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SIMON FRASER UNIVERSITY, 2003¹**



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CONVERSATIONS WITH MY SISTER: AN HIV/AIDS COUNTERSTORY

by

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DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

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ABSTRACT

My decision to become actively involved in the AIDS movement and then to go public about my situation had multiple motives. Yes, I wanted to effect change. I wanted to make a difference. But for me it was also about losing my shame, retaining my pride and my ability to hold my head up and say, 'This is me, take it or leave it.'

Alex Keating, 2004

This is a collaborative ethnographic dissertation between Alex Keating, an HIV-infected woman and activist, and Laura Cooper, a doctoral candidate. It explores what it means to live with the stigma of HIV. Applying a critical interpretive medical anthropology framework, we show how HIV is socially and narratively constructed. We do this by examining the HIV stories that are communicated through mainstream institutions in the form of master narratives. The philosophical theory of master narrative - counterstory critically explores the dominant worldview of HIV as both a gendered and a moral construction. As a counterstory, Alex's narrative finds space to challenge the silencing of HIV-infected persons' voices. Her twelve-year narrative of activism and advocacy work exposes inherent weaknesses in master narratives and restores agency, an essential element to repair an identity damaged by marginalization and stigma. Thus, we argue that Alex's narrative is a successful counterstory.

The methods employed include participant observation, a review of twelve years of audio and videotapes of Alex's public lectures and TV interviews, semi-structured interviews, still and digital photography, conversations on MSN Messenger and email. Relevant literature reviews were undertaken. Throughout we reflexively examine methodological and ethical issues that have influenced this collaborative work between two sisters. While some of the issues result from the project, others arise from our close and extended relationship. Critical to this work is the ongoing processes of negotiation of authority, voice, and representation.

DEDICATION



Photograph 1: James Keating and
Margaret Cooper (1930-1996)²

*For James,
I love you for
all that you are.
Thank you
for loving me
the same.
Ally
February 8, 2004*

For Mom.
Guess what?
I'm finally done and
I miss you a lot.
Love
Laura
May 20, 2004

² Photograph by permission of Laura Cooper.

ACKNOWLEDGEMENTS

I would like to thank my family for their willingness to gain an understanding of this illness and lose some of their fear. To James, I want to express my gratitude for your willingness to be part of this. Laura, my sister and friend, I say thank you. I know this has been, at times, a difficult journey. I also know it has been a rewarding journey. I am proud of you.

I would also like to acknowledge Parin Dossa and Marilyn Gates for their belief in this work and their support and encouragement of Laura as she negotiated the hurdles of this process. I also thank you for the kindness and respect with which you have always treated me and your respect of my story.

Alex Keating, May 2004

There are many who have supported this dissertation work over the years. Firstly, I want to acknowledge Alex, my sister, for graciously and trustingly giving up her story. James, your story is also vitally important, as is your love and support of both Ally and me. My family has provided ongoing support over many years; thanks.

With graciousness I acknowledge Parin Dossa and Marilyn Gates, my supervisory committee. They never faltered in their belief that this work had academic merit and was worthy of pursuing. Similarly, Roger Elmes, Dean of Social Sciences and Music at Kwantlen University College, was consistently supportive of my doctoral research and often helped me to creatively manage my teaching load and doctoral commitments.

Wayne Cooper graciously helped with the final draft photo inserts and template insertions while Lynn Cooper completed the final editing. Jesse James, my son, cared for my home so I could take the time necessary to complete this work. The following colleagues, family, and friends provided editorial insights, critical ideas and emotional support: Seema Ahluwalia, John Bogardus, Lonnie Campo, Janie Cawley, Francis Chiang, Steve Dooley, Margaret Dozario-Migliore, Zeb Fastabend, Richard Floyd, Cheryl Gabriel, Tamara Greenstone, Georgina Kay, Lekeyten, Sam Migliore, Russel Ogden, and Lynda Turner. Simon Fraser University Thesis Assistant Penny Simpson also put her touches on this dissertation.

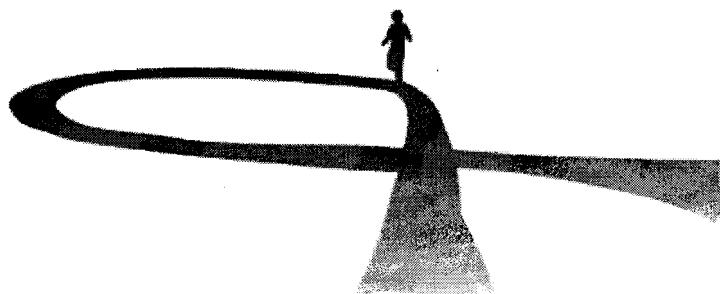
Laura Cooper, May 2004

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³ This vector graphic was created by Holly McFadden from a photograph taken by Laura Cooper.

LIST OF ACRONYMS

ACT UP	AIDS Coalition to Unleash Power
AIDS	Acquired Immune Deficiency Syndrome
AV	AIDS Vancouver
AZT	Azidothymidine
BCID	British Columbia Identification
BCPWA	British Columbia Persons With AIDS Society
CAP	Canada Assistance Plan
CAS	Canadian AIDS Society
CCABC	Cancer Control Agency of British Columbia
CDC	Centre for Disease Control
CHA	Canadian Health Act
CHST	Canadian Health and Social Transfer
CIMA	Critical Interpretive Medical Anthropology
CPP	Canada Pension Plan
EPF	Established Programs Financing
FAW	Financial Aid Worker
GIGI	Gulf Island Guerrilla Immunologists
GP	General Practitioner
HIV	Human Immunodeficiency Virus
IDU	Injection drug users
ITP	Idiopathic thrombocytopenia
KS	Kaposi's Sarcoma
LICO	Low Income Cut Offs
MC	Master of Ceremonies
MHR	Ministry of Human Resources
MSSH	Ministry of Social Services and Housing (British Columbia)
NCI	National Cancer Institute
NGO	Non-Governmental Organization
NIH	National Institute of Health
NIMH	National Institute for Mental Health
PARC	Pacific AIDS Resource Centre
PCP	Pneumocystis carinii pneumonia
PEMA	Political Economy of Medical Anthropology
PWA	Person With AIDS
PWHA	People With HIV/AIDS
SFU	Simon Fraser University
SIN	Social Insurance Number
STD	Sexually-transmitted disease
US FDA	United States Food and Drug Administration

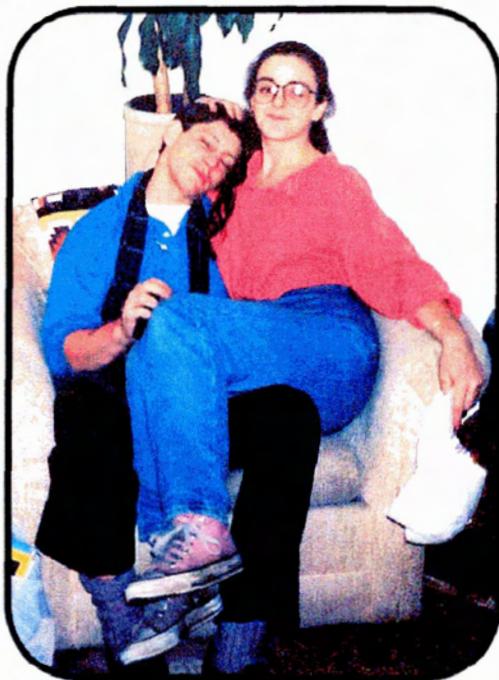
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PREFACE



Photograph 2: James and Alex Keating, 1988⁴

Alex's thoughts

The idea of having my story be the topic of Laura's PhD dissertation was not something that came out of left field. It seemed a logical step in the journey we had engaged in since I was diagnosed. Through my activism, life experience, and limited post-secondary education, I had come to see my situation of living with HIV, and of fighting to be heard, against the backdrop of the social and political reality we lived in. Laura and I had engaged in many conversations and debates regarding HIV. These included the social stigma attached to it, the ludicrous government actions in dealing with it, the struggle for health, the right to die, the struggle with medical and welfare systems, the fear of dying, and many other related topics. We would discuss these things in an academic framework, as struggling activists, and

⁴ Photograph by permission of the estate of Margaret Cooper.

as sisters. We wore many hats while we had these discussions and covered much ground. I believe these conversations allowed us both to process many issues that were personally perplexing. I also think they laid the seeds of an idea that, when the time was right, came to fruition in this dissertation.

Having chosen to not have children for a multitude of reasons, my DNA ends with me. My words and art are some of what I can leave behind. I know I have impacted people's lives doing my public presentations over the past twelve plus years and that is real and will always exist. But this document is something that one can hold and will go on even when all whose lives I have directly impacted are gone. My primary motive for participating in this dissertation was for Laura to get her degree. I think my reasons were hard for her to accept at first. I believe she wanted me to be doing this for myself. What took awhile for her to understand is, that is exactly what I was doing and why. I also got my story on paper for others to read but the main thing I got from participation in this dissertation was the gift of being able to help my sister. Laura has always been willing to be there and help me when I needed her. I was finally able to do the same thing back. We both win with this project, not only because of the degree that will result, but also for our relationship that has grown because of the work we shared. Laura and I have always been close but this project allowed us to go through so much so fast. I think our relationship has gained an intimacy we may never have gotten without this project or would have taken many more years to acquire.

I am grateful for the other benefits that have come from this process. Laura and my husband James have been able to hear each other's stories and gain a deeper love and respect for each other. Their relationship is something I cherish watching grow. It makes them both better for it; it makes all of us better. I am also grateful that this dissertation offered an opportunity for James to tell some of his story. What is in the dissertation is only a small glimpse of who he is and what he has been through but the process of doing this encouraged him to explore many parts of his history that he had not revisited for a long time. For him to do this now, when his perspective on life has changed, allowed him to see things in a less painful light. He also came to understand that his story and experiences have value, that

what he has done in his life does not equal who he is, they are just the steps he took to learn what he needed to learn to get where he is. This is truly a gift.

I also watched my sister Laura process and speak thoughts and feelings she had held inside for a long time. I think she was able to let go of some of the fear and hurt she had carried in her heart for years as she came to realize that she had nothing to fear that couldn't be shared and therefore lessened, and that hurts heal. This project allowed us a reason and forum to speak about things we may never have spoken of otherwise. Much of those discussions cannot be seen in these pages, they exist in our hearts and can be seen in our relationships. The dissertation also offers a chance for the rest of my family to understand my life better. I am a very private person who shuts people out when things are difficult. Most people only see me when life is ok and I'm feeling well. When I'm sick or life is difficult I avoid people, including family. Because of this most people have a very one-sided view of my life. This dissertation will offer those who wish a chance to better understand both James and I. For me these are all rewards from this dissertation.

I hope those of you who read this document would be able to take something away from it for yourself. I ask that you read it with an open mind and look beyond the actions done during a lifetime to the lessons learned that make up a life.

Alex Keating, May 7, 2004

Throughout this dissertation James has been spoken about a great deal. Although he is a big part of this story, Laura's and my words about him portray a very limited view of his life. With this in mind James was asked if he wanted to speak for himself in the dissertation. He agreed and his writing is what follows.

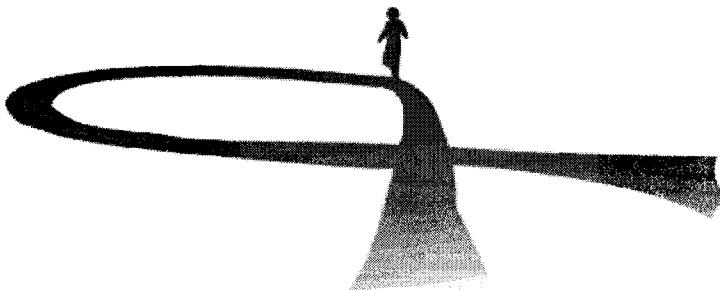
James' thoughts

My name is James Keating. In the late 1990s, my sister-in-law Laura started talking about her idea of doing her PhD dissertation on my wife Ally's HIV status and her activism. I was apprehensive about what Ally's involvement in this dissertation would encompass. I knew by writing this dissertation, Ally would open up not only her life to scrutiny, but mine also.

Once Ally made the decision to participate in the dissertation, it became apparent that I would be a big part of the story. This is because aspects of our lives are so interlinked. Once I understood this, I agreed to take part and gave my permission for Ally & Laura to talk about me. We undertook this endeavour that ended up taking longer than I initially thought it would. I see my contribution to this dissertation as small but I am grateful to be a part of it.

It is my great wish to see only positive things result from this work. My sister-in-law Laura will finish a major phase of her life that will open up new opportunities for her. For Ally and I, we can now move on in our lives happy with the work that's been done. I want to live the remainder of my life as a survivor not a statistic.

James Keating, May 7, 2004



CHAPTER I: INTRODUCTION



Photograph 3: 7,000 crosses planted in the Peace Park, Ganges, Salt Spring Island, World's AIDS Day, 2003 to represent the daily global death toll from AIDS⁵

This dissertation has resulted from many years of shared and individual experiences of both collaborators. Alex Keating, the woman whose life story is presented in the following pages is, biologically, my younger sister and a good friend. Diagnosed in 1989 with HIV while a student at Simon Fraser University (SFU), Alex's story challenges many of the dominant stereotypes associated with the biomedical, moral, political, and economic constructions that currently define it as a terminal illness that is catastrophic yet chronically manageable. The illness narrative through which Alex articulates her lived experiences as an HIV- infected woman has served as a means of combating personal pain, family trauma, public stigma, biomedical and economic marginalization, and the biographical disruption of chronic illness (Bury, 1982, 2001).

The personal and public influences on Alex's agency, or lack thereof, result from a complex set of forces that warrant critical examination. Stigma, defined as "a construction of

⁵ Photograph by permission of Laura Cooper.

deviation from some ideal or expectation” (Alonzo & Reynolds, 1995, p. 304) discredits those whom it defines and often results in social exclusion. When associated with a communicable illness (for which, currently, there is no cure) that is transferred through blood products (where one mode of transmission is sexual), the resulting impact on a person can be tremendous. Historically, communicable illnesses, especially sexually transmitted ones, have carried extreme stigma. This has resulted in varying degrees of exclusion and incarceration to quell the fear of infecting larger society. This reinforces the blame associated to the infected individual (Hatty & Hatty, 1999; Martin, 1994). From the time of her diagnosis, the discrimination and social exclusion that Alex has experienced has challenged access in many areas of her life. She has struggled to find safe and adequate housing, social support, appropriate healthcare, and has lived with chronic financial instability. Bury (2001) refers to such chaotic situations as biographical disruption “in which the relations between body, mind and everyday life are threatened” (p. 264).

In Alex’s life this chaos could not be sustained indefinitely. Since being diagnosed in 1989, I have witnessed her struggle to create a life that is not controlled and defined by the chaos that often accompanies HIV. There are times when the disease and its associated marginalizing completely grip her consciousness, and she wills death to come. At other times the struggle to retain self-control while dependent upon social disability assistance engenders an instability that makes living with HIV the least of her worries. The chaotic nature of these ongoing stressful experiences in her life was coupled with the belief that she was going to die within the first few years of her diagnosis. As a result she developed strategies to minimize the impact of the loss of agency and to allow some semblance of normalcy to return to her life. For Alex, choosing to ‘live’ with HIV has restored her agency. She is asserting control over her own illness experience. One way that she has chosen to do this is by developing and sharing the narratives of her life experience. In doing so, she has created a counterstory to combat the oppressive, though dynamic and complex, master narratives (Nelson, 2001) that ‘typically’ surround HIV/AIDS within the Western world.

Master narratives: Hegemonic social constructions

In developing her theoretical premise regarding master narratives, Nelson (2001) suggests that master narratives are those stories that are often archetypal and serve to reaffirm normative characteristics, behaviours, values, and moral foundations within any society. They provide us with the common sense wisdom that many members of a society accept as truth regarding history, origin stories, and relations between people that include class, gender, or sexuality to name a few.

They define characteristic differences that create ‘other’ categories. Many dominant institutions within a society contribute to the creation of that society’s master narratives. These heterogeneous narratives must be understood as complex socio-cultural creations. The hegemonic nature of master narratives gains strength from their ability to adapt to the dynamic social circumstances that they shape, and are shaped by. The fact that narratives always exist in contested ground (Poirier & Ayers, 1997) is a critical component of deconstructing the hegemonic nature of the master narratives and their ability to absorb opposition within the societies they represent. This contested ground is also a critical space to be utilized by certain counterstories to repair the damage of an oppressive master narrative. Theoretically, critical interpretive medical anthropology (CIMA) provides a framework to analyze the interrelationship between narrative, political economy, and agency and thus provides a suitable model to explore the contested nature of master narratives and their associated counterstories.

An example of this contested ground can be illustrated using generalized understandings about women and HIV. In the first decade of HIV (1980s) in North America, the alleged common-sense knowledge that made up the foundation of the master narrative suggested that homosexuals, injection drug users (IDU), and sex trade workers, those who were engaging in ‘morally deviant behaviour’, were at risk of contracting HIV. Many, while in need of extensive assistance, became marginalized and excluded; often seen as ‘deserving of their infection and its associated suffering’. During this time, many women and men who did not fit within the stigmatized categories of risk groups were becoming infected with HIV and dying from AIDS, often with little assistance or attention from the medical community. They did not fit within the dominant narrative of risk groups. Medically, politically, and socially many of these people were marginalized and denied full medical attention. The reality of their lives and deaths did not fit within the common-sense understanding of HIV and silencing their voices became an integral part of the master narrative. In terms of contested ground, while HIV is a medical phenomenon, it also became a moral issue. This was much to the detriment of medical care for many infected persons, regardless of the mode of infection. Master narratives often do not reflect the array of realities that exist within any society or culture because they primarily communicate norms, beliefs, values, and behaviours of the dominant group.

Alex’s narrative unfolds in a manner that gives voice to the multiple plots, albeit within the developed industrial and post-industrial worlds, that reflects the externally defined contingencies of what is currently promoted as a chronically manageable terminal illness. The emergent nature of HIV as a socio-cultural construction, and the self-orientation that reflects the

personal and ever-changing meanings she assigns to this disease, is also evident in her story. Throughout Alex's personal history/relationship with HIV, the contested nature of the master narratives reveals the shift in the storyline from the early days of the gay plague and AIDS = Death through defining it as a catastrophic terminal illness/pandemic to the current construction of HIV as a chronically manageable terminal illness. The shifting definitions reflect a number of key points for analysis.

