's entire social identity, stigmatizing her as wild, promiscuous, unstable" (Inciardi et al. 1993: 23).

Subsequently, the pervasive and biased discourses of women and HIV/AIDS perpetuate assumptions of women as 'vectors' of HIV and produce and reproduce already existing notions of the female body as dangerous and

³⁸ Researchers have also shown that drug-using women are often more socially isolated and more disconnected from immediate family members and children than drug-using men. For a more detailed look at how drug-using women are stigmatized, see Gomberg 1982; Taylor 1993; Maher 1997; and Sterk 1999.

polluting. In fact, the narratives revealed that women discriminate, based on HIV-status, against each other as well. Lisa explained this in a story she told about a recent experience she had at the Burnaby Correctional Centre for

Women:

I see the attitude, especially with being HIV you know. There's people sitting there whispering, 'you know so and so has HIV,' or 'I heard so and so has AIDS.' I just tell these people, 'Well, I think that's their business and you're gonna have to work with people that you might not want to work with, regardless of their illness. I mean think about it! You're more of a risk to them than they are to you! Then they almost always say, 'Oh, I never knew that.' I don't think that half of the people in BCCW knew that I was positive... three or four ya, but I didn't care I just figured okay, you want to be friends – sure, or no you don't want to hang out, well that's okay too. Why hide who you are. I think it's really on a need-to-know basis. In some circumstances, well ya, people need to know but sometimes I just don't know, you get too stigmatized sometimes when people know. Not only in jail but everywhere. I don't know, but people tend to treat you differently.

(Interview with Lisa, December 1998).

However, it is important to keep in mind here that individuals are often stigmatized not so much for specific acts as they are for being certain 'kinds' of persons, for membership in a devalued category (women, women who sell sex, poor women, Aboriginal women, women who are IV drug users, women with HIV/AIDS...). However, when sex trade workers fail to fulfill their role as 'contaminators' or 'infectors,' this does nothing to alter the ways they are perceived. Thus, in HIV/AIDS discourses, women become their 'deviant' identity, and their stereotyped and monotypical role overshadows the diversity of their individual experiences. Schur (1984) suggests that "when individuals are 'seen' in terms of a deviant status and identity... the tendency is for that to be all the other persons 'see'. Such imputed deviant identity becomes... the individual's essential character" (24). In the interviews that I conducted, Shauna said:

Well, I was in touch with my father, we would talk every month or so but when I told him I was positive, it was such a big fucking deal so I don't even bother phoning him much

anymore. I told him and you know, my Dad is from the fuckin' boonies and he's still got all these misconceptions and myths about HIV and now, all of the sudden, he doesn't want me to come home for Christmas and stuff. But you know it's just all the big myths and that, like I might sneeze on him or something... same with my little brother and when he came to live with me, I looked after him like he was my own - not like a brother but like a son. And then it was just like a total fucking turn-about. I told him I was positive and I really did expect some support from that end, but now he won't even speak to me... They believe in what they want to believe in and I don't know, it's like they think, "God forbid! How could you let this happen to yourself?" But we're still working on it and I know it will take a while for them to get out of their little shells.

(Interview with Shauna, May 1999).

Shauna's story above is also illustrative of the intense stigma associated with HIV/AIDS. As well, her comment highlights the fact that living with HIV-infection can be painful on an emotional level as well because, as Shauna pointed out, "the big myths" but also because of the 'deviant' role HIV-positive women often get cast in. Finally, Shauna's comment points to the importance of the relational aspects of health as relations with others – individuals, family and/or community – can be difficult for street-involved Aboriginal women living with HIV/AIDS.

Before concluding the interview with Lisa, I asked her if there were any other issues or concerns that she would like to talk about during the taped interview.

Lisa replied:

One of my main concerns is that people don't cut each other off when they are positive. There's still a lot of that going on and that really bugs me. When they feel like they get rejected from society, a lot of people just prefer to give up and I hate seeing that.

(Interview with Lisa, December 1998).

That said, it is all the more imperative that researchers resist the tendency to associate HIV's modes of transmission with "risk groups" rather than "risk behaviors." In the media and in political debate, the epidemiological category of "risk group" has been used to further stereotype and stigmatize people already seen as outside the moral and economic standards of the "general population."