As biomedical and scientific researchers continually learn more about the virus, the master narrative controls the dissemination of this knowledge to a society. For example, while it was known, scientifically, very early on in this epidemic that HIV was not 'caused' by gay sex, many media, religious, political, and even medical institutions continued to communicate that HIV was a gay plague associated with risk groups not risk behaviours. Unfortunately, the delay in communicating this important information resulted in many individuals engaging in risk behaviour that increased infection rates across North America. Also, as pop culture icons, such as Magic Johnson, went public about the heterosexual transmission of their HIV, or young haemophiliacs, such as Ryan White⁶, told their stories in prime time movies, the dominant narrative accommodated these while retaining stigmatizing attitudes and actions toward many with HIV.

Life story method

In choosing a method for recounting Alex's story, Ezzy (2000) suggests that illness narratives are, of necessity, woven through many beginnings, middles, and endings. The indeterminate past⁷, present, and future of living with HIV challenges the apparent tidiness and

⁶ Magic Johnson, a well-known former basketball player with the LA Lakers, publicly announced his HIV infection via heterosexual transmission from a sex partner other than his wife on November 7, 1991. In the aftermath of his announcement, the focal point was on the sports world losing a key athlete. There was little critical press looking at his extramarital sexual relations or his engaging in unprotected sex. In the 13 years since his announcement, Magic Johnson has become a key spokesperson for GlaxoSmithKline, a leading AIDS drug manufacturer, promoting the drugs that they develop and distribute. A Google Internet search using the keywords "Magic Johnson" and "HIV" netted 25,000 hits. Ryan White, a young haemophiliac, was diagnosed with HIV on December 17, 1984 while hospitalized for pneumonia. Ryan's family fought many legal battles against the marginalization of their child. Though Ryan died from AIDS on April 8, 1990, his public story has had a profound impact on the stigma facing haemophiliacs with HIV. A Google Internet search using the keywords "Ryan White" and "HIV" netted 71,200 hits.

⁷ While some may argue that the past has already occurred so it can be counted as a clear origin or starting point in Alex's narrative, this is not the case. For example, as the surveillance data regarding HIV definition has constantly undergone change, and indicators of AIDS progression are constantly shifting, so too does the master narrative. Alongside changes in the master narrative are the ongoing changes in Alex's self-assessments, sense of agency, moral identity, and overall well-being that alter her vision of the past, her assessment of the present, and her hope, or lack thereof, for the future.

linearity of a chronological life history method. Though many authors do use life history/life story interchangeably, for the purpose of this dissertation, they clearly need to be distinguished. According to G. Frank,

Life histories focused mostly on diachronic change within anthropology's traditional paradigm of naturalism or realism; research on life stories...focuses on the cultural scripts and narrative devices individuals use to make sense of experience. Life story research emphasizes the truth of telling versus telling the truth. (1995, p. 145)

Frank's (1995a) assertions illuminate the importance of presenting a more complex and contextual frame of reference for the life story to emerge. The contested ground upon which all narratives exist requires one to move away from a culturally prescribed preoccupation with truth, and focus on "how experience is endowed with meaning" (Sandelowski quoted in McAllister, 2001, p. 393). The story unfolds as a life is lived; so do the narrative devices through which one makes intelligible the events being communicated. These narrative devices shift to encompass the audience that is receiving and the multitude of salient characteristics that are deemed most important at that crucial moment. Also, the listener-reader occupies "an active role in the construction of meaning...[therefore] the transmission of meaning between the author and reader is not fixed and thus is not stable across time, place or person" (McAllister, 2001, p. 391).

Does this shifting storyline render the telling less truthful? I argue that it does not. By holding the story in a static position, as often happens with a diachronic life history method, the story becomes more reflective of the linearity and rigidity of the ethnographic present than an accurate portrayal of one person's lived and living experiences. Within a post-modern inquiry, the shifting narrative and its associated meanings, assigned by both the teller and the listener-reader, become critical points for deconstructing the contested ground upon which narrative exists. In doing so, a space is created for understanding that encompasses the central elements as well as those that exist at the margins. In an attempt to deconstruct the manner in which master narratives create HIV/AIDS, critical interpretive medical anthropology (CIMA) provides a theoretical position from which to analyze "the way in which all knowledge relating to the body, health, and illness is culturally constructed, negotiated, and renegotiated in a dynamic process through time and space" (Lock & Scheper-Hughes, 1996, p. 43).

Critical interpretive medical anthropology (CIMA)

The complex political dimensions of HIV coupled with biomedicine(s)⁸ virtual stranglehold/monopoly over its socio-cultural construction makes the analytical framework supplied by CIMA especially appropriate to examine the link between HIV master narratives and the loss of agency of many infected persons. According to Lock & Scheper-Hughes (1996), CIMA is charged with the task to “describe the culturally constructed variety of metaphorical conceptions (conscious and unconscious) about the body and its associated narratives and then to show the social, political, and individual uses to which these conceptions are applied in practice” (p. 44).

Alex’s narrative clearly reveals the loss of agency that accompanied her HIV diagnosis. Biomedically, her marginalization began with an answering machine message about her diagnosis. Following this, her reluctance to take azidothymidine (AZT)⁹ in the early 1990s profoundly impacted the level and type of medical care she received. For a number of years, AZT was deemed the first choice in the treatment of HIV, regardless of its highly toxic side effects. To refuse the ‘benefits’ of the drug was deemed irresponsible, thus impacting how she was treated (Siegel & Gorey, 1997). While advocating for herself and her husband James at hospitals and medical clinics, Alex often questioned the efficacy of medications being prescribed and asked for treatments that she felt were necessary to sustain quality of life. Her questioning of healthcare providers was often met with disdain and dismissal. She believes much of the poor treatment she and James have received over the years has resulted, in part, from her challenging the privileged position accorded scientific and biomedical knowledge and those who administered its practice. Knowing that she needed prophylactic treatment, yet not wanting to completely surrender her will to physicians, positioned her life in a precarious and often chaotic place. The complex interface of medical, political, social, and economic institutions that impact Alex’s life so profoundly can be examined using the multi-level analytical tool of the three bodies (Lock & Scheper-Hughes, 1996).

Lock & Scheper-Hughes (1996) provide the framework of the three bodies to analytically explore the interrelationships between the body self (encompassing one’s sense of oneself as

⁸ I have chosen to represent biomedicine(s) as both singular and plural as I believe that it constitutes complex phenomena that are by no means homogeneous yet it occupies a hegemonic position within a Western worldview on HIV/AIDS. It is my intention to acknowledge its diversity in this manner.

⁹ Throughout the dissertation, Alex does discuss her personal observations of many friends who suffered from the toxic effects of large doses of AZT that were being prescribed in the late 1980s and early 1990s. As a result of this, she opted out of AZT.

separate from other persons), the social body (addressing the social constructions of the body in relation to nature and culture), and the body politic, that which reflects the “regulation, surveillance, and control of bodies (individual and collective) in reproduction and sexuality, work, leisure, and sickness” (pp. 50-51). This model of interpretation facilitates a multilevel analysis of the complexity of factors that influence each other (albeit to varying degrees) in the socio-cultural construction of HIV/AIDS.

Throughout the dissertation I argue that the socio-cultural construction of HIV/AIDS results from hegemonic culturally constructed institutions whose master narratives have the capacity to deny human and moral agency to persons infected with HIV. Within the dominant biomedical discourse, these narratives often judge those who choose alternative treatments and ways of living with HIV as socially irresponsible or as a threat to the common good. The identities that are damaged by the powerful biomedical, political, and social discourse that generate the complex master narratives representing HIV constitute a deprivation of opportunity and infiltrate one’s consciousness (Nelson, 2001). This causes harm and damage while entrenching one’s powerlessness in the face of HIV.

In terms of the three bodies, the body-self with HIV is shrouded with uncertainty, fear, stigma, and in many cases, chronically compromised health. As Alex’s narrative will demonstrate, HIV serves to silence its hosts, often leading to an acceptance of self-imposed blame, alienation, and powerlessness. Sexual and other behaviours that are often deemed acceptable within society at large become the focal point of an accusation of moral deprivation when HIV is contracted.

The social body applied to those with HIV reveals a complex web of descriptive and constitutive language and metaphors that revolve around the polluted body. Here infected persons become homogenized as part of a contagion-spreading pariah community (Sontag, 1989). As we enter the third decade of HIV (2000-2010), many of the powerful, though erroneous, metaphors by which people have come to understand this virus still make up the core beliefs of much of Western society.

In analyzing the complexity of meanings around HIV/AIDS and the links to political agendas and the body politic, Paula Treichler (1999) suggests that it is difficult to discern which meanings will make up the official story/version that informs and guides the master narrative. For this reason, she argues, “We need an epidemiology of signification--a comprehensive mapping and analysis of these multiple meanings--to form the basis for official definition that will in turn constitute the policies, regulations, rules, and practices that will govern our behavior

for sometime to come” (p. 39). Treichler further sees “disease as language, the body as representation and medicine as a political practice” (p. 36). One must move beyond the master narrative of ‘factual’ rhetoric to enable oneself to understand clearly and write critically of the multiple impacts of a master narrative that do not include “certain voices that need urgently to be heard” (*ibid.* p. 39).

A good example of the silencing of voices can be seen in the early homosexualization of HIV that has had a profound impact on treatment, care, and social acceptance and rejection of HIV-infected women. Furthermore, on a global scale, heterosexual transmission among non-sex trade workers makes up the majority of newly infected persons, though there is still considerable official rhetoric that suggests otherwise. The political will of the master narratives that render many living with HIV as deviant and morally depraved can be found woven through political, economic, and biomedical policies aimed at containing and/or controlling HIV. This is a narrative made possible through the silencing of many voices.

Nelson (2001) asserts that a deprivation of opportunity results from persons being targeted by members of the dominant group whose master narratives deny moral agency to the individual. The narrative of the social body limits life opportunities. Further exacerbating the situation, when an individual is oppressed through the narrative of the social body, the “oppression often infiltrates a person’s consciousness, so that she comes to operate, from her own point of view, as her oppressors want her to, rating herself as they rate her” (p. 7). This infiltration of consciousness further constrains one’s agency; damaging identity and rendering one’s political will silent.

A person’s freedom of agency is associated with how competently one presents oneself within morally and socially acceptable parameters, and others’ recognition of this. One’s self-identification in relation to a society’s moral prescriptions is also crucial to freedom of agency. As Alex’s narrative will reveal, the stigma and various forms of marginalization associated with having HIV have both deprived her of opportunity and infiltrated her consciousness to the point that for many years she saw herself as dying from AIDS rather than living with HIV.

While some narratives can damage a person’s identity (Nelson, 2001), they also have the potential to restore agency to the ill person, present a moral story about the link between suffering and culture, repair identities damaged by sickness, give meaning to life experiences, have emancipatory qualities, and open up a dialogue of alternative healthcare (Kleinmann, 1988; Migliore, 2001). It has been argued, however, that we need to caution against uncritically presenting romanticized narratives of the suffering and pain of ill persons whose stories we

witness (Bury, 2001; Williams, 2000). While Alex Keating's illness narrative has evoked both empathy and sympathy from me, this has not diminished its ability to repair identity, give meaning to life experience, and open up an alternative healthcare dialogue. In doing so, I argue, it also possesses the criteria of a successful counterstory, as defined by Nelson (2001).

Illness narratives and the HIV counterstory

When one is faced with a chronic terminal illness, such as HIV, one's life path is disrupted. This situation is exacerbated by the hegemonic position of biomedicine(s) in the Western world that renders the HIV-infected person subordinate to their diagnosis. The political nature of biomedicine(s) is to construct HIV in an objective manner. The resulting power that the diagnostician has over the illness narrative influences the way in which an ill person's story is often subsumed under the clinical demands of physicians (Good, 1994; Kleinman, 1988). This leads one to question the degree to which biomedicine(s)' determination of HIV actually reflects the lived experience of those infected. The contested ground upon which meaning is assigned to one's life with HIV is apparent in the divergence between medical description, public perception, and personal experience. This can be found threaded through Alex's narrative.

In an effort to grasp the meanings that accompany such an emotionally and politically loaded diagnosis that is often framed in moral terms, Skultans (2000) has suggested that narratives open the door to comprehending the life stories of those marginalized by illness. Further, she suggests that, "narrative understanding is suited...to certain deviant groups...and to women enmeshed in the concreteness of everyday living. Thus narrative is thought to have a particular affinity to both women and illness" (p. 5).

Nelson (2001) presents the concept of a counterstory as one that facilitates the 'narrative repair' to a person's identity that is damaged by the physical or emotional aspects of illness. Also impacting one's identity are the master narratives of the dominant groups in society. These define what an illness is, how one with the illness should act, and the parameters within which one should live their life as a sick person. Contemporary Western society promotes health as the moral responsibility of the individual and, when attained, it carries with it positive social rewards or benefits.

Conversely, sickness is an indicator of one not maintaining the social and moral responsibility of good health. Certain sicknesses are constructed with a greater degree of moral disdain than others, thus focusing on the individual as morally defective (Nelson, 2001). HIV is one such sickness that, while clearly a medical condition, becomes subsumed under the weight of

moralizing stigmas. Hatty & Hatty (1999) argue that we are living in the age of the epidemic and “central to this ethos is the logic of contagion...which shapes and guides social relationships” (p. 237). HIV, they contend, is socially constructed as apocalyptic proof that causes many to live in fear of contagion, and to alter their social relationships accordingly. The associated fear-mongering provides the rationale for surveillance over people’s sexuality and lifestyles. It further justifies the physical incarceration and social and moral isolation of some infected persons in order to ‘protect the public’. Alex’s fear of disclosure and its associated stigma led her to tell people that she had cancer in an effort to explain her illness. There were times in her life when public knowledge of her HIV led to threats to her safety and, once, resulted in eviction from her home.

Though there are many complex factors that have led to the ‘dominant wisdom’ regarding HIV, which will be discussed throughout the dissertation, the deeply-rooted master narratives that construct one living with HIV as deserving of their condition serve to usurp one’s moral agency. Nelson suggests, “the extent to which our moral agency is free or constrained is determined by our own-and others’-conception of who we are” (2001, p. xi). Interestingly enough, while dominant HIV/AIDS narratives are often damaging to those infected or, by association, members of what are listed as high-risk groups, it is precisely the constraint on moral agency that has led to powerful and narrative reconstructive activism within much of the HIV-infected community. It is this battleground that provides an interesting framework for Alex’s counterstory.

Given that illness narratives are very heterogeneous, Nelson suggests that not all of them “resist an oppressive identity and attempt to replace it with one that commands respect” (1995, quoted in Nelson 2001, p. 6). While many alternative narratives exist, not all constitute a counterstory, “The proper target of a counterstory is a master narrative that has been generated by an abusive power system to impose on a particular group an identity the system requires” (Nelson, 2001, p. 155).

An example of this can be found in the highly controversial yet groundbreaking safe injection site for IDU in Vancouver, British Columbia. This site resulted from years of political lobbying by former and current users, associations for assisting those living in marginalized areas of the city, street nurses, needle exchange workers, other street-level care providers, sympathetic politicians, and other interested persons. The focus was to reduce the associated dangers of unsafe and high-risk injection drug use in an attempt to control the spread of HIV and other infectious diseases transmitted through blood products. Injection drug users have long been constructed as morally defective, individually responsible for their addiction, and a growing

problem for property owners and residents in areas where they congregate. The dominant narrative in Vancouver, at least for now, is that society needs to take more responsibility for the safety of this marginalized group, at least in reducing the spread of HIV. While there is not consensus among the population at large, the pressure brought to bear on the local government has created political havoc for many politicians. However, like all master narratives and counterstories, the safe injection site exists within a dynamic context where the meanings associated to the opposing sides are heterogeneous. The safe injection site and its narrative rationale clearly exist on politically, medically, socially, morally, and economically contested ground.

Master narratives have both strengths and weaknesses that a successful counterstory will identify and toward which it will build its resistance. Master narratives are complex in that they are a product of and constitute dominant norms, beliefs, and values that provide the guiding framework by which a group finds cohesion, develops its identity, and guides its internal order. Changing an oppressive master narrative is no simple feat, as they are deeply rooted within many social institutions. Further complications arise when those resisting the dominating influence are starting from a position of subordination and relative powerlessness. However, it is the heterogeneous nature of oppressive master narratives and the dynamic nature of society that may provide areas of entry into challenging and changing these systems of marginalization.

Nelson (2001) identifies a successful counterstory as an act “of purposive moral self-definition...that could itself be a master narrative, though it never oppresses the individual it identifies” (p. 157). While I agree in principle with Nelson’s suggestion, HIV as a gendered illness exposes a weakness in her argument. The very nature of HIV initially being communicated as a gay plague has resulted in a powerful movement to counter the public image of the disease and the alleged ‘immorality’ of those infected. The monies available to agencies that provide services to those who are working to alter the master narratives are often fought over by the many agencies attempting to provide services to advocate and remain active in counterstory building. Thus, one can find within the HIV counterstories many examples of the oppression of women and other minority groups by those very agencies that are mandated to improve the situations facing HIV-infected persons. With present funding cuts to HIV services, at a time when many people are becoming desensitized to HIV or are complacent about its potential public health risk, the political posturing and infighting among many HIV/AIDS non-governmental organizations (NGOs) calls for a revaluation of Nelson’s assertions.

In relation to Alex's narrative as a counterstory, she has spent many years lecturing in classrooms and engaging in physician-sensitization workshops aimed at healthcare workers who encounter those living with HIV. She has conducted similar workshops for Financial Aid Workers (FAW) as well as representing women with HIV at various conferences and in television interviews. Her efforts to communicate an alternative reality aimed at countering the fear and ignorance of many who have heard her speak, as well as the advocacy position she takes in mediating both her and her husband's healthcare, also reveal elements of how she both narrates and lives her counterstory. She also writes of how working in AIDS does take its toll, often as a result of political and economic infighting between and within agencies. These political struggles can also marginalize those who are working for change.

Chaos, quest, and restitution

A. Frank's (1995) discussion of narrative plots for illness stories supports Nelson's assertions of the counterstory as a means of repairing identity and restoring moral agency. Using the plot framework of chaos, quest, and restitution, Frank makes it clear that the nature of chronic illness constantly interrupts one's life such that the journey between chaos, quest, and restitution is not linear, and that the plot lines constantly intersect. Frank's exploration of the dynamic and multilinear nature of the illness plots can be found within Alex's story and in tracing the unfolding of her narrative through these plot lines, the restoration of her moral agency, though at times fragile and vulnerable, becomes evident.