Instead, ethnographers are better off focusing on the concept of risk practice/behavior which moves the emphasis away from characterizing and stigmatizing people as members of groups, focusing on risky "behaviors" and not risky "people."

Critically, the symbols and logics of science anchor this educational environment, making it virtually impossible to escape certain ideas, like the notion that some people are intrinsically at risk because of who they are... People have the right to understand the ideologies of science and of education: HIV/AIDS education must always be political. HIV/AIDS education either reinscribes the sexual, class, and racial ideologies that are propped up by moralism and science, or disrupts the hierarchical formations of knowledge and opens up space for groups and communities to work out their interrelationships with information they have decided is relevant (Patton 1990: 104-105).

Patton goes on to point out that HIV/AIDS strategies frequently require interdisciplinary approaches and involvement of peoples whose vast stores of knowledge are not designated as "expert" by traditional standards. This expertise is found within the stories that I collected for this particular study but many other stories need to be heard. Moreover, relevant information, knowledge, and direction must come from the women who have 'something at stake' and this sort of information is readily available to health researchers willing to listen.

The myth of shared understandings

Although many feminists argue that feminist research is an "intellectual system that knows its politics" (Whittaker 1994: 357), it has yet to resolve some fairly significant contradictions with regards to the theoretical and political complexities of women studying other women. In "Feminism and Anthropology: The Story of a Relationship," Moore points out that:

The end result is that feminism as a cultural critique, as a political critique and as a basis for political action is identified with women – not with women in their socially and historically distinct context, but with women as a sociological category. The problem for

feminism is that the concept of difference threatens to deconstruct this isomorphism, this 'sameness,' and with it the whole edifice on which feminist politics is based (1988: 10-11).

Thus, feminist anthropologists are struggling to establish the theoretical and empirical grounds for a feminist anthropology based on difference. However, this notion of 'difference' applies not only to 'other' women but to every woman and to every way of 'knowing' about women's experiences. The notion itself raises the question of the basis of comparison and the grounds for affiliation.

For example, while conducting research for this project, I found that being a mother provided *some* 'shared understandings' in our conversations and interactions, but our individual experiences of mothering were also dependent on social, cultural and economic positioning and this became very apparent to me while I was conducting this research. Thus, it would be naïve and erroneous for me to claim a complete connection, a shared understanding, and a common experience with the four women I interviewed – on the basis of mothering. As well, it would be inaccurate for me to claim a common experience and a shared understanding with these four women on the basis of my Metis heritage for again, understanding is in no way guaranteed by race alone. Narayan (1993) refers to the "multiplex nature of identity" which includes ones race, gender, education, class, sexual orientation, etc., and she suggests that people can highlight and downplay identity accordingly. As a researcher with a mixed background, I find Narayan's discussion interesting, perhaps because I recognize and acknowledge that I too pull on the strands of identification and this has undoubtedly affected my interactions with the participants of this project. Further, my position as a researcher, able to walk away from but not forget, the complex

issues facing the women I interviewed highlights the very real bridge that separates our worlds.

As Devault (1990) points out, women do not always (or even usually) understand each other easily. She goes on to suggest that while understanding and familiar comfort are benefits of some of the ways that women have come together, they are not guaranteed by gender alone. "Women who are positioned differently learn to speak and hear quite different versions of "woman talk," adapting to distinctive blends of power and oppression. Failures of understanding abound" (Devault 1990: 98).

For myself, this project has clearly demonstrated how powerfully positionality and theoretical frames affected the ways I viewed this research topic, my research intentions, my decisions in the field, my interactions with participants and the eventual 'writing up' of this thesis. Extending this line of thought to each participant also means that we cannot possibly expect the data to fit into neat and tidy titles and sub-titles, as each of the women looked through their own lens of experience, with their own important agendas, and this makes the writing process challenging as well. That said, I recognize that I have made many generalizations here.