The restitution plot/narrative suggests that the sick person's foray into illness will ultimately end with her re-entry into the world of health, facilitated by the science of medicine and its supporting institutions. This is a master narrative that ultimately guides much social action and belief around sickness. The restitution narrative suggests that illness is a temporary state of disrepair until the body can be fixed and the person returns to 'normal' health. Where responsibility is concerned, Frank suggests that this "is limited to taking one's medicine and getting well, wellness being defined in contrast to illness" (1995, p. 91). While this is a socially acceptable and ancient plot line (Frank, 1995), it does not fit well within the parameters of chronic terminal illnesses such as HIV. The early AIDS = Death campaigns that infiltrated social consciousness have served to create confusion for those infected. Knowing that the illness is terminal, regardless of its present chronically manageable designation, the plot of restitution provides brief respite from the realities of living with HIV. Throughout Alex's narrative, one can find times when the restitution plot serves to facilitate a re-entry into the socially perceived world

of ‘normal’ health. Equally, however, the master narrative also serves to usurp her agency when she has disagreed with physicians as to a care plan for herself and her husband. At these times, she has often been seen as irresponsible, uncooperative, and has even been called a “bitch” by an emergency room doctor. Her advocacy position has been interpreted as threatening by those attempting to implement a biomedical plan of action and exert their expert control over her life and death.

The chaos plot is the opposite of restitution and is seen as a non-plot (Frank, 1995). The illness around which the chaos story exists is so encompassing that the ill person cannot grasp a position from which to reflexively narrate the story. These stories are as difficult to hear as they are to tell. There is no socially acceptable return to health, and the chaos narrative becomes “an anti-narrative of time without sequence, telling without mediation, and speaking about oneself without being fully able to reflect on oneself...these stories cannot literally be told but can only be lived” (Frank, 1995, p. 98). This is evident in much of Alex’s early life with HIV disease, and resurfaces throughout her narrative. It clearly reflects the contingencies of living with a virus that encompasses a complex syndrome of illnesses that, if untreated, will end her life. If treated her life may be prolonged with a dependency on increasingly toxic doses of combination drug therapy. As Alex’s narrative shows, the interface with the many institutions that influence her life on a daily basis can exacerbate the chaos. At points in time HIV becomes the least of her worries. As a result, though, as Frank suggests, “the need to honor chaos stories is both moral and clinical” (*ibid.* p. 109).

The quest narrative is the third plot that Frank (1995) introduces. In this plot the ill person has a greater degree of agency over her story, as she is able to wrest control over her narrative and use the illness story to “hold chaos at bay” (p. 115). In relating these plot lines to Nelson’s discussion of the counterstory, the quest story is of paramount importance in restoring moral agency to the ill person. Though chaos and restitution are still present, they do not assume a central position in the narrative. In narrative reflection they can assume meanings that a narrator can utilize to morally and ethically build on her counterstory. In Alex’s narrative, all three plot lines are instrumental in the abstraction of her life story. The narrative devices of restitution, chaos, and quest create a more active telling; one that reflects the uncertain and contingent day-to-day living with HIV, yet places her voice as central to the telling and ultimately restores her agency throughout the building of the counterstory.

The crisis of representation, reflexivity, and authority

While the academic tenets of positivism still resonate in many disciplines, including anthropology, the legitimacy by which researchers position themselves as the expert or authority to speak for an individual or a social group is increasingly being called into question. Renato Rosaldo (1993), in discussing classic norms within ethnography, explores the ‘myth of the lone ethnographer’ as one who underwent fieldwork in a far away location, collected data, and “returned home and wrote a ‘true’ account of the ‘culture discovered’ while in the field” (p. 30). In the discovery of a people the ‘other’ was created, effectively silenced, and kept at a great distance from the objective, literate, and authoritative researcher.

The colonizing discourse that resulted perpetuated itself within the patriarchal academe and was fuelled by the objectifying gaze of modernity. While contemporary anthropology is continually wrestling with its colonial past, Denzin and Lincoln (2000) suggest that the twenty-first century has led to a narrative turn in qualitative research that requires researchers to open themselves, and their text, to multiple voices and mediums for the expression of the story. In contrast to the commitment to value-neutral research and the creation of the ‘other’ that are paradigmatic cornerstones in positivist academic traditions, narrative ethnography in the “seventh moment” (Denzin and Lincoln, 2000) calls for “the social sciences and the humanities [to] become the sites for critical conversations about democracy, race, gender, class, nation, freedom, and community” (p. 1048). Given the commitment to a moral and ethical discourse where all knowledge is seen as situated, all texts as multi-voiced, and the personal as political, narrative ethnography in the seventh moment presents an opportunity to engage in experimental and collaborative ethnographic research that critically addresses the crisis of representation in anthropology.

Medical anthropology is one field of ethnographic research that has navigated its way through the crisis of representation. A. Frank (1991,1995), Good (1994) and A. Kleinman (1988), among others, have explored narrative ethnography with the intent to critique the hegemony of biomedicine that constructs the ‘other’ as a diseased body, and also draw attention to the idea that “it takes a strong act of consciousness to denaturalize disease [from the biological domain] and contemplate it as a cultural domain” (Good, 1994, p. 2). By seeing disease as cultural, the task facing the narrative ethnographer is to create space for the illness story to reveal itself as multi-voiced and dynamic where ‘truths’ are relative and often shifting from moment to moment.

The post-modern experience of illness, according to Frank (1995) “begins when ill people recognize that more is involved in their experiences than the medical story can tell” (p. 6). The task of giving voice to one’s illness narrative that lay with the researcher is to see “listening as a fundamental moral act” (*ibid.* p. 25), thus the ethnographer must engage an ethic of listening. Frank refers to this in the context that we can easily dismiss the voices of ill persons due to the often chaotic and socially problematic nature of their stories. In dismissing, ignoring, or partially listening to the voices of ill persons, we can shift our thoughts away from our own vulnerabilities, pass off their stories in a placating manner, or render their voices silent by suggesting a trajectory of healing, a restitution narrative, that fits socially acceptable parameters within the master narrative.

Applying the ethic of listening to this research is perhaps one of the most difficult methodological concepts to put into practice. A Kwantlen First Nation elder and dear friend once told me that we were created with two ears, two eyes and one mouth, thus we must look and listen twice as much as we speak. In practice, this meant that I reflexively acknowledged the ethical, cultural, academic and familial filters that influenced my listening while I struggled to allow the meanings which Alex assigned to the words, the order of events narrated, and the purpose of her telling to retain their own intent. As an older sister, I also had to be vigilant in my desire to make everything okay and to guard against placating her, or becoming too enmeshed in my own fear and sorrow when she was actively ill. Attempting to listen ethically has sensitized me to the subjectivities that enter into the narrator-receiver relationship. I believe I would be remiss if I did not own the influence that the meanings that I attached to my sister’s story had on the outcome of my analysis. Rather than being seen as diminishing the quality of knowledge produced due to the subjectivities discussed above, I argue that it is precisely the act of reflexivity that brings depths to this research that otherwise would not have existed in a more positivist-focussed methodology.

Ethnographic narrative, as a methodology, emerged in response to the ethnographer’s need to include their own experiences in the text while portraying the life story and memoir of their subjects (Tedlock, 2000). It also provides a map for anthropologists to document the richness of people’s lives and to critique inequality and domination while examining the degree to which a researcher’s cultural and personal baggage has contributed to or been influenced by master narratives, whether oppressive or not. Situating the production of knowledge in this manner can be empowering to the subject of the study as well as to the researcher. Balancing the power relationship between ethnographer and subject has long been a necessary element of

critical feminist and humanist research. Denzin & Lincoln, (2000) believe that as we move further away from grand narratives (master narratives) common in positivist social scientific inquiry, we come into a humanist middle ground that sees the “world always from the perspective of gendered, historically situated, [and] interacting individual[s]” (p. 1047).

It is in this context that Dossa (2002) chooses ethnographic narrative as a research paradigm for studying the narrative structure of Iranian women’s perceptions of “emotional well-being” (p. 342) in relation to mental health, social, gendered, and political factors embedded in many immigrant women’s experiences. She defines ethnographic narrative as “a mode of research that is embedded in the genre of dialogues among the research participants, between the participants and mainstream service and health providers, and between the research participants and the researcher” (p. 342). Similar to Nelson’s concepts of infiltrated consciousness and deprivation of opportunity that accompany the constraint of free agency, Dossa’s ethnographic narrative demands that the contexts within which immigrant women, as individuals and as members of a community, live their lives be given voice. In doing so we can deconstruct the ‘invisible veils/walls’ (p. 343) that are created by the racism and sexism embedded in an oppressive master narrative.

As for the crisis of representation and its relationship to ethnographic narrative, Behar (1995) asserts that “anthropology need[s] to encourage more innovative, dialogic, reflexive, and experimental writing [while seeking to] decolonize the power relations inherent in the representation of the Other” (in Behar & Gordon, 1995, p. 4). It is my assertion that all knowledge is situated and as such must be seen as fluid and open to multiple interpretations. Positivism and structuralism, while powerful and dominating elements in master narratives, suggest that ethnographic material should portray the researcher as the value-free recorder, analyst and authority of the information, thus silencing individuals whose lives they allege to portray. While many attempt to present more ethical and representative texts, ethnographers are always in positions of power over the subjects of ethnographic inquiry and the act of self-reflexivity is fundamental to presenting a more rich, interactive and balanced story.

It has long been asserted that people are natural storytellers and that while traditional anthropological methods involve participant observation, they also rely on informants who tell stories, researchers who interpret the meaning within the stories, and/or narrate the significant portions of the story for the reader. The literature abounds with warnings of how to gauge the story for its truthfulness, the agenda of its teller (narrator), its relation to the larger cultural milieu within which the story appears, and, perhaps more importantly, the role of the researcher in

influencing the story being told. Throughout the years of being actively involved in each other's lives, Alex and I share elements of this story with a degree of intimacy that may not exist in many other forms of ethnographic work; thus critical discussion of representation and reflexivity are crucial to this academic piece.

Amit-Talai (2000), in writing of ethnographic work, has suggested that, "there is surely no other form of scholarly enquiry in which relationships of intimacy and familiarity between the researcher and the subject are envisioned as a fundamental medium of investigation rather than an extraneous by-product or even an impediment" (p. 2). While I concur with Amit-Talai, I would add that the researcher must consciously acknowledge the vulnerability of both self and subject which goes hand in hand with intimacy and familiarity. I believe the positivist preoccupation with value-neutrality presents a weakness as it negates the two-way impact between the researcher and the researched.

Throughout the process of writing this dissertation, Alex and I have worked to openly address and critically discuss how the process has impacted each other and our resulting stories. The questions of whose authority and whose voice, that are critical in academia, are at the core of this work. The act of ethically receiving another's story does require an intimacy that belies positivist objectives, and in doing so, can give space for more meaning-centred and honest conversations to occur. The relations between researcher and subject of the research are often not conducted in as neat a manner as many ethnographers would have us believe. Alex and I have had arguments, have shared laughs and tears, have explored past and present family dynamics, and throughout, have often struggled with each other's story. In our work we are both trying to ethically accept each other's stories and life experience. Coming from a family where judgment and discipline were key strategies for holding each other in check, we have, with varying degrees of success, had to work very diligently not to fall into the trap of the 'righteousness' of our individual truths.

Collaborative methodology

Smith (1999) in her book, *Decolonizing Methodologies*, calls for researchers to "question the most fundamental belief of all, that individual researchers have the right to knowledge and truth" (p. 173). As a self-identified indigenous academic, Smith supports research methods that empower people through inclusion of voice rather than silencing and objectifying them through the exclusion of input into the research process, as evidenced by positivist methodologies. Though the method of sharing power and decision-making with the subject(s) of research is

uncomfortable to some academics, Alex and I intentionally chose a collaborative methodology to redress the loss of personal power that accompanies chronic illness and to test Nelson's (2001) theoretical foundation that agency can be restored and identity repaired through counterstories.

Collaboration with the subjects of research is not a homogenous endeavour, nor can it be fully balanced. Rather, it is a process of constant negotiation of meaning, intent, purpose, personal agenda, power (in a multitude of forms), intellectual property, academic demands, and in the case of illness narratives, the health and well-being of all persons involved. Given the complex challenges to one's identity that accompany chronic terminal illness, collaboration is a start in the process of shifting the balance of power and working toward more equitable representations and of reducing the tendency to objectify lived experience.

Ethnographic collaboration is not a new strategy in addressing the above-mentioned concerns. G. Frank (2000), in writing of Diane DeVries' life with no arms and legs, Kasper (1994), in writing on women and breast cancer, and Lather and Smithies (1997), in writing on women living with HIV/AIDS, all provide cogent examples that have utilized the informants' collaborative commentaries to enhance the text and to balance the power differential between the researcher and the researched. In this sense the teller of the story retains her own voice and articulates her own suffering experience, regardless of how uncomfortable this might be to the researcher or receiver of the story. Within Western society, the clinical narrative is organized around biomedicine(s) as providing salvation from suffering (Good, 1994) and the restitution plot outlines the individual's responsibility in this. Thus when one speaks of her suffering without relief, this story is often silenced within both clinical and societal settings. To change this requires the listener to "think with the stories and not think about them" (Frank, 1995, p. 22) and to allow the discomfort of suffering to exist in that uneasy space that is not controlled by the authoritative researcher or clinician. Frank (1995) suggests that to do this is to see the illness story as complete in and of itself. The story is dynamic entity, with a life of its own that is influenced as much by the initial experience as it is by both telling and reception.

Bearing witness to illness narratives or to a testimony of suffering is often deemed necessary when the intent of witnessing has an ethical basis. In terms of a successful counterstory that is aimed at challenging oppression, being called to bear witness is of fundamental importance. Bury (2001), however, suggests that the religious overtones of language calling for a researcher to 'witness suffering' need to be recognized as cultural constructs with definite historical linkages. What Bury fails to recognize is that there are other cultural interpretations regarding witnessing beyond those linked to a Judeo-Christian context from which he articulates

his concerns. I also argue that the reticence within some academic circles to engage witnessing as a research strategy is telling about the problematic of giving up power over the manner in which another's suffering is recorded. Among many First Nations peoples in British Columbia, who historically practiced oral traditions, being called to witness carries with it responsibility for an accurate and subjective remembering of what one has seen and heard. From this perspective one bears responsibility for empathetically remembering what occurred, though there is recognition that each person witnesses from his or her own unique perspective. That there is no objective perspective from which to bear witness is not a problem; rather, it enhances the value and truthfulness of recording the event.

Witnessing Alex's and James' suffering as, firstly, a family member and, secondly, an anthropologist, has been a very difficult process for me. While witnessing suffering may appear gallant and honourable on paper, in practice it poses a myriad of methodological, theoretical, and personal complexities that challenge the positivist portrayal of distanced and objective/unbiased observation. Of vulnerable observation Behar (1996) writes:

Loss, mourning, the longing for memory, the desire to enter into the world around you and having no idea how to do it, the fear of observing too coldly or too distractedly or too raggedly, the rage of cowardice, the insight that is always arriving late, as defiant as hindsight, a sense of the utter uselessness of writing anything and yet the burning desire to write something, are the stopping places along the way. At the end of the voyage, if you are lucky, you catch a glimpse of a lighthouse, and you are grateful. (p. 3)

While Behar has received extensive criticism and praise within anthropology for her self-reflexive practices and the positionality of this in the ethnography, *Translated woman: Crossing the border with Esperanza's story* (1993)¹⁰, the above quote does reflect some of my experiences throughout the years of conducting this research.

I recall a time when James was in hospital, Ally was sick but not in hospital, and still advocating for better care for her husband. The hospital wanted to release James, who was extremely sick with uncontrolled vomiting and diarrhea, to be cared for at home. Alex would have provided his care, as government home support was not available to them during this period. Insistent on maintaining her advocacy position, Alex spent countless hours on the phone and at the hospital trying to find a way to keep her husband in hospital though she was too ill to

¹⁰ The final chapter (prior to the epilogue) of *Translated woman* (1993) is titled, "Biography in the Shadows." The chapter is a self-reflexive exercise in which Behar situates her personal life in relation to both her research with Esperanza and the demands of her academic position. While this discussion takes 22 pages, it has become the focal point of much attention among reviewers of the ethnography, primarily because of its self-reflexive nature.

adequately care for herself. My offer to care for her or advocate for James was initially met with rejection. The helplessness and frustration that I felt at this time, coupled with fear for the health of my sister and her husband, was monumental. As well, I felt an almost blinding rage about the medical decisions that were made by the healthcare team. Clearly, it was impossible to gain adequate distance from what was occurring to adopt an academic position. Was this a detriment to the research? Did my recurrent vulnerability diminish the academic integrity of the dissertation? These questions, among others, have remained with me throughout and present important points for discussion throughout. Furthermore, they caused me to question methodologies that require the ethnographer to write of sorrow and suffering through a distanced and objective lens. I found myself questioning then, as I do now, how an anthropologist could turn off their emotions, sympathy, and empathy to write free of bias and, if they were unable to do so but refused to acknowledge it, how did this impact the truth of the telling about another's life?

In learning to reflexively and ethically listen to my sister's narrative and to witness her lived experience, I realized that I first needed to unpack my own baggage about HIV/AIDS, its relation to my sister, and the complex and dynamic manner in which I have constructed my sister as a person living with HIV/AIDS (PWHA). In the early years, seeing my sister as a dying woman became a filter through which my interactions with her were influenced. I responded to her in ways that revealed my view of her as not only being terminally ill, but that her end of time was always imminent. This belief gained expression in a myriad of ways including overprotection, invasion into her private life, blaming anyone who looked like a suitable source for the displacement of my anger, and in giving her perishable gifts that ultimately were concrete indicators of how I saw her life, or lack thereof. As part of the dissertation work I began the process of situating my actions and reactions within the master narrative that influenced my perspective of how one with HIV should live her life or prepare for death. No matter how I envisioned her life to be or what I thought was best for her, I had to back off and let her live her own life on her own terms. I had to reflexively deconstruct my own knowledge and the still snapshots of what I determined my sister's life to be, and my role in that.