Ultimately, this thesis was directed and controlled by myself. It was informed, for the most part, by my decisions as a researcher and writer of significant privilege. While I no longer feel the need to make apologies for these facts, I do recognize the contradictions and incongruencies in how the project actually played out compared to how I had hoped it would turn out. However,

Judith Stacey highlights the contradiction between the desire for collaboration on the final research project and the reality that “the research product is ultimately that of the researcher, however modified or influenced by informants” (Stacey 1988, cited in Mascia-Lees et al. 1989: 21). In the final chapter, I offer a brief overview of this research project before taking a retrospective look at the limitations of the study, noting some areas that might have been approached differently. Also, I explore some of the theoretical questions and directions that stem from the results (especially the women’s voices) of this research project.

CHAPTER SIX: READING WOMEN'S LIVES – A DISCUSSION

**"Never doubt that a small group of thoughtful,
committed people can make a difference;
indeed it's the only thing that ever has."
- Margaret Mead**

This project was about listening, observing, better understanding, analyzing and documenting 'things as they are' for the four street-involved, HIV-positive Aboriginal women who participated in this research project. Kelly, Lisa, Shauna and Nadine shared their personal stories with me and echoed in their four stories is the fact that the advantages associated with good health are not shared equally in this province. Taking a more comprehensive view of health that encompasses the historical, social, cultural, economic and physical factors as they interact with race and gender, this study has shown that narrative method can contribute to our understanding of the wider picture of health, in particular spaces, as told by particular story-tellers. The narratives I've presented reflect the particular situations and circumstances in which four Aboriginal women live that contribute to their vulnerability, not just to HIV/AIDS but to a number of constraining factors that affect their overall health status, factors that I take into further consideration below.

These four women's lives, and therefore their health, are affected first and foremost by crushing poverty and policies, programs and research must take into account the everyday realities of poor women's lives, as played out in particular spaces – such as the DTES. The four Aboriginal women that participated in this study spoke about the various strategies they employ to survive their particular

circumstances in the inner-city and beyond, as was currently the situation for Nadine who was residing in South Burnaby at the time of the interview.

Nevertheless, the necessary strategies that secure their survival 'today' are often at odds with their long-term wellbeing and health and these realities must inform and direct policy development.

Through their stories, we heard that their lives and their health are affected by inadequate, unstable and unsafe housing; relentless violence and abuse; deep-seated addictions that continue to go untreated; as well as the gender-inscribed role of 'caring for others' despite their compromised immune-systems and day-to-day survival strategies. Also, we heard that their lives, and therefore their health, are affected by low self-esteem and low self-worth which often plays out in active suicide attempts but also by their participation in high-risk activities. Further, their lives, and therefore their health, are affected by the fact that they live in poverty, and as poor women with few options, they must struggle to find ways to support their addictions, to find shelter, to eat, or to take care of children and family – which again often involves high-risk activities. However, Aboriginal women's 'health' is not just about the absence of illness – for health is also about feelings, emotions and social relationships. Just as important, health is about having options. It is about quality of life, and the women's stories highlight the desperate need for an increased societal commitment to decrease inequities, injustices and poverty for women most at risk.

In review...

In Chapter One, I outlined the purpose of this study and the various paths that brought me to and through this particular research project. In Chapter Two, I briefly outlined an historical context in which to view the current state of Aboriginal health in this country. Clearly, the substandard health experienced by many Aboriginal peoples around BC now is historically linked to the poor policies and practices put in motion by the federal and provincial governments in the early development of this province. Chapter Three went on to describe the current situation in Vancouver's Downtown Eastside, but it also looked at some current research in the DTES, before outlining the methods utilized in this particular study. In Chapter Four, we heard from the women who agreed to participate in this project. Through the women's narratives, I've shown how 'substandard' health actually plays out in four Aboriginal women's lives. I've also shown the importance of regarding the subjective experience of illness (in this case HIV/AIDS and addictions) as a valuable source of knowledge in attempts to address the diverse health needs of *all* women. Knowing and accepting women's varied, everyday realities and experiences living with HIV/AIDS is an important step in this process. We heard 'what was at stake' for each of the women and in this way, we can better understand the multiple and complex constraints to attaining safety and health that some women face daily as well as the barriers to exiting their current circumstances. Moreover, their stories pointed to the importance of including those who have something at stake, for they are the real experts and this was especially pronounced in their critique of and

discussions around current treatment options, facilities and directions – including harm reduction. In Chapter Five, I revisited social theory in an effort to describe the theoretical frames that guided the planning, process, analysis and 'writing up' of this particular project. I looked specifically at aspects of feminist ethnography and population health, pointing out contributions and contradictions, as related to this particular study. In the remainder of this chapter, I describe some of the limitations of this project before I explore some theoretical directions and questions that flow from the data (voices) and findings.