Methodological discussions between Alex and me have brought to light the concern that her voice does not become subsumed under my authority as the recorder of her narrative. We were also concerned that we represented the dialectic nature of our intersecting stories. It became important for us to give voice to the reality that at times perspective was lost while one or the other of us struggled to retain agency in the face of the demands of the research process itself. Through collaboration we intended her voice to remain central in her narrative while providing a

space for me to wrestle with the academic and personal issues of conducting research in an area so close to home. The method chosen was not without its difficulties, however, as it required us to be in a constant process of negotiation of meanings, intent, and relationship to best meet the demands of academia, while attempting to remain honourable to each other's needs and requirements through the writing of this dissertation.

An area that has posed degrees of difficulty for both of us occurred, I believe, as a result of the intimate knowledge that we have of the other's life because we are sisters and close friends. It is here that I have had to learn to accept that Alex would share only those portions of her life that she chose. There were times when I tried to influence Alex's narrative along a certain trajectory because of knowledge that I had of her life. My rationale had been the academic value of her narrating these events to further enable the critical discussion that I wanted to engage in. At times this created tension for us and I had to differentiate what I would know about her as a field-working anthropologist from the more extensive and intimate knowledge I have because we are family. Further still, there were times when I struggled to hold myself in check so that I did not use the varying degrees of knowledge I have of her life to deny her agency simply to further the dissertation. On a few occasions the tension between us built to a point that we took breaks not only from the work but also from each other for a few weeks at a time.

The complex webs of interactions that make up one's life raised the issue of multiple truths as discussed earlier. In a practical sense, Alex and I encountered stories of events that we both shared and to which we assigned different meanings. This opened the opportunity for us to recognize that differences of opinion and perspective had always been a part of our lives as sisters. We examined how we addressed these in the past, how we negotiated them in the present, and how we might deal with them in the future. We have learned (are learning) how to listen to each other's stories, and to allow differences of opinion, experience, and intention to coexist, albeit sometimes in a precarious way. We were careful not to usurp the other's lived experience and repackage it to fit our own beliefs. However, while we were both committed to hearing the other, it remained my intention to keep her voice central in this work.

The collaborative research officially began in 2000 when I was able to put together a doctoral committee that was critically supportive of the project. We agreed that Alex was a collaborator and, as such, would be party to all communication between the committee and myself, be able to communicate directly with the committee, respond to their comments, and ask questions. While this practice was not an issue for my doctoral committee, it became a point of concern voiced by an external examiner during my dissertation defence and thus warrants

discussion here. Stevenson (1998) problematizes the circumstances facing many post-modern qualitative researchers who do not couch their research ethics proposals within the language of positivism to gain ethical approval. He suggests that many committees are concerned that the authority remains with the researcher and that proposals are “part of well-rehearsed societal narratives which equate science and knowledge” (p. 790). Positivist language underlies many health and social science research proposals that clearly define the study parameters and reflect the ‘correct’ way to do research. I intentionally chose a methodology in which my collaborator was enabled with as much power over the narrative process as she chose to have and, in so doing, was questioned on whether or not this diminished the overall academic merit of the dissertation.

The choice of a collaborative methodology over other techniques was driven by a number of factors, some of which have been discussed earlier, and others which derived from recognizing that my sister was a content expert in her own life and illness narrative. Alex’s long history of activism, advocacy and resource work within various PWHA communities and educational institutions gave her an intellectual competency that I acknowledged by insisting that she speak for herself wherever she chose. She was very capable of situating her story in relation to medical, welfare, and other societal institutions, thus she often moved beyond description to engage in analytical praxis. Conversely, there are places where I narrate for her and James; in essence, tell their story. Where this occurred, however, Alex had the opportunity to ensure that I represented her story accurately to her interpretation. Thus, she did retain the right to ensure that my telling did not alter the meaning she or James attached to the narration. At another level of telling, there are places where my story of an event in her and James’ lives exists as my story, unedited by her. In these places, my telling of their story is more from a self-reflexive position. This is aimed at situating the various influences in my understanding of the intersections between our stories and its relation to the academic context through which the stories were being filtered for theoretical and analytical purposes. Ultimately, the existence of multiple voices in this manner created methodological complexities that, in belying a simple telling, reflect many levels of subjectivity thereby giving depths of meaning to this work.

Alex having authority over her own voice included her having both the first and last word in the dissertation. The preface and epilogue that resulted were unedited by me though she initially asked me what each could contain and I provided her with a brief and generalized definition. The end results were of her creation and not mine. Though I initially did not agree with the way she chose to represent some of her ideas pertaining to me, I, necessarily, did not have the power to influence her writing. Through this process I learned a considerable amount

about how it feels for someone to write about you and of not having the opportunity to change those words. It caused me to reflect on how traditional ethnography can disempower those about whom it alleges to represent. When the tables are turned and we, the researchers, must read what is written about us, it can be a very humbling, but worthwhile, experience. While I could have chosen a more structured interview process that would have guarded my privileged position as a researcher, this would not have been conducive with presenting a space for Alex's counterstory to emerge.

M. Crewe (1997) writes of the concern with HIV/AIDS illness research among marginalized groups that appear as "*reflections* rather than a critical analysis of how social meanings are mediated and constructed in society" (p. 967). This is done, she argues, at the level of description of what it means to live as a marginalized person in the face of biomedical or societal control over ones' life. She suggests that to engage a critical explanation of how marginalizing processes set themselves up and are perpetuated we need to develop different methods of articulating how power and ideology are understood. She writes:

As commentators and researchers about HIV/AIDS and its effects and meanings, we need surely to take people out of the margins and to put them back onto the pages. ...they need to be neither in the margins, nor in footnotes, but firmly back in the society which both created them and spurned them-back in the center fold. (p. 969)

Following along the argument presented by Crewe above, I suggest that the research design of repositioning Alex's voice as central and of facilitating her to conduct her own analysis of power and ideology is, in effect, bringing her back to the "center fold." Furthermore, Alex's access to the doctoral committee throughout the entire process reinforced our intent to challenge traditional academic power structures that also marginalize those whom we study. In allowing her these measures of control over how her words would be used by myself, as well as the doctoral committee, we were all held accountable to the ways in which academic and personal power were exercised. I applaud my doctoral committee for their willingness to take this step with Alex and me. In so doing they encouraged me to envision a research methodology where academic egos and theoretical posturing were not given fertile ground. We 'all' negotiated, collaborated, and learned to listen to each other. As a result, we successfully worked outside of the traditional boundaries of power that typically shroud the doctoral process while producing a dissertation that became a counterstory in more ways than one.

With Alex's and James' consent, as well as my committee's support for the methodology, ethical approval was successfully obtained and the collaborative dissertation officially began (see

Appendix 1 for ethical approval). Aside from the earlier-mentioned sources of data, research was also collected through what would traditionally be called participant observation. Fieldwork was conducted when we were together doing any of the myriad of activities that have resulted from years of being sisters and good friends, including events that are part of our support network for chronically and terminally ill persons. Though the boundaries became blurred between research time and the ongoing processes of our lives, there were times when the experiences we shared were too raw or emotional, or too special and intimate to lay bare for academic critique or a wider audience.

The research locations spanned from Salt Spring Island, British Columbia, to central Alberta, from Vancouver, British Columbia, to South Dakota, from hospital rooms to Alex's garden, from healing ceremonies to doctor's offices, and so it went. At times we met primarily to discuss the research and our interactions took on a more formal and disciplined academic tone. We also worked independently, communicating by phone, MSN Messenger, or email with little to no physical interaction for weeks at a time. The natural relationship that we have took precedence over the dissertation and afforded me degrees of latitude that an ethnographer who goes into the field, and is restricted by funding and other work commitments, does not have. Conversely, our family ties presented other dilemmas causing and Alex and me to work through other personal issues in order to complete this research.

Alex is a strong, independent, and tenaciously stubborn woman. She would not allow her story to be subsumed under my authorship any more than I would allow this to happen. She drew the boundaries around which aspects of her life were private and which were public. Her personal journals were not given to me to read; rather, she selected those portions that she felt were necessary for the dissertation, while other areas were strictly off-limits. The public lecture audio and videotapes of her activism and advocacy work were available to me in their entirety, though how I used them to construct a storyline were under her editorial control. Alex chose the poems and art pieces included, though some at my urging, to reflect feelings and meaning that textual narrative and analytical discussion cannot convey.

Alex's husband, James, has also played a key role in this dissertation. For this reason James was asked to introduce himself and to present a few of his thoughts on this work. As with Alex's narrative, James also was afforded the opportunity to comment, unedited, within this dissertation. His choice was to present a brief introductory paragraph, which I chose to place following Alex's preface. He also wrote a longer essay that is contained within chapter 4, directly following Alex's story. My intention in having both Alex's and James' words precede

mine was to further illustrate their central position within this ethnographic narrative. I wanted to use this visual method to reaffirm to the reader that there are many ways to share power in an effort to give voice to those who are often silenced within oppressive master narratives. I intended to remain in a collaborative relationship with them from the beginning to the end of this project and am grateful that they willingly accepted their positions.

Chapter overview

The layout of chapters two through five open with Alex's story, which is drawn together from her public lectures, personal writing, and our ongoing conversations. For chapters two and three, I first compiled a storyline from the transcripts of her lectures. She then edited it to more closely reflect the narrative elements and life changes that she wanted to communicate. Alex wrote her portions of chapters four and five, rather than working from transcripts of prior lectures. I was asking for her story to include elements that were not in the transcripts. While it may appear at first that Alex's story has a linear and chronological nature, it does not remain fixed within chronological rigidity. There have also been editing changes made by Alex that reflect a new perspective on a certain event, though the influences on the new perspectives are varied and often complex. These serve to challenge the rigidity of the life history method and problematizes with the ethnographic present. Between Alex's sections and mine, she has created scrapbooks of images that add a visual dimension to her story and serve as a bridge between the two stories (hers and mine).

In chapters two through five, my response that follows Alex's story addresses the theoretical foundations for the arguments presented earlier in this introduction. I also engage in reflexive and, at times, personal discussion. Also, I refer to vignettes of Alex's story often in the form of my 'telling her story.' She admits that some parts of her narrative were too painful to speak of, but agreed to their inclusion. This is not intended to subsume her story under my own; rather, it serves to place the narrative clearly within the individual, personal, familial, and academic context within which her/our lives are lived.

Chapter two addresses Alex's initial experiences with HIV and the socio-cultural climate within which she received her positive diagnosis. Throughout this chapter she addresses the growing marginalization and stigma she lived under while exploring the context of her life as a women living with a socially and medically gendered illness. The homosexualization of HIV is examined theoretically in the process of critically deconstructing the role of mainstream institutions in the dominant HIV/AIDS narrative. The chaos of her early years with HIV becomes

evident throughout the narrative though it is interspersed with insights and perspective borne of having lived through the AIDS = Death public perspective.

Chapter three provides critical insights into the impact of welfare disability and its associated marginalization and stigma. Alex cogently narrates her experiences advocating for both herself and her husband through the ever-changing policies and practices of social assistance in British Columbia. The chapter critically examines the embeddedness of the structural marginalization toward people on social assistance by tracing the historical and contemporary treatment of public assistance in Canada and British Columbia. Throughout this chapter an attempt is made to show how historical attitudes towards those in financial need perpetuates stigma and marginalization that, for a person with a compromised immune system, further exacerbates an already problematic situation. The dominant neo-liberal narratives that suggest ‘beggars can’t be choosers’ are examined in terms of their challenge to social welfare as the responsibility of the state.

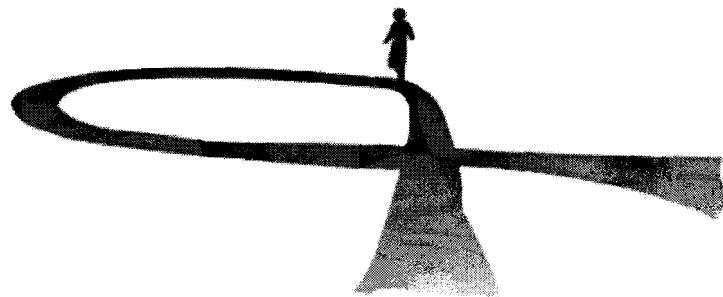
Chapter four explores the biomedical marginalization and socio-cultural constructions of HIV/AIDS and the degree to which these dominant narratives usurp one’s agency. Alex’s narrative provides insights into the problematic nature of how biomedicine subsumes alternative treatments and perspectives. She brings to light the personal cost of HIV being constructed as a sickness of immorality rather than primarily a medical condition. Further, this chapter examines the historical roots of medical anthropology, giving an overview of the various influences that have led to CIMA. It also provides space for James Keating to present his story.

Chapter five focuses on Alex’s advocacy and activism that has guided much of her public work as an HIV-infected woman. Throughout the years she has continuously found ways to challenge the way dominant narratives have infiltrated the worldview and public consciousness defining those who are infected with HIV. Using her narrative, this chapter explores Nelson’s assertions discussed earlier regarding the construction of a counterstory. Drawing on earlier chapters that expose the myriad ways in which HIV is socially constructed and communicated through master narratives, this chapter applies Alex’s narrative as a counterstory challenging many of these marginalizing aspects.

Chapter six concludes my analytical discussions of the theoretical issues raised throughout. As well, it addresses ethical issues that surfaced throughout the research process. Methodologically, collaborative research becomes a key point of discussion here.

In chapter seven, Alex and I have a conversation about the research. In this chapter we comment on and critically examine the process of collaboration on her life story. We explore the goals we began with, how they changed throughout the years of the writing, and how the writing has impacted both our lives. Further, we examine the theoretical foundations applied to the narrative in an attempt to address many of the methodological and theoretical elements involved in collaborative writing between two individuals who have a close biological and social relationship.

Following chapter seven is an epilogue in which Alex provides her closing words on the dissertation and the research process. We had thought that this would be the end. At the formal defence the external examining committee raised a number of issues that warrant clarification and critical discussion by both Alex and me. As a result we have chosen to address these in a post-defence conversation in which Alex does have the last word.



CHAPTER II: HIV: DIAGNOSIS AND DENIAL

I've never before had to sit so close to your doorstep

Although I know you are coming your arrival is always too soon

In watching you work I find your speed terrifying

You remove all hope then back off to let us linger in fear

Treating lives like pawns in your sick game

Never knowing when you will execute your winning move

Bringing to the surface emotion that is alien

Leaving the mind at peak performance as you slowly

drain the life from my body

It is said that greatest awareness is just before death

How unfair to be given insight when I can no longer utilize it.

Alex Keating, 1988

Alex's story

My name is Alex Keating and I am a 39 year-old woman. I have been living with HIV since I was 21. How it all happened for me is that I was working in the West End of Vancouver in a place that happened to have many gay people working there. I started working there in probably 1983 or 1984, right around the time when the AIDS epidemic was really hitting the gay population and was in the news all the time. It was very new. Up until

1984, it was commonly called GRID, gay-related immunodeficiency¹¹, after that the name was officially changed to AIDS, acquired immunodeficiency syndrome. Initially, it was called GRID because it seemed mostly only gay men were getting it. Once enough people who were haemophiliacs or women started being diagnosed with this illness there was enough of an outcry about the name, and the stereotype associated with the illness, then the name got changed.

At the restaurant where I was working, I had a number of friends who were infected and dying from this illness. At that time, people were being diagnosed very late and dying very quickly. I was seeing it firsthand and I knew all about the disease, or what there was to know at the time. I was one of those young women of the '80s who were going around to bars on Saturday nights giving out condoms to people and 'on me not in me' pins which promoted one of the safe sex campaigns of the day. I tried to advocate and educate without passing judgment, telling people to play safe and do safe things. When it came to my personal life, I didn't implement that. I did not have a sense of myself, or enough self-esteem to allow me to negotiate safely. I compromised what I knew to be right for myself and it was a bad choice I can tell you that.

On my birthday in 1986 when I turned 21, I partied in the States with my buddies who were going on a boat cruise. I had a great weekend with lots of fun and I was intimate with somebody I had known for quite a while. I did not practice safe sex. I didn't play safe at all that weekend, not at all. About six months later this friend died. Nobody had known this friend had HIV disease. He had not disclosed to anyone. He was in denial, which is something that happens to a lot of us who get HIV. Sometimes it's overwhelming, you sort of shut down. Most people sort of work through that and start dealing with the illness before

¹¹ Originally referred to as GRID by various individuals working on the new virus in 1982, understanding the syndrome in a cohesive sense was marred by the lack of a unifying name that communicated the variability of illnesses attacking people's immune systems all over the world. Though HIV, believed by many to cause AIDS, was not identified until 1983, at a meeting in Washington DC, on July 27, 1982, members of the US Center for Disease Control, the National Institute of Health and the Food and Drug Administration, as well as many others, agreed upon the need to develop a name that did not focus on one group of people - gays. Acquired Immune Deficiency Syndrome (AIDS) suggested sexual neutrality and the word acquired "separated the immune deficiency syndrome from congenital defects or chemically induced immune problems" (Shilts, 1987, p. 171).

they die. Unfortunately, this friend either didn't or he chose to go out and do what he did. I just knew there was no way I was going to be lucky this time. I knew I had pushed the envelope one too many times and I had gotten myself infected. I didn't want to have to confront the fact that it was true. I avoided going to get tested. I had also seen the impact that HIV had had on my friends and the way they were treated by co-workers, family, medical personnel, and I also had ears and eyes and I saw what was in the media and I read what was in the newspaper.

I will give you a little idea of what it was like at that time. As I said the name had only been changed a couple of years previous to AIDS from GRID and the stigma attached to this illness was still very strong. It was, and still is, being treated as a moral issue and not a medical issue by many people. It was common for the big name religious personas of the day [1980s] to talk about it as being God's retribution for an immoral life¹². Guilt vs. innocence, the victim vs. the deserving. There were many, many people involved in the religious circles that were also very empathetic and realistic in dealing with HIV/AIDS, but there were also those reinforcing the fear tactic. I watched people being ostracized because of this disease. I watched people being left to die alone because their families wouldn't be with them or even claim them after death. When families did claim the bodies one would see a notice in the newspaper saying they had died of cancer¹³.

What was really common around that time, and I think one of the things that kept me from pursuing an HIV test for confirmation that I had this disease, was every few days in the newspaper one could see articles about HIV. The messages included some of the following: beware of mosquito bites or if someone comes to your house with HIV don't let them pee in your toilet or if they use your cutlery, bleach it. Lots of fear-based information was out there that wasn't necessarily true. The media were very powerful in influencing public opinion. People testing positive were being labelled as belonging to risk groups. Gays, prostitutes,

¹² Jerry Falwell, a well-known televangelist in the United States, has been documented as promoting anti-gay legislation during the Regan administration. In 1983 during an ABC documentary called, "AIDS: The anatomy of a crisis," Falwell is recorded as saying, "When you violate moral, health, and hygiene laws, you reap the whirlwind" (quoted in Shilts, 1987, p. 347). Falwell's moralizing about HIV/AIDS has impacted the way in which socio-cultural constructions of those with HIV/AIDS are disseminated.

¹³ See Robin Gorna (1996), Vamps Virgins and Victims: How Can Women Fight AIDS. Pg. 4

injection drug users, and those labelled promiscuous, were stigmatized and stereotyped as belonging to high-risk groups. I knew it wasn't just junkies, gays, and prostitutes who got this disease but I also knew in my heart that I felt guilty about it. I felt very ashamed about the disease and I didn't want anyone to know I might have it. All of this led to an atmosphere where I didn't want to go and get a diagnosis. With all the terrible things happening to people with positive diagnoses, I was afraid of those things happening to me. I didn't get tested. I just went on with my life and went on with my own denial. I can assure you that this gave me a great deal of understanding of how my friend ended up in denial.

At the time that I was infected the modes of HIV/AIDS transmission were being broken down into 'risk groups' and not 'risk behaviours'. Unfortunately they are still seen this way today. This is something that has great impact on the lives of people being diagnosed HIV+. If you contracted HIV through unprotected sex or injection drug use then you were categorized as being in one of 'those groups' and therefore deserving of whatever you got. If you were in one of 'those groups' you were seen as having the illness because of your vices, an illness of choice. Those who contracted HIV through blood transfusion, haemophilia, or mother to child transmission were seen as innocent victims. This opened up another can of worms because it is said that you can choose not to do drugs or choose not to have unprotected sex but the events in people's lives that lead them to make the choices they do aren't quite as simple as saying you can or you can't.

People became stigmatized and stereotyped based on the above groups. The cause and blame of this disease was being separated into groups based on the type of people who would get HIV instead of identifying the specific actions and behaviours that result in infection. But that's a really dangerous thing when you start separating people into groups it is easy to see them as disposable and dismissible. The way I see it, it should have been broken down is into risk behaviours not risk groups. The use of unclean, or sharing, IV drug needles, the activity of engaging in unsafe sex, those types of things are what lead to the spread of this disease, not belonging to a specific group.

One of the main public education campaigns of the early 1980s was AIDS = Death. They were trying to get the message out there and were using a fear tactic to try and get people

to be aware and, believe me, that fear tactic worked. Today you see campaigns that say Silence = Death. I have no problem with that one. AIDS = Death, that one caused me a lot of grief. I lived that one for a long time, believing it. It made me very hesitant to confirm my diagnosis. I didn't want it to be me so I went into denial. I stopped getting tested.

I kept working. I decided I wanted to go to school so I went to Douglas College for a couple of semesters in 1988 to re-learn how to study and write for school, as I had been away from school for 7 or 8 years. I then applied to Simon Fraser University (SFU) to study criminology and sociology. I was like many students today, I was going to school, working, struggling through starting my life, and making plans for my future. While going to Douglas College I came across a friend of mine, James, whom I'd known for a few years and wanted to date. He did have HIV and I knew I needed to find out what my status was so there would be no question as to where my disease came from. James and I began to date, then to live together in the West End of Vancouver while I worked and went to school. My application for admission to SFU, as a mature student, was accepted. To make this work I quit my job downtown. I got a job in Coquitlam and we moved into residence at SFU in Louis Riel House. I began going to University.

When I went in to the campus health clinic, the doctor I was seeing there was just excellent but unfortunately they were very ill-prepared to deal with me. Having not ever tested anyone for HIV before she had to check what tests to order. At this time it took about three weeks to get results back. Those were a terrible three weeks. I went and got tested early in December and on December 23rd I got a phone message on my answering machine from the Simon Fraser University (SFU) health clinic saying they had been trying to contact me for a couple of days. They asked that I contact them immediately because they had my AIDS test results. I knew by the way she was approaching me on this message that my test had come back positive. My sister, who also lived in residence at Simon Fraser University, got a message the next day on her answering machine when she returned from Hawaii saying, "We are trying to get hold of your sister and we have her test results and she must contact us."

From day one, all of my fears had come true. I was treated differently right from the beginning. The marginalizing started right from day one of the diagnosis. This disease was

treated differently. Why did this receptionist have all my test results? Why did she know I had been tested let alone have access to my test results? She should have known no more than my name and my medical number and what I chose to tell her. Right from the beginning, it was different. In my gut, I knew all my fears would be real. I just thank God they didn't have all my other family member's phone numbers because I'm sure they would've kept calling until they got hold of somebody. Needless to say, my choice of whether or not to disclose my HIV status was taken away at that point as far as my immediate family went. I never did actually go back to the SFU health unit because I knew what my results were at that time. Since then I have been retested and it was reconfirmed.

If I can get any piece of information about testing out when I give presentations, it is don't get tested with your own doctor unless you are very comfortable with him/her. Even then I would strongly suggest that you go to an STD clinic because there you have the choice of anonymity. The best part is that they book you a return visit to get your results at the time you are tested. They also counsel you before and during testing. You can't get your results over the phone, and you won't get them on your answering machine. They make you come back in to get them. That way they have the contact with you so they can begin intervention from day one, even if that intervention is someone saying that a positive result doesn't mean you're going to die tomorrow. I didn't have that. My sister getting the message on December 24th shouldn't have happened. It showed me that the discrimination that I had witnessed my friends living with and my own fear of what this disease would mean to my life had begun. That made me scared so I just shut down. For a few years I stayed away from all doctors, I didn't want anything to do with doctors.

After I got diagnosed with this disease I continued working and going to school. James and I did get married in February 1990 and have been married ever since. I continued for a while but emotionally, I tried to shut myself down and put it out of my mind and get on with my life. This was really difficult and, though on the outside I looked like I was really together, on the inside I was pretty much a mess. I started getting sick and that really frightened me. What happened was I stopped participating in school. I wouldn't get the work done or if I had, it wouldn't be up to par. The school was really good; they forgave me a

semester where they deleted it from my record so that it wouldn't affect my grade point average. Realizing that I would have to ask to be forgiven another semester, I felt it wasn't fair to them or me so I withdrew from school.

I did continue to work, but a year or so after that I got really sick. I had been having a lot of respiratory problems. They were keeping me down, making me fatigued and reducing my immune system. Then I started having cancer problems. I had two different surgeries for cancer. Then after the third one, I was unable to go back to work. That was a real shift in my perception of myself and who I am. Through the process of getting sick, when I say I had shut myself down, I also shut my world down. I became very isolated. I became very self-destructive. As I started getting sicker, and having watched many people die from this disease, I didn't want to go the way I had seen them. There are some really sad ways to die from this illness; it's not very pretty. I think for me the real clincher was when a friend of mine who was in his early '50s was dying and they said he would last nine weeks and he lasted almost nine months. He had severe AIDS dementia, severe wasting syndrome, and he had no control over his bodily functions. It was common to walk into his room and he would be sitting in a corner having pulled off his diaper, pulled out his catheter, and not know who you were, with feces and urine on his body. Throughout his decline, there were moments when he was lucid and I saw his pain and shame at what he had become. Seeing his loss of dignity broke my heart and made me so terrified. At moments like this, I didn't want to be there, not in his room, and not when facing my own death.

Based on my conversations with the doctor at SFU when I was being tested, I was given the impression that a positive diagnosis meant that I had a couple of years to live. Fortunately, she was wrong, but it really did affect me. I knew that it wasn't necessarily the truth that I was going to die in two years, but, in the long run, it really did have truth to it. There was no cure, no real treatment. Unfortunately, by internalizing this perspective I was making it true sooner than it had to be. I shut everybody out and waited to die. I didn't die. A year or so later I was still alive and I was a mess, a serious mess. Of the people that I knew in the mid 1980s only three of them were still around in the mid-1990s. This is really frightening. They are all in my age group, between 30-40. By the time I was twenty-five, I

could count on less than one hand the people I had known for more than five years, most of my friends were dead.

As I said earlier, a lot of the death I had seen was not very pretty. I did not want to lose my mind, I did not want to not know where I was, and I did not want to wear a diaper. I did not want to waste away. I have to admit that I really hoped I would die, that it would just be over with and I would be taken. It's not that I didn't want to live; I just didn't want to die in a really bad way. I guess there are two things I really wanted, one was not to die alone and the other for it not to hurt. I still feel those things very strongly today. I don't want it to be too painful or ugly and I don't want to be alone when it happens. I don't think that is too much to ask for.

During the early 1990s, I had been very sick and was getting groceries delivered from AIDS Vancouver Food Bank by an elderly woman volunteer. She was like a grandmother to me because of the relationship we had built up. She was such a wonderful woman in her mid-seventies who would show up once a week and give food, encouragement, and hugs. One Friday, she showed up and told me there was a new organization that had been started and it had six members. It was a woman's support organization that was having a retreat for three days on Bowen Island and she had signed me up and I was leaving the next Friday at three pm. This would have been February 1993. I really credit her with saving my life.

The Bowen Island retreat was a gathering of 26 women who had HIV and although I had been living with HIV for six or seven years, I had never met another woman face-to-face who had the disease. On one occasion in 1990, I had called an AIDS help line and left my number asking for an HIV-positive woman to call me back. A woman did call and we talked for a half an hour or so. This was my only contact with another woman who had disclosed she was HIV-positive. As fate would have it, I met this woman a couple of years later at this Bowen Island retreat. Meeting other women living with this disease was a huge thing for me. It allowed me to look at all these other women and internalize the fact that we were just women. We had not done anything wrong. We were not immoral. We did not fit the stereotype. There were a few who identified IDU, street work, and sex trade work. There were some who were married and identified no risk behaviour, never had an affair, never used

a needle, and some who had simply had unprotected sex. We were just a really normal group of women who had been doing nothing more than just being human, doing one of the most human things that we do which is being fallible and making mistakes. Trial and error is a big part of life. Before the retreat I felt ashamed of the fact that I had gotten this disease. I would lie about being sick and wouldn't tell people that I had HIV. I would tell them I had cancer. You have to be careful what you tell people because I kept telling people that I had cancer and I did get cancer...three times.

What this retreat allowed me to do was to pick my head back up for starters. I really had a perception shift, a change of focus. I went from dying from AIDS to living with this disease. I wanted to get on with my life and to plan for my future. After three days of doing workshops, and sharing, getting massages, and going for long walks I came home and within a week was volunteering for the organization.

Within weeks I was doing presentations and media interviews and within months I was going to conferences and speaking to doctors, financial aid workers, and home support workers, educating and sensitizing around HIV issues. This work allowed me to pull my shoulders back, hold my head up, stop telling everyone I had cancer, and stop being ashamed of what I was living with. It was a huge step to admit that I had HIV and to do it with my head up in a strong voice. What it made me realize is that there is no such thing as a risk group, there is no such thing as a group of people who can get this disease. It is not gays, it is not IDU.

There are risk behaviours such as using unclean needles and having unprotected, therefore high-risk sex, the sharing of body fluids. Those behaviours in any group of people can result in this disease. My work with other positive women helped me to realize that the prevailing stereotype and fear-based information that had defined HIV/AIDS was not the truth. Once I internalized this I got back to living.

Alex's scrapbook



August 2, 1986

Photograph 4: Alex's 21st birthday¹⁴

*My 21st Birthday
Party aboard the
Goodtime II*



Photograph 5: Goodtime II

¹⁴ Photographs 4 and 5 by permission of Alex Keating.

Diva



Photograph 6: Alex Keating,
1987¹⁵



Photograph 7: Alex Keating, 1987



Photograph 8: Alex Keating,
1987

Divine

¹⁵ Photographs 6, 7, and 8 by permission of James Keating.

Laura's response

When Alex and I first started having conversations about HIV/AIDS it was in the mid-1980s. Living in the West End community in Vancouver she would recount her experiences of supporting friends who were ill and dying, and of living with a growing fear of the spread of HIV. Unbeknownst to me, she had already been infected but, as she stated, was in denial. My son and I moved to Vancouver in September of 1988 and before this, I had seen Alex only a few times a year throughout the 1980s. I remember feeling very good about the life she was living and of seeing it as much easier than her tumultuous teenage years. She communicated that she was a strong, vibrant, young woman. Her communities of friends were very creative and artistic; including talented performers and activists. She developed close relations with many of her co-workers and, as a creative woman, had found a niche within which she could develop artistically.

When HIV/AIDS began to surface with increasing regularity within her community, she became actively dedicated to promoting HIV awareness. I remember a coat that she used to wear that had a large safety pin on the lapel and the pin was a significant reminder to 'play safe.' She spoke of her experiences through a filter of growing knowledge that was borne from living in a community that was one of the early centres of HIV infection in Canada¹⁶. Alex's immersion into the stigma and marginalization attached to a positive diagnosis did in many ways precede her HIV-positive confirmation by a number of years. The circumstances of her life that drew her to live in the West End of Vancouver to some degree resulted from a need to find safety, security, and acceptance within a circle of predominately gay and bisexual friends¹⁷.

Born the youngest of five children to lower middle-class parents, Alex was an adorable and spirited little girl. Loved by her siblings, she was dressed up as a princess and paraded about as 'our baby' but years later, when she was struggling with coming adolescence, most of her siblings were gone from home, having started their own adult lives. By the time Alex was five, our home was often a place of turmoil as our parents laboured long hours outside of the home and we children were left to look after one another against a backdrop of sibling rivalry. Since Alex was the youngest by six years, she faced her adolescence and teen years without the closeness that

¹⁶ A summary of HIV in Canada, based on cumulative surveillance data from November 1, 1985 to December 31 1995, lists British Columbia as having the second highest incidence of HIV-positive test results in Canada (24.1%), preceded by Ontario at 45.4% (Daley, 1997).

¹⁷ The West End is a densely populated community in the downtown area of Vancouver, British Columbia. The community is characterized by diversity of ethnicity, income, sexual orientation, and occupation. Within the West End is a well-established gay community with varying degrees of institutional completeness that affords residents certain freedoms of lifestyle that are not so readily apparent in other areas of Vancouver.

the other four of her siblings had shared. In these years, our mother communicated clearly to her daughters the low self-esteem she felt as a wife and a woman. She fought a battle with her weight, and suffered silently while her flirtatious and extroverted husband adopted the public persona of everybody's friend. Being put on her first diet by our mother by the time she was in grade four, Alex began an association with low self-esteem and body image that certainly laid a groundwork for her inability to negotiate safely in intimate sexual circumstances in her early 20s.

By the age of thirteen, Alex was in the adolescent psychiatric unit at Foothills Hospital in Calgary, Alberta. She was struggling with her own personal demons that resulted, in part, from the family dynamic within which she grew up. As Alex's parents lived four hours away in Cranbrook, British Columbia, the staff in the psychiatric unit obtained permission to reward her progress with an overnight pass to go home with her friend, also a patient in the unit, whose parents lived in Calgary. That evening the two 13 year old girls went to the home of an older man who was dating Alex's young friend. At this home, Alex was given alcohol and later gang-raped by a number of adult men while the rest of the adults watched the show. Witnessing this, Alex's friend fled the party alone. During the rape, Alex passed out. In the morning, realizing what had happened, Alex attempted suicide with broken glass. An adult woman in the home, who was also present during the rape the prior evening, wrestled the glass from Alex, and said, "What are you crying about, you seemed to be having a good time last night." Managing to dress Alex and take her from the home, the woman dropped her off at the front entrance to the hospital. Alex expressed, in recounting this story to me, that she was shocked how the woman acted as though nothing improper had gone on, and that this group of adults was so blasé about raping a child.

As a sexually abused teenager with nowhere to turn, Alex internalized her powerlessness with men and her fear of sexual abuse. Believing that she was a bad girl, a belief that was reinforced by her actions within her family and social setting, Alex struggled to hide her pain in drugs and alcohol and looked for an escape from home. At fifteen, she moved to Victoria, British Columbia, to attend hairdressing school. After returning to Cranbrook to complete her apprenticeship, she moved to Vancouver and by 1984 was living in the city's West End. Many of the gay males who made up her circle of friends admired her in a non-sexual way and gave her love without sex, friendship without judgment, and a community within which she could heal from her past.

It was in this setting that I began to see my sister in a different light from the angry and confused little girl that stayed home when I left in 1977. During 1986, I visited briefly with Alex in Vancouver in her West End apartment. Her life seemed so exciting to me and, because I did

not know of the risks of HIV infection for women, I felt little fear of her contracting HIV. I was proud of her activism and awareness about HIV/AIDS in her community and of the gentle and loving way she cared for her friends who were becoming sick. Regardless of the news that HIV could also be transmitted through heterosexual sex, I naively assumed that my sister would only be having “ordinary (heterosexual) sex” (Patton, 1994, p. 10) and not be having sex with any of the bisexual men in her circle and, thus, she was safe. My own ignorance of HIV transmission among women reflected the homosexualization of HIV and AIDS that was prevalent in the master narrative at the time. With my sister’s positive diagnosis, HIV/AIDS entered my life and, as a young single mother and social science student at SFU, I began to discover how many myths made up ‘my truth’ about HIV/AIDS.

The homosexualization of HIV/AIDS

In the late 1970s and early 1980s, a syndrome of illnesses resulting from immune suppression began to gain the attention of medical practitioners in North America. Although there were 34 cases reported among Haitian immigrants to the United States by early 1981 (Stine, 2000), the medical and media focus remained on gay men and a lens of morality and judgment descended over public consciousness regarding the spread of what came to be called AIDS. The focus of early AIDS biomedical research and subsequent knowledge centred around lifestyle activities of gay men and included the use of poppers¹⁸, attending bath houses, having multiple sex partners, and various mechanisms of sexual stimulation that were used in gay male sex. Regardless of the activism within many gay communities that was aimed at attaining sexual freedom and legitimacy, “the homophobic narrative of degeneracy could argue both that homosexuals ‘recruit’ (and will ‘spread germs’), *and* that the homosexual lifestyle makes ‘unnatural’ impositions on the body which weaken it” (Patton, 1994, p. 9). Sexual activities and freedoms exercised within the gay and bisexual communities were becoming the target of medical, political, and religious moralization and stigma that was played out within the mainstream media (Elwood, 1999; Shilts, 1987; Treichler, 1999). People were getting the message that the new disease was one of sexual immorality and lifestyle and as a gay disease it would not harm heterosexuals. In trying to make sense of a disease that was alleged to attack the

¹⁸ In relating AIDS to a gay lifestyle, the use of amyl nitrate, an inhalant believed to heighten orgasms and often associated with homosexual sex, was researched as to whether it was contaminated and therefore associated with AIDS. Studies conducted by the CDC in the early 1980s refuted the contaminated popper theory. See Treichler, 1999, for a more full discussion of the amyl nitrate theory.

gay lifestyle, David Black in a *Rolling Stone Magazine* article asked, “How could a disease pick out gays? That had to be medical homophobia” (1986, p. 40 quoted in Treichler, 1999, p. 21).