In retrospect...

I mentioned previously that *my* research intentions did not converge with the participant's intentions in that I had hoped that the women would be interested and willing to offer more feedback and possible directions, *after* the interview process. However, there are some other areas that I want to consider, with regard to what I might have done differently in this study. For example, I think it would have been preferable to have had the transcripts reviewed by more than a single researcher, perhaps by having each of the participants review the data (like a peer review process) and I could have offered payment to each of the women that expressed an interest in doing so. In retrospect, I realize now that I should have built (budgeted) this into the research design, and in this way some of the women might have chosen to stay involved with the project beyond the collection of data. I believe that this would have added more depth to the analysis and the construction of the final report. I realize as well that this direction would have had to have been worked out beforehand, with consent

being given by all involved parties. This might have taken the form of a focus group, where participants joined the researcher to discuss what was said, what was contested, what was possibly left out, or it might have involved working closely with one or two interested participants, who could have directed their own involvement in light of this being a paid work opportunity.

As well, I believe that an additional, more experienced researcher or community member would have proved invaluable in reviewing and coding the transcripts but again, this sort of strategy would need to be worked out early on in the design of the project. Recognizing that participants would have to be fully informed that another researcher would be reviewing their recorded interviews, I mention these strategies as possibilities for future research in light of the fact that I thought often about how others might organize, classify and piece together the data, *especially* the women themselves. I cannot speak for other graduate students, but in my experience I found it difficult to piece the project together in large part because of the fact that the women who participated in an interview were not able to invest more un-paid time into the project. That said, working along-side a more experienced researcher (one who has been in this predicament) might have helped in getting me through the 'frozen,' inexperienced and ill-prepared state that I found myself in after the data had been collected. However, I also realize that getting out in 'the field' and 'doing it' is a necessary step in gaining experience in ethnographic research and that the 'writing up' of women's voices presents its own challenges, that must be respectfully worked through. I recognize as well that these research strategies involve much more

time and energy from all involved parties and without sufficient funds, researchers, and commitment, these sorts of research strategies could prove problematic to individual graduate students. I suspect as well that collaborative research strategies are, in many ways, a privilege of academics and agencies who have secured the funds and frameworks necessary to 'assist' participation amongst women whose day-to-day survival takes obvious precedence. I want to point out that collaborative, participatory research involves more funds, more energy, more commitment and more bodies than traditional researcher-dominated methodologies. Increased funds and multiple researchers/parties makes this important process more 'doable'. Without providing an answer, I've been reflecting on how this plays out with poor women/participants. If a project can "afford" to keep people "involved" that is worthwhile, for there is definitely the potential for certain benefits for certain participants, but what kind of pressure does this place on participants to get involved because they are poor, because essentially, they need more money? The same sort of (unresolved) issue arises from my decision to compensate participants with \$20. I might have saved and budgeted to offer paid research opportunities to these four women – *beyond* the interview process – but this didn't occur to me in the initial design and planning of the project. Again, I mention these strategies, in retrospect, for possible future research strategies, recognizing that although this project has been an intense learning experience for myself, many issues go unanswered.

The last word

Conducting this research and getting to know women in the DTES, I do not mislead myself into believing that relief will come soon for these four Aboriginal women, that opportunity will come knocking once they've 'kicked' their habits, or that this research project will, as one participant stated, "do a whole hell-of-a-lot". Moreover, I don't pretend to know the answers, but one thing I can say with certainty is that it is much more difficult for *some* Aboriginal women to avoid HIV-infection and it is more difficult for *some* Aboriginal women to experience health and well-being. As these four women's stories have shown, illness and disempowerment are heavily connected to poverty, race, and gender as well as the particular spaces occupied by street-involved, drug-using Aboriginal women and the difficult and complex circumstances that moved them towards their current predicaments.

However, I believe that current policy and practice can be re-worked and re-directed by the women themselves – for they hold many important answers, if we are willing to hear their stories about the multiple and complex factors (past and present) that constrain their attainment of health, safety and increased quality of life. Just as important, however, we must value the lives of *all* women, especially those most marginalized and stigmatized by society, so that relevant research, policy and practice can begin to address and perhaps relieve some of the constant constraints and barriers to health that some women must face and contend with daily. With regard to Aboriginal women specifically, there are also the negative and narrow images perpetuated in certain contexts that depict

Aboriginal women in the DTES as easy, immoral and disposable. These images directly and indirectly affect their health. Discussing destructive attitudes and racist stereotypes, Emma LaRocque states:

They do affect Native peoples, real human lives. I believe there is a direct relationship between racist/sexist stereotypes and violence against Native women and girls. The dehumanizing portrayal of the "squaw" and the over-sexualization of Native females such as in Walt Disney's *Pocahontas* surely render all Native female persons vulnerable (1996: 12).

Moreover, through my research, work and observations in the DTES I've come to better understand that fundamental question asked by researchers working within a population health framework, which asks why are some people healthy, while others are not? Highlighting some of the gendered and racialized inequalities that shape the health and well-being of four Aboriginal women, I have shown that health is powerfully affected by social position, and I have drawn out some of the social links between health and inequality. In fact, throughout this thesis I have stressed that health must be viewed in its larger contexts and in researching and writing about Aboriginal health, an historical approach is fundamental to better understanding the injustices and substandard health experienced by many Aboriginal people, families and communities. Rather than viewing health in terms of disease alone, this study has taken a more 'holistic' or comprehensive perspective to emphasize and illustrate that 'health' is affected by every aspect of life: health goes beyond the body to encompass emotions, thoughts, attitudes, and feelings. In listening to these four women's stories, it is vividly apparent that we must better address the deep-seated emotional pain that many drug-using Aboriginal women contend with, which is further compounded by the stigma and rejection that the women spoke about in relation to being HIV-

positive. As their stories revealed, emotional pain was discussed as both a reason for entry into, and the maintenance of, their drug addictions - but the fact remains that their emotional needs continue to go unaddressed and unresolved and this is an area that needs further attention.

The quality of their physical surroundings must be seriously taken into account as well for health also depends on the state of the environments that they exist within. Following from the women's stories and my own observations in the DTES, the issue of safe, secure and affordable housing for women in this neighborhood desperately needs further attention and action. As it stands, poor women living with HIV/AIDS and addictions have very few affordable housing options. This means that women often live in vulnerable situations, where they are at risk for further violence and decreased health - where a working stove, fridge and basic heat are a luxury of few, while roach and rat infested, damp and confined spaces are the reality for most women. For poor women with HIV-infection, substandard housing clearly contributes to the early progression to AIDS. Creative and flexible housing strategies for and by drug-addicted women living with HIV/AIDS are desperately needed; but again these initiatives must be based in the everyday realities of the women's lives.

Finally, this study recognizes that not being sick is an important aspect of a healthy existence and through the women's stories, I heard discussions related to HIV/AIDS but more pronounced, I heard them speak openly and honestly about their addictions and how those addictions have been a significant factor in their decisions to engage in high-risk activities, as they do what they can to

survive. The women spoke about current treatment options and facilities and their various critiques highlighted some of the limitations of detoxification services as well as the fact that their health needs are diverse. Lisa pointed out that as an urban crack user, her needs do not converge with the current trend of promoting safe injection sites for intravenous drug-users and this highlights the fact that treatment options, facilities and harm reducing strategies are best conceptualized by this diverse population of drug-using women. It is their voices that can best express their specific needs. *Many* voices need to be heard for only then will prevention efforts truly be by and for *all* women.