Regardless of sexual orientation, the politics of knowledge of AIDS in the early years further exacerbated the oppression and marginalization of many people who were becoming infected at the time. Open public discussion of sexual activity and sexual risk was not a common part of the socio-cultural fabric in North America and many dismissed the new disease as merely a gay plague. “Until 1983, articles on HIV/AIDS could be located under the listing of Homosexuality in the *Times Index* and also in *The Reader’s Guide to Periodical Literature*” (Baker, 1986, p. 243), both mainstream sources of publicly-accessible information.

Further compounding the development of master narratives that were articulated as common sense AIDS discourse were the early biomedical definitions of HIV as primarily another sexually transmitted disease (STD). While HIV can be sexually transmitted, the more appropriate description of it as a blood-borne disease did not infiltrate the public consciousness for many years. “To present HIV as an STD is to disregard other potential transmission scenarios, with possibly fatal consequences, and to locate HIV in an already stigmatized category of diseases” (Wilton, 1997, p. 4). Hatty & Hatty (1999) provide a thorough discussion of the historical stigmatization of STDs by tracing the management of polluted bodies within the Western world. Looking at socio-cultural and medical responses to syphilis in 1497, the authors cogently explore the deeply rooted beliefs that STDs have been associated with immoral behaviour, unclean bodies, sin, and social scourge. Throughout their analysis, one can clearly see the historical institutionalization of stigma attached to STDs that was not only present in the beginning of AIDS, but is still prevalent today.

With injection drug users (IDU) as the next group to show increasing rates of diseases related to immune deficiency, moralizing, stigmatizing, and alienation were even easier to entrench within the master narratives and the concept of risk groups became deeply embedded in the public consciousness. “By 1982 and 1983, the disease was reported in haemophiliacs, adult heterosexuals and children” (Stine, 2000, pp. 33-34). Regardless of the increasing diversity of those being infected, mainstream media publications, television and the religious and political right were promoting anti-gay, anti-Haitian furor. IDU were seen as deserving of their sickness, as it was common to hear the commentary that AIDS was God’s way of punishing wrongdoers.

Many public figureheads, such as politicians or religious leaders, responded to the sexual risk associated with the spread of HIV/AIDS by espousing sexual abstinence and moral behaviour as mechanisms of prevention. Suggesting that these preventative strategies reflected both the

citizenry and the church set a dangerous precedent. Certain individuals often used their public position and resulting political power to present a personal opinion that came to be represented as the belief of the people (Farmer & Kleinman, 1989; Weitz, 1990) and thus made up core beliefs embedded within the master narratives. Reverend Billy Graham, a well-known televangelist and spiritual guide to many American presidents and other influential people, was quoted as saying, “AIDS is a judgment of God” (Graham quoted in Stine, 2000, p. 34). Reverend Jerry Falwell, another well known televangelist and outspoken AIDS critic “stated that AIDS is God’s punishment, the scripture is clear, ‘we do reap it in our flesh when we violate the laws of God’” (Falwell quoted in Stine, 2000, p. 34).

In 1575, a French surgeon stated that it was “God’s wrath, which allowed this malady [syphilis] to descend upon the human race, in order to curb its lasciviousness and inordinate concupiscence” (Pare quoted in Hatty & Hatty, 1999, p. 207). Social constructions leading to the moralizing of certain diseases, whether being voiced hundreds of years ago or today, have become embedded in the social fabric to the point that they infiltrate perceptions that indiscriminate organisms are morally discerning. Social constructions, like those above, became part of the accepted discourse on HIV/AIDS. As a result it was very easy to group people together and, as Alex earlier suggests, to dismiss them as deserving of the outcome of their own behaviour regardless of the socio-cultural context within which each infected individual lives. Blaming the victim is a hegemonic process. In the case of HIV infection, “what societies choose to call risky is largely determined by social and cultural factors, not by nature” (Bloor quoted in Clark, 1999, p. 14).

The socio-cultural construction of HIV/AIDS

Treichler (1992) suggests that when attempting to analyze a cultural construction we must see it as:

[A] way of talking about how knowledge is produced and sustained within specific contexts, discourses and cultural communities; it takes for granted metaphor and other forms of linguistic representation; it presupposes that ideas are produced out of concrete contexts and have concrete effects; it takes for granted hermeneutic activity; it is a complex of ideas and operations sustained over time within a given community; hence it is institutionalized. (p. 89)

Patton (1994) suggests that:

[S]ocial construction theory, [is] now widely accepted as an appropriate framework for understanding the complex, mediated experience of the HIV

epidemic. This approach assumes the social categories have been constructed through historical and social processes, and in such a way that the ideological and institutional interests served by a particular construct are erased and the categories appear to be natural. (p. 4)

Throughout the first decade of AIDS, influential social, medical, and political institutions acted in such a way as to lay a foundational master narrative for the way in which many came to articulate *expert* knowledge about HIV/AIDS and the risk factors associated with it. Politically, the biomedical discovery of the virus (1983) believed to cause AIDS became enmeshed in a battle between the research teams of Luc Montagnier of the Pasteur Institute in France and Bob Gallo of the National Cancer Institute (NCI) in the United States as to which group first discovered the retrovirus later to be called HIV (Shilts, 1987). The legal battle that ensued resulted in a delay in reporting the discovery while increasingly more people became infected with HIV and died from AIDS (Corea, 1992; Shilts, 1987). What one can learn from the 1980s is that the taken-for-granted information that was being promoted about HIV and AIDS at the time reflected the political economy within which both AIDS research was being conducted and the resulting information was being disseminated. As Treichler (1992) earlier suggests regarding cultural constructions, HIV/AIDS information was seen as deriving from objective research (a concrete context) and having the effect of defining not only the victim but also the context within which transmission would take place (a concrete effect). The taken-for-granted assumptions of objectivity of the scientific method of compiling AIDS data became absorbed into AIDS discourse such that when this was called into question, those ‘dissenters’ were effectively silenced.

Biomedically, the field was divided, from the beginning, between immunology and virology. Goldstein (1997) crudely defines the difference between them such that:

Immunology upholds an idea of health based on the body as an ecosystem; in this model, health is balanced and sustained by careful management of the individual human body. By contrast, virology typically seeks to restore the individual human body to health by embarking on a mission to stop killer cells from replicating inside it. (p. 3)

These biomedical paradigms, while powerful reductionist models of constructing disease, presented little in the way of consideration of the complexity of socio-cultural factors that also influenced the transmission of the virus not only in North America but also around the globe. The “overemphasis on virological research also enabled scientists to discount the growing clinical

perception that HIV disease was expressed differently in women than in men" (Patton, 1994, p. 10).

Within academe, the process of research and publication has always been subjected to gate keeping such that research grants and papers to be published must first be vetted through a review process whose panel of reviewers is made up of experts in the field. With HIV/AIDS being a new area of research, the gatekeepers were a very small group of individuals and organizations who supported proposed research and publications that did not challenge the status quo. Individuals who began research among HIV-infected women or wanted to research factors other than HIV as the sole cause of AIDS were finding their grant proposals rejected and their papers not being published (Corea, 1992; Herdt, 1992; Shilts, 1987). Treichler (1992) suggests that a careful review of journal literature on HIV reveals the way in which Gallo (NCI) and Montagnier (Pasteur Institute), as co-discoverers of HIV, were able to stake out and control their academic territory by citing each other's work. In doing so, they gained an "early (if ultimately only partial) control over nomenclature, publication, invitation to conferences, and history" (p. 77).

Those being denied access to research funding included medical practitioners, public health officials, and social scientists who wanted to diversify the field of HIV studies. Some of the areas of interest were the spread of HIV among women, and alternative socio-cultural and psychological indicators of risk of HIV infection. By wanting to expand the knowledge of HIV beyond the biomedically-based Center for Disease Control (CDC) surveillance data, many researchers were seen as challenging the supremacy of the AIDS experts of the day. Repeatedly, the requests for the HIV/AIDS research beyond the parameters defined within the master narrative were ignored.

An example takes place in 1990 in New York. Dr. Anke Ehrhardt and a team of researchers submitted a grant proposal to the National Institute for Mental Health (NIMH) in the United States to conduct a comprehensive three-year study on how HIV affects women, primarily those in inner-city areas (Corea, 1992). Having formerly received the largest-ever multimillion-dollar research grant from the NIMH, as well as supportive critical commentary on the research design from her peers, Ehrhardt felt confident the proposal would receive a positive review.

Quite to the contrary, the NIMH reviewers resoundingly rejected the proposal¹⁹.

Also worth mentioning here is the powerful reaction within the dominant HIV narratives toward those who question HIV as the sole cause of AIDS. Perhaps most notable among the dissenters is Peter Duesberg, a molecular biologist at the University of California, Berkeley. Believing that “AIDS is caused by non infectious agents”, for example, social factors, or ‘lifestyle’”(in Watney, 1994, p. 258), Duesberg states, “I have been excommunicated by the retrovirus-AIDS community with noninvitations to meetings, noncitations in the literature and nonrenewals of my research grants, which is the highest price an experimental scientist can pay for his convictions” (quoted in Stine, 2000, p. 42). Duesberg further believes that the drug companies have invested so much money in the status quo of AIDS research that they can’t afford to be proven wrong and thus will continue to silence those who challenge the current research paradigms. As noted by Stine (2000), Duesberg has not received any new laboratory grants since 1987. In an attempt to further discredit dissenters, Duesberg and his supporters have been targeted for activities in their personal lives that have little to do with their position regarding HIV/AIDS research²⁰.

Suggesting that HIV is not the cause of AIDS has led to passionate responses from persons in the medical community. Canada’s leading AIDS researcher, Dr. Mark Wainberg, in a scathing interview in which he suggests that “those who maintain that HIV does not cause AIDS are a criminally responsible public health menace” and should be jailed, suggested that an HIV-positive mother, whose children were taken away after her refusal to give them HIV drugs, was somehow responsible for their ill health (quoted in Ko, 2000, p. 53). Though he maintains, shares in, and receives considerable research funds from pharmaceutical companies, Wainberg believes this has no influence on his position.

Like Duesberg, Christine Maggiore, an AIDS activist and organizer of Alive and Well AIDS Alternatives, a non-profit organization in Burbank, California, has also taken a very public

¹⁹ See Gena Corea (1992) for an account of the commentary by the NIMH reviewers as to why the research proposal was not seen as worthy of funding. Further, Corea’s book provides a plethora of examples of the ways in which research on women and HIV/AIDS was denied funding throughout the 1980s and early 1990s.

²⁰ Gerald Stein, who authors a yearly series, *AIDS update*, has been writing about AIDS since 1981. In his discussion of Duesberg, Stine also writes of Kary Mullis (Nobel prize winner in chemistry for his invention of the polymerase chain reaction) who supports Duesberg’s theory. Perhaps to discredit such a notable supporter of Duesberg, Stine chose to write that Mullis’ publication, *Dancing Naked in the Mind Field*, “covers his disbelief that HIV causes AIDS and, among other things, his passion for hallucinogenic drugs and his belief in flying saucers” (Stine 2000:44). Clearly, Stine’s objectivity and political agenda need to be called into question as to why this information is included and, further, how his (Stine’s) opinions have contributed to the social construction of certain academics as dissenters.

position against the biomedical community for their position that HIV is the sole cause of AIDS (Maggiore, 1997). Encouraging people to stop taking AIDS medications, Maggiore has the support of South African President Thabo Mbeki in the call for more extensive research to be conducted regardless of the “5,000 flabbergasted scientists [who] signed a declaration calling the laboratory evidence clear-cut, exhaustive, and unambiguous” (France, 2000, p. 47). There is little patience within the dominant AIDS discourse for alternate theories such as those discussed above.

Women, limited visibility, and HIV/AIDS

In the early 1990s, HIV/AIDS was still being presented as a disease that infected gay white men though globally this was not the case at all. Infection rates were growing among IDU, babies through transmission from the mother, women who had sex with infected men, women who had sex with infected women, those who had received blood products through infusion or clotting agents, and those who had become infected in work-related incidents. The knowledge existed by the early 1980s that HIV was a virus (like any other virus). It did not discriminate based on race, age, or gender but this information was still not being acted upon in a proactive way by mainstream institutions. “HIV had been studied primarily as a biological rather than social or cultural phenomenon in the United States [and Canada], and as a male virus in female bodies” (Goldstein, 1997, p. 1). Gender-biased rhetoric and its subsequent action that constructed AIDS as a male virus paved the way for misinformation and marginalization to blanket those millions of women who would become infected with HIV. The political nature of the social construction of HIV as a male virus is exemplified in tracing the development of AIDS surveillance data and the resulting exclusion of women from drug trials.

The arguments being presented by funding and research agencies that justified the lack of resources being put forward for both researching women with HIV/AIDS or including women in drug trials were often convoluted and based on inadequate information or on maintaining the status quo. On the one hand, the lack of statistical representation of women among those infected clearly indicated that, compared to men, women showed less of an incidence of HIV infection. By 1990 in Canada, AIDS surveillance reflected “a homosexual predominance, with 76.6 percent of the adult AIDS cases reported to date having homosexual or bisexual activity listed as the sole factor” (Hankins, 1990, p. 6). When one looks at the CDC AIDS surveillance definition prior to 1993, “it did not include a single female-specific HIV-related condition. In January 1993, under intense pressure from feminist health activists, the surveillance definition finally expanded to

include cervical cancer, which had gone unrecognized in positive women since 1981" (Goldstein, 1997, p. 8).

Given that AIDS is a syndrome of illnesses that varies from person to person, and between genders, it is not surprising that the homosexualization of HIV did not include women's gynaecological manifestations of the syndrome in the surveillance definition. Women appeared to have a lower incidence of AIDS than men. Not only did this reflect the "male bias in AIDS diagnosis" (Larkin, 2000, p. 138), but also once the definition changed to include invasive cervical cancer, "the number of reported female AIDS cases in the United States doubled in a single year" (Farmer cited in Larkin, 2000, p. 138). There is evidence that cervical cancer, if detected early, is highly treatable and need not be life threatening (Goldstein, 1997, p. 8). Sadly, we may never know how many HIV-positive women died because of prolonged and/or undetected cervical cancer that was not accepted as an opportunistic infection associated with AIDS prior to 1993. One is left to question the degree to which the skewed AIDS surveillance data, upon which policy was and is developed, has rendered many women's AIDS-related lives and deaths invisible.

With HIV being defined, biomedically, as a terminal illness for which there is no cure, one course of action within medical research communities has been to focus on treatments. The political economy of AIDS drug research is aimed at maintaining the status quo of gender bias. While in North America sexual transmission of HIV between men who have sex with men is the most commonly occurring source of infection, this is not the case globally. Heterosexual transmission is the dominant mode of infection globally with the direction of infection being more commonly from men to women. Given this trajectory of infection one could question the efficacy of drug research that has historically ignored women in all stages of its clinical drug trials not only in North America but around the globe as well.

Many of the drugs that have been and are being developed, at great expense, are based on male responses to HIV/AIDS and are being prescribed to women without accurate knowledge of how they will react. Research reveals that adverse drug reactions are the fourth leading cause of death in the United States (Lazarou, Pomeranz, & Corey, 1998 quoted in Corrigan, 2002) and that women experience adverse drug reactions more frequently than men (Corrigan, 2002). Prior to 1993, women were routinely denied access to participate in the clinical trials of drugs being developed to treat HIV. Corrigan (2002) has examined the variety of political and ethical positions of many stakeholders, including pharmaceutical companies, physicians, and activists regarding women's exclusion and inclusion. The rationale for the exclusion of women from

clinical trials in the phase one and two stages was based on a number of factors. Critical was the potential liability associated with women's offspring being impacted by the drugs if the women were pregnant during the drug trial, if the drugs affected the offspring, and if the offspring chose to sue at a later date. Further barriers to the inclusion of women included "the concern that variations in hormonal status will affect laboratory test results and the possibility that fluctuations in the response of surrogate markers in women at various stages of the menstrual cycle, or while taking oral contraceptives, might affect inferences about treatment effects" (Hankins, Lapointe, Walmsley & the Canadian Women's HIV Study Group, 1998, p. 1364). Biomedically, "[w]omen's bodies are conventionally viewed within pharmacology as messy and unstable...and are referred to as 'sub' or 'special populations'" (Corrigan, 2002, p. 49), and thus were not convenient drug trial participants.

By the mid-1990s, most of the clinical drug trials involving women were aimed at reducing the vertical transmission of HIV between mother and child. The goal was the protection of the infants regardless of the fact that three-quarters of the babies born to infected women will be HIV-negative. At the same time, it is increasingly likely that the mothers will die from AIDS complications (Murrain, 1997, p. 66). In 1993, the National Institute for Health (NIH) in the United States mandated that diverse populations must be recruited for medical research in federally-funded projects, thus the NIH Revitalization Act (1993) was designed to address issues of exclusion and invisibility of minority groups and women from clinical trials and medical research (Roth & Hogan, 1998). While a politically astute move, the Revitalization Act did little to improve the inclusion of women in private-sector clinical trials, though there were minimal improvements in federally funded projects. Given that major research was being conducted in the United States, these policies had minimal impact on Canadian women and their continued invisibility in Canadian AIDS treatment research. For many Canadian women, living with HIV meant medical marginalization, gender discrimination, increasing poverty and stigmatization, being denied compassionate participation in clinical trials, and accessing services that were largely aimed at gay males with HIV. In 1996, the Medical Research Council of Canada stated that, "an urgent need exists for studies of the factors that impede or enhance the recruitment of women into clinical trials" (Hankins *et al.*, 1998, p. 1360). Using data that resulted from the Canadian Women's HIV study in which 413 HIV-infected women were tracked through their clinical visits and varying rates of participation in drug trials, Hankins *et al.* (1998) found that, regardless of the call for increased inclusion of women, there were/are still many barriers to their drug trial participation. Beyond those listed above, they found that ethnicity, education, and geographical location were also factors needing to be addressed.

The socio-political and biomedical climate within which Alex received her HIV diagnosis was one that was driven by public health campaigns promoting AIDS = Death and that resulted in her “induction into a league of loathed and fearsome persons” (Elwood, 1999, p. 5). The role of the media, as gatekeepers to the rhetoric of AIDS, was one of moralizing and fear mongering. Alex knew that the stigma and marginalization she would face because of her HIV infection had begun with the first call from SFU Health Services. That she had been infected through unsafe sex would be deemed by many to be her own fault. There would be little sympathy for her as she attempted to understand the cruel assumptions of those who would judge her as deserving of the HIV because she knew about safer sex but was unable to negotiate safely for herself. A disease that targeted *immoral behaviour* had infected her. There would be little interest in personal history or personal pain, the die was cast and the judgments would be swift.

Women, AIDS, safer sex, and sexual abuse

In discussing women in the first decade of HIV/AIDS, Gena Corea (1992), through her poignant writing, develops a thesis based on a growing body of work exploring the link between experiences of sexual abuse and an HIV-positive diagnosis, whether the mode of HIV transmission or risk activities are listed as sexual or IDU or both. Her book, *The Story of Women and AIDS: The Invisible Epidemic*, reveals that sexual abuse in a woman’s early life inhibits her ability to negotiate safe sexual encounters for herself. This finding is compounded by society’s oversimplified and erroneous dichotomization of a woman as either a whore or a Madonna (Hatty & Hatty, 1999), while promoting images of a successful woman as sexy and inviting. Compounding this are the biomedical communities that ignore women as anything but vectors of disease.

Patton (1994) illuminates this discussion by suggesting that women were not rendered invisible during the first decade of HIV, rather they were divided into “women-who-do-not-count-as-women” categories that included non-white women who engaged in ‘exotic’ sexual behaviour, prostitutes, IDU, and women who had sex with IDU. This was set against those who ‘counted’ being portrayed as middle-class white women who engaged in ‘ordinary’ (penile/vaginal) heterosexual sex and were led to believe they were not at risk. While these women might not be seen as a risk group, once a diagnosis was delivered, many no longer could find shelter within their protective middle-class worlds. Ethnicity and status were not always guaranteed protection from moral judgments embedded within HIV master narratives.

The media, as gatekeepers to the rhetoric and marginalized images of women and HIV infection, served to communicate to the public that infected women were/are a threat not only to men but also to the moral fibre of society²¹. “This representation has contributed to widespread discrimination, with women being positioned as ‘dirty, diseased and undeserving’” (Lawless, Kippax, & Crawford, 1996, p. 1371). As little research was being done into the areas of multiple risk within which many women negotiated sexual relationships, it was easy for society to construct HIV-infected women as immoral and deserving of their status, unless they were ‘innocently’ infected through transfusion or through ‘straight sex’. This construction cannot be separated from the encultured patriarchy within which many women have tried to develop a sense of self and self-worth. “Even those who recognize the risks cannot always translate this awareness into action” (Panos Institute, 1990, p. 19).

While considerable research has been conducted into the epidemiological and immunological aspects of HIV infection, this does not address why safer sex knowledge has not been enough to stop the spread of HIV. Also it does not explore the specific and varied circumstances in which women are at risk of infection. While power relations are at the core of many sexual relationships, women often occupy unequal positions and “do not have the power to request safe sexual intercourse” (Brimlow & Ross, 1998, p. 71). It is imperative that we learn to listen to women’s stories in an attempt to discern the rootedness of women’s sexual powerlessness and thus better understand the lived experiences of those with HIV/AIDS. Certainly, with this understanding, one is in a better position to challenge the social constructions and stereotyping of the ‘kind of women’ who become infected with HIV.

Throughout the years that I have been witnessing Alex’s life and hearing her story, I have come to re-examine the judgments that I have passed upon her diagnosis. Short of believing she deserved it, I had, in the early years, struggled with how she became infected given that she was a self-described poster girl for safer sex. At the same time, I was recognizing that I too had engaged in risk behaviours. As an anthropologist, I struggled with trying to frame an understanding of this woman that I loved becoming infected with a virus that was at the middle of a moral controversy. The young and vibrant woman who became infected was so impacted by the moralizing society within which she faced the campaign of AIDS = Death that she spent many

²¹Hatty & Hatty (1999) provide an illuminating account of the spread of syphilis throughout Europe in the late 1400s. The disease followed the movement of the armies as the infection spread. Initially all classes were affected; however, upper-class men seemed to be hardest-hit. In an effort to reduce the stigma attached to syphilis infection, women became the focal point of blame for infecting the men. Little regard was given to the idea that, in most cases, men were the transgressors. Men came to be depicted as the hapless victims whereas women were deemed responsible for the conditions facing the syphilitic men.

years dying from AIDS rather than living with HIV. It was very difficult for me to understand how she became a social pariah, literally overnight, from engaging in sex with a friend, a not-uncommon behaviour that is promoted as normal and healthy and is used to sell films, books, products, and political ideology but is also used to convict men and women as immoral and deserving of HIV.

In talking with Alex about the findings between sexual abuse and HIV infection, she concurs with Corea's theory (1992). She believes that she was unable to negotiate safe settings within which to have an intimate relationship with a man due to many factors that framed her sense of self. Alex's experience of being gang raped when she was to be in a protected hospital unit, and subsequent abuse by boyfriends who professed to love her, silenced her voice. Her own self-image, instilled during her childhood and reinforced through her life experience, contributed to her becoming a hurt young woman; one who went on a boat cruise with her buddies in August of 1986 and had sex with a friend whom she trusted.

In listening to the years of Alex's narrative of HIV, I have learned how easy it is to dismiss that which makes us uncomfortable, and then create an 'otherness' based on judgment and stigma. From the many people I have encountered, including hundreds of students I have taught over the years, I have gained insight into how easily we categorize and create groups of people that are disposable. I have witnessed how simply we can deflect our own moral or ethical responsibility by refusing to critically challenge the social constructions of master narratives that threaten not only our sense of humanity but also our ability to think outside of our own narrow worldviews. Whether the basis for marginalization is gender, race/ethnicity, sexual orientation, or some other aspect, it seems that part of the treatment for HIV lay in the ability of individuals to question 'objective knowledge' and, as Alex says, "to see HIV/AIDS as a medical and social problem and NOT a moral one."

I have watched the impact of Alex's story on classes of students for many years now. I have seen the value of storytelling as a powerful mechanism for challenging stigma and marginalization. Evidence of this is the transformation of many young college students who may never before thought about how they came to develop their personal knowledge about HIV or the 'people who get it'. For many, the process of understanding how stigma becomes embedded in unquestioned social constructions is an uncomfortable one, especially when the moralizing is around intimate sexual behaviour that is not commonly and openly discussed by many in North American society. For one to talk about one's own HIV/AIDS means to risk further marginalization, alienation, and stigmatization. For one to listen to this talk can bring to the

surface fear, ignorance, and pain. Through the sharing of stories, however, lives can be healed, fears assuaged and understanding reached.

Healing through stories

Many people living with the stigma of HIV/AIDS have described themselves as the “modern world’s equivalent of lepers” (Weitz, 1990, p. 26) and thus have been silenced. With the case of HIV/AIDS, many infected people have already been marginalized by sexual orientation, gender, IDU, poverty, and/or ethnicity. Their pre-existing lack of agency will likely be further compounded by a positive diagnosis. In the early years after Alex’s first positive HIV test, she withdrew from many people. Her phone would remain unanswered for months at a time, she would not return calls, she would not answer her door; she shut down her social world. I remember her seclusion becoming increasingly more severe after she left the university. As she says, she was waiting to die. The stigma and shame that shrouded her life during these years reinforced the silencing of her voice. Of stigma, Arthur Kleinman (1988) suggests that the stigmatized individual comes to internalize the societal reactions toward themselves and that they come to anticipate the resulting marginalization even before it occurs. The negative self-perception that results from stigma begins to shape the ill person’s identity (p. 160). Nelson (2001) refers to this as infiltrated consciousness; that powerful and controlling acceptance of the identity assigned by and supported through oppressive master narratives.

Alex’s narrative during her early years of HIV reflects the internalized negative self-perception to which Kleinman and Nelson are referring. With a tempered voice, her chaos story was filled with sadness, fear, despair, self-loathing, and hopelessness. While trying to maintain self-control in relations with family, she was determined that we would accept her on her terms or not see her. I can only speak for myself here in saying that during the times when she would not answer the phone or to allow me in to her life for months at a time, I became hurt and felt that she was lashing out at me personally. Not understanding the chaos that HIV had inflicted on her, I added to this through my own anger, frustration, and judgment of how she was choosing to live her life. During the self-destructive times when she was willing herself to die, I went through periods where I would shut her out of my life while I tended to my ego, bruised by the helplessness that comes with not knowing how to bear witness.

Kleinman (1988) suggests that the immediate family members of people with stigmatized disorders do not shun them (p. 160). HIV/AIDS challenges this concept for many families. Weitz’ (1990) research on stigma and AIDS reveals that often family members cease contact with

the infected person for varying periods. Given that Weitz' research was conducted in the late 1980s one is left to question whether or not the current state of promoting HIV/AIDS as a "chronically manageable illness" would result in different outcomes in familial relationships. I know that in my case, the AIDS = Death campaigns of the first two decades of HIV profoundly affected me. Seeing my sister as a dying woman became a filter through which my interactions with her were influenced. I responded to her in ways that revealed my view of her as, not only being terminally ill, but that her end of time was always imminent.

These chaotic years in Alex's life placed her in a position where she could not voice the horror of living with a death sentence hanging over her head, thus she believed herself to have no choice but to shut down her world. Arthur Frank (1995) writes of the chaos narrative as an anti-narrative. He suggests that for one to engage in the narrative process they must be reflexive and, that with chaos being a lived and all-consuming event, there is no time for reflection. While Alex's journal entries during the chaotic times in her life challenge Frank's tidy picture of the chaos narrative as presenting no time for reflection, her writing was a private affair often representing her tenuous hold on life. The chaos narrative holds no place for life to improve, it is difficult to listen to, and the anxiety that chaos produces affects both the teller and the listener. The loss of control over one's life is critical to this narrative. In Alex's case, HIV, as a chaos-defining illness, is ultimately post-modern. The powerlessness of biomedicine (modernity) to provide the path to restitution, to bring the illness under control, reinforces the lack of future and hope experienced by many people living with HIV/AIDS (PWHA) for "there is no modernist category for living a life of overwhelming trouble and suffering" (Frank, 1995, p. 112). The public campaign AIDS = Death became like a mantra or a self-fulfilling prophecy for Alex, and as a core element of her chaos narrative, helped her to erect a wall around herself that prevented her from being assisted and comforted by many people in her life. This was further compounded by a physician's advice to get her affairs in order, that she might have a couple of years at best.

Research conducted by Stevens and Doerr (1997) on the trauma of low-income women who are diagnosed as having HIV has revealed that in 55% of the cases, those being informed of their seropositivity have reacted with "unrelenting misery, escalated drug use, transmission risks, and destabilization of relationships, income, and shelter" (p. 1). The scenario that many women who participated in the study revealed was one of unending chaos. Believing themselves to be polluted in a way that required seclusion to protect others, expecting death imminently, and fearing to infect children and loved ones, many of these women were traumatized in a manner that made it difficult to seek help and in certain cases suicide became a viable solution to their

HIV infection. Conversely, Grove, Kelly & Liu (1997) conducted a study among middle class, educated, Anglo women infected with HIV and found that the symbolic capital associated with their class and status afforded increased control over disclosure and negative stigma. Problematic for many of the women interviewed, however, was obtaining HIV tests. As their physicians believed the women did not fit into the socially constructed risk group, the result was many were diagnosed late and died much faster. Hiding their diagnosis was crucial for these women for many of the same reasons as those identified by the low-income women in Stevens' and Doerr's study (1997).

Unlike Frank's (1995) supposition that the chaos narrative has no place for relationships, as they can be dangerous, and that the body lacks desire as it becomes unmade through illness, one finds a radical departure here when listening to Alex's story of these years. During this despairing time for her, she began a relationship with James Keating, married him, and while struggling with her personal demons, built a life with him in spite of the self-destructive focus of their lives. It is important to note here that the chaos narrative is very much present-oriented and linear (Ezzy, 2000). It does not provide a theoretical explanation for future-oriented actions such as Alex's marriage to James. The marriage did, to a degree, serve to reduce some of the psychological trauma associated with waiting to die and with the loneliness that often accompanies HIV/AIDS. Alex became a caregiver and nurturer to James and in doing so took time out from her own situation to devote to his healing. Having always been a nurturer, with James in her life, Alex was able to restore some semblance of normalcy in an otherwise chaotic time.

In a longitudinal study conducted by Squire (2003) on HIV-infected heterosexual women and their romance narratives, she explores "the story of a quest for an ideal heterosexual love relationship, characterized by mutuality and transcendence...[whose] contents are, superficially at least, optimistic and life-affirming" (p. 77). The findings of her study show that among the research participants, telling their stories of finding romantic love were very empowering. For many of these women, the "desexualizing effects" (*ibid*, p. 93) of HIV also brought with it, as in Alex's story, an expectation that romantic love and sexual relations would no longer be possible. When they did appear in women's lives, they presented themselves like quest stories, very similar to the quest plot outlined by Frank (1995). Alex found romantic love while in the midst of a very traumatic and chaotic period in her life. I believe this is telling in the human need to normalize one's life through social relationships. In the quest for agency that has been denied through both illness and the social stigma associated with possessing a life-threatening virus, these are

important events. Transmitting a deadly virus through intimate and romance-laden acts becomes a crucial hurdle for many HIV-infected people.

Squire (2003) also raises a critical point when she discusses the way in which much writing about gender politics and HIV, particularly by feminist researchers, neglects women's romance narratives. Having witnessed this time, which included wedding plans and being her maid of honour, the romance with James became a focal point in Alex seeing her life as being worth living, if only to protect and care for James.

While the stigma and fear associated with HIV was certainly a factor in Alex's seclusion from her family, her fierce protection of James also played a role. Many in the family wanted to blame James for infecting Alex, as he was an accessible scapegoat for us. Having engaged in high-risk activities over a period of years, he had also been a blood transfusion recipient in 1982. James fit our stereotype of the HIV-infected IDU. In defining James, we denied him any alternative identity than one constructed around blame. While wanting to support my sister's choice of husband, I also wrestled with wanting him to leave her so that she might have a 'better' life until she died. Without a doubt, it was difficult to watch Alex and James during these self-destructive years, but the pain of it could have been eased had I not tried to silence Alex's chaos narrative and impose my will the way I saw fit. Frank (1995) writes:

To deny the chaos story is to deny the person telling the story, and people who are being denied cannot be cared for. People whose reality is denied can remain recipients of treatments and services, but they cannot be participants in empathic relations of care. The chaotic body is disabled with respect to entering relations of care...it cannot tell enough of its own story to formulate its needs and ask for help; often it cannot even accept help when it is offered. (pp. 109-110)

While marriage is a future-oriented activity for many persons, for James and Alex it occurred within a worldview that was often locked in the present. Michele Davies (1997) writes of the present orientation of many PWHA that resulted, in the early years, from the "uncertainty of time and death" (p. 565) as well as fearful AIDS = Death campaigns. The suffering that Alex had witnessed among her friends and within her community was like a continuously looping instant replay of the kind of death facing her at some undetermined point in the 'near' future. Waiting to die from AIDS created a traumatic temporal situation for Alex and with the inability to see a future, she clung precariously to the present. Often living without hopes and dreams of a future, without aspirations and possibilities, drove Alex further into the spiralling abyss of self-destruction:

Living in a liminal state with HIV was clearly distorting Alex's present orientation in her life. Waiting to die, when death was not coming, presented a traumatic psychological position that Alex could not sustain indefinitely. In the beginning, she was led to believe that HIV meant that death was imminent and inevitable, but by the late 1980s the HIV = AIDS = Death campaign was being challenged by the numbers of long-term survivors (five years or more) that were being recorded. Davies (1997) writes of the trauma associated with the "difficulty of sustaining two mutually contradictory life orientations or two ways of being" (p. 565). The present orientation of waiting to die, not planning for the future for fear of being let down or of wasting time, juxtaposed with a glimmer of hope that death might not be as swift or as assured as the master narrative of the time had suggested, creates an HIV-positive in-between position in which the trauma inflicted is immense (Davies, 1997). The angst created by this position is clearly indicated in the poem that opens this chapter written by Alex two years after her infection.

The chaotic "death-infused environment" (Crossley, 1997, p. 1867) within which Alex had been living was not sustainable for the long term. This is evidenced by her willingness to go to the Bowen Island women's retreat at the urging of her elderly woman friend. It is here that Alex's narrative takes a turn, the chaos begins to lift, and some level of agency is restored to her life. Crediting her elderly friend with saving her life is a powerful indicator of a change in orientation from present to future, bringing with it the beginnings of self-empowerment and a reduction in self-loathing. Alex turned a corner in, once again, seeing value in her own life, that she had a life worth living and she had a story worth telling. The elderly woman's willingness to bear witness to the chaos of Alex's narrative fulfills what Frank (1995) calls for as a duty-bound ethic of listening. Someone who was not afraid of the horror of HIV/AIDS embraced this moral imperative. She valued Alex's life enough to know that she was a woman in need of a friend. As a result, a chain of events was set in motion in which Alex Keating started living with HIV rather than dying from AIDS.

CHAPTER III: LIVING UNDER WELFARE

Alex's story

Around the topic of poverty, especially in dealing with HIV/AIDS issues, many of the infected people are between 30 and 45 when they start getting sick and have to stop working or have their work interrupted. At that age, you don't have a lifetime of work behind you, you haven't reached 65 with retirement benefits, and you don't have a lot of savings to fall back on. When I had to quit work, it put me in a position of serious poverty.

I grew up in a working-class family and my folks always owned a business or two, usually just enough to support their family and keep their children busy and working. This was okay because it taught me a strong work ethic at a very young age and allowed me to grow up knowing I would never want for anything because I could work. I believed that was how it was going to be for the rest of my life, that I would always be able to earn what I needed. Not having the ability to make an income and be in control of that part of my life was one of the hardest things I had to face, it was a very disempowering thing. I have a father who believed that if you weren't working, you were lazy; if you were on welfare, you were a bum. There was no middle ground. We internalize the things we hear as we grow up. I always believed my worth came through my work and my accomplishments. When I had to quit work and approach welfare, it really did diminish my own sense of self-worth. I must say that the welfare system is set up in such a way that it doesn't do much to encourage self-worth anyway. Having to swallow my pride and walk through the door of social services was terrible, especially since I knew that I wasn't going in for a couple of weeks of help, I was going to be on assistance for an indefinite period of time.