Spending time observing and listening to Aboriginal women in the DTES and through the telling of these four women's stories, I better understand why so many Aboriginal women find themselves in Vancouver's DTES, what sorts of constraints women face once there, and why their health status continues to decline. However, as I have suggested in this study, the solutions to the complex and wide range of constraints and problems faced by Aboriginal women must not only be grounded in their voices, which too often go unheard, they must address the larger issues of decreasing Aboriginal women's poverty, uprooting sexism, and eliminating racism. Collectively, we must also not forget the deep and complex factors impinging on Aboriginal women's health, stemming from historical policies and practices that continue to negatively affect overall Aboriginal health and well-being in this country today. Through the colonization process, there has been a breakdown in Aboriginal structures – stemming from the clear-cut exploitation of Aboriginal lands, resources, peoples and traditions.

However, as shown in Chapter Two of this discussion, the breakdown in Aboriginal individual, family and community health is also directly related to the poor policies and practices put in place by the federal and provincial governments in their misdirected efforts to protect, civilize and assimilate this country's Aboriginal population. As I illustrated in Chapter Two, the residential school system is a prime example of the undeniable relationship between poor government policy and practice and poor Aboriginal health.

These four women's lives, and therefore their health, have clearly been affected by the colonizing process and the dysfunctional and depressed state of their larger networks of family and their community. I struggle here, for I do not wish to further 'pathologize' Aboriginal peoples, families and communities but at the same time, I cannot avoid discussing the social and political factors that have contributed to these women's particular circumstances (past and present) and the constraints they face as Aboriginal women. As I have stated, an important aim of this particular project was to ground the research in the voices and experiences of the participants and their four stories call attention to the serious problems that continue to exist in many Aboriginal communities today. However, their stories also call attention to the cultural legacy of abuse and mistreatment, especially in relation to educational discourses and practices, and the strength and determination of Aboriginal peoples to adapt, resist and survive an evolving political process that undoubtedly impinges on individual, family and community health today.

Finally, I want to point out that Aboriginal women have in the past, and continue today, to actively participate in improving the health and quality of life of their communities and Lisa's story was especially telling in this regard. Her work and active involvement in the DTES portrays the strength and determination she brings to nurture and care for others in her current community, despite her own illnesses. However, this often results in an added health burden for her and other Aboriginal women with compromised immune systems because of HIV-infection and addictions, who continue to take care of blood and non-blood family relations. In fact, many of the women that I came to know have/had family networks within the DTES – some living, some not. On the basis of this study, two of the participants spoke about their mothers and aunts living in the DTES. One participant spoke about a brother living in the DTES, while another mentioned living, temporarily, with her grown daughter in the DTES. Finally, two of the women made reference to cousins who also live in the DTES. Caregiving is an important and crucial aspect to some Aboriginal women's identity in the DTES and this is an area worthy of further attention. Speaking about herself and other Aboriginal women, Paula Gunn Allen has stated that, "We survive, and we do more than just survive. We bond, we care, we fight, we teach, we nurse, we bear, we feed, we earn, we laugh, we love, we hang in there, no matter what" (1986: 190). These four women do "more than just survive" and I hope this narrative has portrayed, not just the oppression and constraints these women face daily, but also some of the active strategies being evoked by street-involved, Aboriginal women living with addictions and HIV/AIDS.

Nadine, Kelly, Lisa and Shauna are fellow human beings living with a deadly illness and addictions, in dilapidated housing (if they have housing at all), where violence is central, where women's bodies go missing, and they deserve our time, energy, resources and commitment to improving their quality of life, safety and health. If, as a society, we can better assist them in concrete ways, directed by the women themselves, then we should take the time to listen, we should take the time to hear what they have to say about their experiences, their lives, their health. In getting to know the women and actively listening to their stories, I've created a space where their voices could move beyond their own circle. Having entered into their circle, I have tried my best to work and write from a place of respect but I realize that I made some poor decisions, that I might have done some things differently, and I've tried to write openly and honestly about this as well. It can be intensely difficult to discuss peoples' lives, hard lives, that are often looked down upon by the 'general public' or the 'middle-class'. My anxiety about representing HIV-positive, substance-using, Aboriginal women was only compounded when I got to actually know the women - enjoying their company, looking forward to seeing them and wondering how they're doing. I've struggled from beginning to end with how to research and write respectfully and honestly about HIV/AIDS and street-involved Aboriginal women tied to the DTES but I realize that I too have made generalizations here. However, I will not stop researching and writing on topics that need and deserve to be heard. That said, I make no effort to mislead the reader into thinking that these women's experiences, living with HIV/AIDS in a community where basic survival is a

moment-by-moment preoccupation, are simple or predictable. Rather, what I have tried to do here is let the women speak for themselves about the sorts of issues that they felt were worthy of further attention. However, I have also attempted to highlight and discuss certain areas that impinged on their overall health - as 'heard' through their stories.

Significantly, ethnographic health-related research can work to challenge the ways in which both health planners and practitioners define the Indian health 'problem' in Canada, in British Columbia and in more specific locations (such as the DTES). Furthermore, ethnographic research is playing an important part in moving us beyond the 'standard' solutions and approaches by redefining the ways we think about and act on issues affecting health. Local contexts, knowledge and voices can inform, direct or re-direct health-related policy and practice by considering the larger context and complex determinants of substandard Aboriginal health in this country, in relation to the everyday experiences and realities of some Aboriginal women's lives. The stories reveal the connection between inequality, poverty and health and they illustrate the specific constraints that some Aboriginal women face in their daily situations – and that there is little space left to heal wounds of the past. Importantly, the stories are illustrative of the importance of developing more socially responsible policies and programs that look seriously at the whole individual, within her historical, social, political, cultural and economic contexts. Coming full-circle, I will repeat the words of Nadine who started off this story when she explained that:

I think we Aboriginal women somehow need to find a way to develop a tighter circle together because I don't reach out to women that often, but I'd like to have healing circles, or talking circles, or Indian medicines, or Indian ceremonies or just anything that collects us together as a group... we need to be together in a circle because right now, we're all so fragmented. I'd like to be involved in that...

(Interview with Nadine, June 1998).

Appendix One: Interview Schedule

1. Could you tell me about yourself?
 - where did you grow up?
 - when did you come to Vancouver?
 - can you tell me about your neighborhood?
 - do you have any children?
 - what does a 'typical' day hold for you?
2. When did you test positive for HIV?
 - how did you become infected with HIV?
3. What did you do when you first found out?
 - who told you that you were positive?
 - What advice did they offer you at the time?
 - Who did you tell when you first tested positive?
 - What was their response?
 - What do you do when you get sick? Where do you go for help? (family/friends?)
 - Do you receive the help that you need? Why or why not?
4. Why did you decide to participate in this project?
5. Are there any other issues/concerns that *you* think we should cover in this Interview?
6. How did you find this interview?
 - any suggestions that may have made it better for you?

Appendix Two: Informed Consent

SIMON FRASER UNIVERSITY

INFORMED CONSENT BY PARTICIPANTS TO PARTICIPATE IN A RESEARCH PROJECT

The University and those conducting this research project subscribe to the ethical conduct of research and to the protection at all times of the interests, comfort, and safety of subjects. This form and the information it contains are given to you for your own protection and full understanding of the procedures of the research described below. Your signature on this form will signify that you fully understand the procedures of the research, that you will not be at risk by participating in this research, that you understand the benefits of this research, and that you have received an adequate opportunity to consider the information in this document, and that you voluntarily agree to participate in the project.

The purpose of this research is to better understand the lived experiences and actual needs of Aboriginal women with HIV infection; thus, by participating in this study, you will help to document the experiences and needs of Aboriginal women living with HIV/AIDS in the Lower Mainland of Vancouver. Participation in this research consists of an in-person interview with Shannon Ryan that will be tape-recorded and transcribed. Participation in this project is entirely voluntary and you may refuse to participate in the study at any time. If you do decide to take part in the study, the results will be used to identify ways to improve the care, treatment and support needs of women living with HIV/AIDS, which may be of some benefit to you. I will guarantee confidentiality of both identity and information provided by using pseudonyms and omitting all identifying characteristics in the data; furthermore, you will in no way be at risk by participating in this project. Your HIV status will be known only by Shannon Ryan, the principal investigator of this project and will not be released to anyone else. All documents and computer files storing information collected from you will be assigned a pseudonym and will not contain your real name. This pseudonym will also be utilized in the written report (MA Thesis) and again, the written report will not include any other identifying characteristics. You will also be asked to review a transcript of the interview, with a two-week time limit, in order to identify any areas that may not be included in the final thesis. Please take this opportunity to ask any questions you may have regarding your participation in this research project.

Having been asked by Shannon Ryan of the Sociology & Anthropology Department of Simon Fraser University to participate in a research project, I have read the procedures specified in this document.

I understand the procedures to be used in this research project and the possible benefits to me in taking part, as described in this document.

I understand that I may withdraw my participation in this research project at any time.

I also understand that I may register any complaints I might have about the research project with the chief researcher named above or with Dr. Ellen Gee, Chair of the Sociology & Anthropology Department at Simon Fraser University. Dr. Gee can be reached at (604) 291-4297.

I may obtain copies of the results of this study, upon its completion, by contacting: Shannon Ryan at (604) 421-2389.

Appendix Two: Informed Consent (continued)

I have been informed that Shannon Ryan, the principal investigator, will hold the research material confident.

I agree to take part in this research project by participating in an interview with Shannon Ryan for approximately two hours, as described in the document above, during the period: June 12, 1998 to August 30, 1999 at a private place agreed upon by both the participant and the researcher.

NAME (please print): _____

ADDRESS: _____

SIGNATURE: _____ **WITNESS:** _____

DATE: _____

*Once signed, a copy of this consent form and a subject feedback form should be provided to you.

Appendix Three: Resource List

Healing Our Spirit: BC First Nations AIDS Society

Outreach office offering confidential personal services and support to First Nation, Inuit, and Metis people living with HIV/AIDS.

212 – 96 E. Broadway

Vancouver, BC

Tel: (604) 879-8884 (Ask for Ken or Alex)

Oaktree Clinic

Provides care to HIV-infected women, children and youth.

For information call (604) 875-2212

Positive Women's Network

1170 Seymour Street

Vancouver, BC

Phone: (604) 681-2122, ext. 200

Vancouver Native Health Society (Outreach Office)

Food bank every Tuesday from 1 – 3 p.m. (except cheque issue week).

441 East Hastings Street

Vancouver, BC

Phone: (604) 254-9949

AIDS Vancouver

1107 Seymour Street

Vancouver, BC

Phone: (604) 681-2122 or the Help/Crisis Line: (604) 687-2437

Drop-in Lunch for Positive Women: In the Positive Women's Network kitchen. Every Tuesday from 12:00 to 1:30 p.m.. Meet with other positive women. Hot lunch provided. Call Bronwyn for more information or to become a PWN member at (604) 681-2122, ext. 276.

BC Persons with AIDS Society

Peer and Support Counselors available 10 a.m. to 4 p.m. Monday through Friday in the Support Office area (off the Lounge). Counselors see people on a drop-in or appointment basis.

Phone: (604) 681-2122, ext. 326 or go by 1107 Seymour Street (upstairs).

Care Team Program: Small teams of trained volunteers can supplement the services of professional home care of friends & family for people experiencing HIV/AIDS related illnesses. Care teams can provide companionship, in-home cleaning, meal preparation, etc., for people who are in immediate need of support. Call AIDS Vancouver Support Services at (604) 681-2122, ext. 270 for more information.

Appendix Four: Participant Feedback Form

SIMON FRASER UNIVERSITY UNIVERSITY RESEARCH ETHICS REVIEW COMMITTEE

PARTICIPANT FEEDBACK FORM

Completion of this form is **OPTIONAL**, and is not a requirement of participation in the project. However, if you have been a participant in a research project and would care to comment on the procedures involved, you may complete the following form and send it to the Chair, University Research Ethics Review Committee. All information received will be treated in a strictly confidential manner.

Name of Principal Investigator: Shannon Ryan

Title of Project: Aboriginal Women's Experiences Living with HIV/AIDS

Faculty & Department: Faculty of Arts - Sociology & Anthropology

Did you sign an Informed Consent Form before participating in the project? _____

Were there significant deviations/changes from the originally stated procedures? _____

I wish to comment on my involvement in the project above which took place:

(Date) (Place) (Time)

Comments:

Completion of this section is OPTIONAL:

Your name: _____

Address: _____

Telephone: _____

* This form should be sent to the Chair, University Ethics Review Committee, c/o Vice-President, Research, Simon Fraser University, Burnaby, V5A 1S6

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