The welfare system is not set up to deal with persons in my position. The system was set up as a short-term safety net; it was not set up to deal with long-term, ongoing, unending

illness. Many people with HIV are young when they get this disease and are still young when they start getting sick. Many don't have a lifetime of savings and by the time they end up at welfare they usually have few, if any, remaining resources to fall back on. Welfare is set up as a system of penalties. The whole goal is to give you assistance for as short a time as necessary and encourage you to get back working. If that encouragement takes the form of penalizing people to get them back working that is what they do. The fact is that the chances of my health improving to where I can go back to work full-time to support myself are minimal at this point. I am looking at being within this system for what remainder I have of my life unless a cure or a treatment is found that will allow me to regain my health to the point where I can, once again, earn enough income to support myself.

Walking into welfare and asking for help was one of the hardest things I have ever done. I think it was as hard as walking in to that clinic and asking to be tested for HIV. We put a lot of emphasis on people's worth based on what they do for a living, the kind of income they make. Think about it, when you first meet someone it generally goes something like "Hi, what's your name? What do you do for a living?" It is one of the first things we ask of new acquaintances. One's social status is truly impacted by both occupation and income. There is a real stigma attached to being poor. There is even a bigger stigma attached to being on welfare or governmental assistance.

Within moments of filling out one application form for welfare, I went from being a contributing member of society to being a drain on society. For some that may not be a difficult transition but for me it was devastating. Work had always been my way of normalizing my life after any upset or trauma and it was so after I was diagnosed HIV+. With my going on welfare, that normalizing tool was gone. I had lost that place to hide with my HIV. I also knew that I was now one of 'them,' the 'takers' of my childhood teachings. I felt utter shame at that thought and hopeless towards my future. It was like my life was being taken from me all over again. I shut down and shut the world out.

I had applied for basic benefits from welfare, then with a letter from my doctor I was labelled as unemployable while I applied for disability benefits. Medical disability status took a little over a year to be approved. It took doctor's appointment after doctor's appointment

and between these and the welfare appointments we would sometimes have fifteen appointments in thirty days. I understand that they want you to document your need but, like most things with the government, it wasn't done in the easiest or most efficient way possible. It took a great deal of effort. Unfortunately, these types of requirements tend to happen when you have the least amount of energy to do it. Between my health and my husband's health, trying to get welfare disability benefits became a very long process.

Having to be in a position where I am supported through social services is a bitter pill for me. There are certain groups of people that I speak to where I don't want to get that word welfare or social services out there. When they ask about my income I comment on the disability aspect of it but the word welfare doesn't follow. It's my own pride and other things that I haven't overcome. I have a hard time admitting that I have to go to welfare for money. I do appreciate everything that they do for me and without them we wouldn't be able to survive. I also have to admit that there is a part of me that is very resentful because the income level that I now live at means that my healthcare options are limited. I don't have the luxury of choosing to do whatever is best for my health and therefore extend my lifespan. I have to make the best choices that I can, based on what my limited income will allow.

Quality of life

In 1995, there was a study done regarding issues of poverty and what have been termed catastrophic illnesses, like multiple sclerosis and HIV²². One of the things that came out of this report is that people who live on \$10,000.00 a year or less are recorded to die five times faster than people who live on \$10,000.00 a year or more. I have to be honest, this makes me a little bit angry that my lifespan is most likely going to be shorter due to my inability to afford what I need to stay as healthy as possible.

Going on welfare was a reality shift for me from knowing that I would never want for anything in my life to knowing that my resources depended on someone else's whim and their

²² British Columbia Persons with AIDS Society. (1995). *National Catastrophic Disability Program: A Proposal to Reform the Canadian Social Security System*. This is a draft copy of a working paper/proposal that was submitted to the federal government with the objective, "to create a federally administered universal program which provides adequate income security and maintains quality of life for persons living with diagnosed catastrophic terminal illnesses and permanently disabling conditions" (p. 1).

mood for the day. I was no longer in control. I was no longer independent. As I said before, welfare is a system of penalties and the disability benefits are no different. Disability benefits were originally designed for short-term medical intervention within a system that penalizes you if you stay on too long. The British Columbia Ministry of Social Services and Housing (MSSH)²³ utilizes penalty in order to encourage you to get out and find work but when, due to illness, your need for assistance has no end in sight, the penalties sometimes feel overwhelming. I will share a few examples of some things that have happened, both good and bad, during my years on welfare.

The penalties of welfare

The Financial Aid worker (FAW) one gets can make all the difference in the world. If you get someone who does their job as a job and doesn't take it too personally, doesn't take it like it's their money you are taking out of their pocket, then you are okay. Someone who allows you to retain your dignity and doesn't make you grovel and beg, who objectively evaluates your request and gives you an answer, is a good worker. But there are workers out there who are on real power trips and you know what they say about a little person with a little bit of power... they can wield it like a big stick. Within the welfare system the FAW has a great deal of power. This is because in the welfare manual the phrase, "Your worker may..." is attached to almost every policy. This gives the FAW almost absolute discretion when processing valid requests, although some try to tell you they can't help or that it is not in the manual. If a request is valid, the FAW can often authorize it or, if it exceeds their discretionary powers, the FAW can take it to the supervisor, who can authorize almost anything.

I have had some excellent FAWs who have made my life a lot easier. By a good worker, I don't mean someone who gives me whatever I want. In my opinion, a good worker is someone who treats me respectfully and allows me to retain my dignity when I have to go in

²³ The Ministry of Social Services and Housing has undergone repeated name changes over the years as the portfolio shifts thereby reflecting changes and restructuring within the government. Prior to June 2001, MSSH was called the Ministry of Social Development and Economic Security. As part of the restructuring that was announced in June of 2001, the new Ministry of Human Resources emerged.

and ask for assistance; who doesn't treat me like I'm less than human because I'm on welfare. The supervisor of the office in Vancouver that I dealt with between 1998 and the spring of 2001 is someone I respect for the way she approaches her job. I will call her Toni. Our paths had crossed in the past when I had been involved with the FAW educating and sensitizing workshops, before I became a client at her office. In her position as office supervisor, she's never been able to say yes to me on any request or appeal I've submitted to that office, but she is still one of the best supervisors I've come across. I've had to appeal and go to tribunal to get her decisions overturned, that's just how it goes. She treats me respectfully and she values my perspective. My encounters with her left me feeling I had been heard and my perspective was treated credibly, not necessarily a given when dealing with welfare.

When you are on welfare, you can get a yearly bus pass for use in the Lower Mainland for \$54.00. It is good for any zone, any time of the day. We had used this service for a long time but then Jim and I were getting sicker. Every time we would get on the bus, we would get sick with the flu or whatever else. Just riding in that enclosed environment was frightening, think how many times people cough, wipe their noses and mouths, and then touch the handrails. That is a dangerous environment for us; the germs and diseases being spread in this type of environment are massive. During this time, we were going to the emergency three or four times a month with Jim's bleeding disorder. I was having respiratory problems and pneumonia problems. For both of us, our resistance was low. So, I approached our worker with doctor's letters to support our request. You have to have a letter from your doctor for anything to do with medical requests. The doctor's letter said that due to our deteriorating health we both had to avoid crowded public environments, especially public transportation. Our request to welfare was to assist us in achieving this. We listed the options we could see and their costs. Those options were, 1) insuring our car, that we already owned, at a cost of \$65.00 a month, or 2) using taxis, which would cost a great deal more than the car insurance. Our worker took our request to her supervisor and they agreed to give us \$27 each a month to keep our car on the road. This decision allowed James and I to retain the health we had. We were also able to get stronger due to avoiding crowded public environments that had been the cause of much ongoing illness. This is a good example of an FAW decision having direct life

and death impact on our health. We were fortunate that at this time our worker was empathetic to our needs. Unfortunately, that isn't always so.

How one is assigned an FAW is as follows. FAW #101 sees clients with surnames beginning with A, B, C. FAW #102...D, E, F, etc. Every year or so, everyone shifts down one space so you don't tend to have a worker for more than a year or two. It seems to me like welfare is afraid that if you get to know your worker too well they may see you as people not clients. So, needless to say, we got a new worker and our welfare experience changed again.

We get a dietary allowance that we have to reapply for every year. Our January 1998 cheque arrived in December 1997 and was short the amount of our dietary allowance. I phoned our new FAW and said, "Our cheque is short and I am assuming that our dietary allowance has expired." She looked it up on the computer and said "yes" and that we needed "to submit the doctor's form and, by the way, what's this transportation allowance of \$54.00 you are getting?"

I explained the circumstances of this allowance to her and she said, "You're not supposed to have this," she hit delete key on her computer and it was gone. We appealed the FAW's actions. We fought the loss of our transportation allowance for over a year and a half and we've never gotten it back. This new FAW that we had never met in person, just decided that we shouldn't have the transportation allowance that another FAW and office supervisor had authorized, so now it is gone. Now the money for our car insurance comes out of our food budget. (See Appendices 3 and 4 for a record of the communication between Alex and the FAW regarding the appeals on this issue.)

I remember an FAW we had during the mid-1990s when I was involved with doing what are called financial aid worker sensitizing sessions where people with HIV would go in and talk with the workers. We would hold seminars and two-day workshops. I had just started doing these two or three months before I had to go in and see yet another new worker. I was telling her about the workshops and I said, "Have you attended one?" Her response was, "I have been dealing with you people since the beginning and I know all I need to know."

I remember thinking that she needed it more than anybody. Some of the workers call us "you people" and some of them treat us like the average Joe.

On a different occasion, but with this same worker, we had gone into the office to request assistance for \$35.00 to clear up an outstanding hydro bill. Assistance was refused. The FAW suggested that since our wedding rings had diamonds in them, something she didn't think we needed, we should sell them and buy plain gold bands then we could use the money to pay the bill. Imagine this, to be told to sell our wedding rings that we had taken a year of small payments to pay for; the rings that we placed on each other's finger with a vow. I felt sick at this suggestion, later it just made me angry. What angered me was the suggestion that just because we are on welfare we shouldn't have nice things. I am not talking about having big houses, 2 BMW cars, and a jewellery box full of precious things. I am talking about our wedding rings, items that to me have sacredness. I believe this FAW's suggestion was inappropriate and it left a bad taste in my mouth.

Around 1996, due to a change in the boundaries that denote which MSSH office services a specific area, our office changed. We were transferred to the MSSH office at 666 Hastings Street, an address that seemed like an omen. The first couple of years at this office were not good. The office was staffed by workers who were assigned temporarily, many of them for a matter of months, to a location at which most did not want to work. This was because the Downtown Eastside of Vancouver was serviced at this office, along with the neighbourhood where we lived up at Commercial Drive. Vancouver's Downtown Eastside is a hard place, full of sadness due to the rampant poverty, homelessness, drugs, crime, and prostitution. Many de-institutionalized mental health patients are found living in this area due to low income and cheap housing. Some MSSH clients from this neighbourhood bring sadness and anger with them into their dealings with social services.

There was a time, shortly after we transferred to this office, that we went to ask for some additional assistance. It had been an expensive month for us with a few unexpected health-related expenses. We went to see our FAW to ask for a grocery voucher for \$20.00 to help us get through the last week of the month. I wasn't asking for money per se, I was asking for a piece of paper that I could exchange for food. Grocery vouchers were a way that a

FAW could give assistance without having to give cash/cheque, therefore when one was in need, vouchers were generally available, but not this day.

On this occasion, when we requested additional help, something we rarely ever did, our worker made it unnecessarily difficult. The FAW demanded that we go back home and get all of our receipts for our expenditures for the month so that she could, first, see if we had truly spent our money and were therefore in need and, second, see if our money was spent in such a manner that she approved of. This was not the manner that, to my knowledge, the request for a voucher had ever been dealt with before. I had never heard of anyone having to produce receipts to prove valid expenditures in order to get a voucher. Also, this was at a time when both James and I were sick and one trip that day to MSSH was difficult; two became a hardship. I still do not know what motivated this particular FAW to behave this way on that day. What I do know was that we were out of food and money so I had to jump through the hoops the FAW put before me and I was forced to plead for help, very demeaning.

I believe it was in 1998 when the office at 666 Hastings Street changed. Because this was a challenging office to work in, the decision was made to staff it with permanent employees who chose to be assigned to this location. Our new worker, I'll call her Diane, was a breath of fresh air. Unlike with some other FAWs, our appointment times with Diane did not cause me anxiety. In the late fall of 1999, when James had been very sick and had lost large amounts of weight, she assisted us with getting a clothing allowance for him that was the maximum allowable of \$200.00. This allowed James to get a couple of new pants, shirts, and underclothes, a decent amount of clothing. Why this is important is that Diane understood the psychological effect of wasting (weight loss) and how important it was to normalize one's body image. Seeing one's self as healthy is difficult when the clothing that fit two months before is now literally falling off your body.

Diane's actions here went beyond the minimum required by her position yet she did not exceed her authority. Your FAW is only supposed to give clothing allowances when medically required, as this one was, but then only for the very least amount needed. What she did was word the request in such a way as to state the maximum allowable was the minimum amount needed. Just to clarify, Diane did not give us extra allowances of money on many occasions

and we didn't ask for any unless truly in need. As a result, we were able to get assistance on most occasions when we requested help.

The most important and life impacting request for assistance that we made to Diane and the supervisor of the 666 Hastings office, Toni, was when we decided to move. Between the years of 1999-2000 our lives had been very difficult. James had been life-threateningly sick on a number of occasions. I was getting sick again and our world was closing in. We were still living just off Commercial Drive in Vancouver, in the same place we'd been since 1992, but the atmosphere had changed. Due to the city's fledgling efforts to clean up the Downtown Eastside (gentrification), some of the drug dealers had moved further up Hastings Street into our neighbourhood. A crack house had opened directly across the street from our co-op, another drug house opened three blocks away, and sex trade workers were working right in our neighbourhood. In the summer of 1999, a pimp had beaten up a prostitute in front of the children's play yard of our co-op, sad stuff. Then in the late summer of 1999, one block away, a triple shooting happened. It seemed that two men were sent in to do a drug hit but went to the wrong apartment. The man in that apartment told them what suite they wanted. These two men went down the hall to another wrong apartment and shot the people inside, then when leaving the building, came across a woman and shot her too. Three people shot and none of them involved in the drug world, all were innocent, who had done nothing but be home. This was truly scary to both James and I.

The fear we felt outside our home was exacerbated by our sadness within. Our apartment was dark as it was ground level. The mice that used to be the exception were now ruling the building and the constant mouse droppings were a health hazard. Both James and I were very unhappy and very frightened. It was like, if this is as good as life is going to get for us here then why do we struggle so hard to stick around. For me, I was afraid that the futureless feeling might turn into a lessening of James' fight to live. This was very important, as on numerous occasions, the main thing that brought James back from the edge of death was his tenacity, his will to go on. If he were to see no light in his future, would he keep fighting so hard? Something had to change.

That change came about because of our traveling to Salt Spring Island for a prayer meeting during the Christmas season of 2000. James and I had talked about wanting to move from the city for the past ten years but the right location never inspired us. This trip to Salt Spring changed that. While on the island we began talking about possibly moving there and by the end of the three-day trip we had decided to do it. We returned to Salt Spring in January 2001 to look into rentals. Though we found nothing we realized that we just had to jump in with both feet. We returned home and gave sixty days' notice to our co-op on January 31st, we would be moving on the last day of March 2001. We began looking for a home on Salt Spring, something we finally found on March 14th and began the process with welfare to approve the move.

This process began by documenting in a letter all the reasons that staying in our Vancouver apartment was not an acceptable choice (see Appendix 5). That included much of what was previously explained about the neighbourhood and our home. This letter also focused on our physical, mental, and spiritual states. We put in this letter that if we stayed where we were that the city would kill us; that we would die. I know that to some extent this may sound extreme but that was truly my fear. I knew how much despair and helplessness I was feeling about my life at the time and I felt even more fear and helplessness regarding James. I was afraid that he may give up fighting to stay alive and I knew if he gave up in his heart, it was only a matter of time until his body followed. All this I expressed in our letter to welfare. We also got a letter from our doctor reinforcing what we were stating about our situation and included his support for our move to Salt Spring (see Appendix 6). The other letter we submitted to welfare to support our request was from our home care worker, whom I will call Sue (see Appendix 7). She was a woman who was assigned by the Vancouver Department of Health to come into our home once a week to help us out. She could do personal care like bathing, dressing, etc, but for us she mainly did logistical help like washing down the bathroom and kitchen, vacuuming, and running laundry. Sue had been our worker for almost four years so she had an important view of our lives. Her letter supported our statements about the unhealthy state of our home, especially the hazardous mouse droppings that she personally cleaned up weekly.

All these letters were given to MSSH along with our specific request for assistance. That request was for MSSH to assist us with a refundable security deposit for a new rental. More importantly, we requested MSSH to pay our moving cost. This request was sizeable so I did my homework before submitting it. What I found out was that if we were able to move five days before the end of the month, the moving expense was almost half of what it would be at the end of the month. That fact, coupled with our luck of finding a home on Salt Spring Island that we could move into early is what I believe made a big difference to our request.

We submitted our request to Diane, who truly understood our position and what we were trying to do. Diane supported our position but was unsure if she would be able to help us. She took our request and supporting documents to the office supervisor, Toni, who was also in support of the changes we were attempting to make in our lives. With many phone calls between all of us and true dedication on the parts of Diane and Toni, our request was approved. I'm not sure how they did it but I do know that their belief in what we were trying to do made a difference to the outcome. These two women cared. The humanity on their part allowed us to make the change to our lives that have truly been a blessing. Life is good over here on Salt Spring. We still have difficulties, we still have life and death battles, and we once again are negotiating a new MSSH office and have had two FAWs in the past year, but that's life. There will always be challenges, hurdles to overcome, disappointments to mourn, and successes to celebrate.

The difference is due to two MSSH employees caring enough to go the distance. Our lives have improved; we are happier and more at peace. We still have health struggles but I know our lives have been and will be extended by our move to Salt Spring and the commitment of these two women whom we were fortunate enough to have as our FAW and office supervisor. For Diane and Toni I am truly grateful.

Shortly after our arrival on Salt Spring Island we went in to our new office in Sidney, on Vancouver Island, for the purpose of completing the transfer of our file to this office. At this appointment, we were required to show our identification and to have photocopies of this put into our file. Due to James not having any picture identification we put forward a request for him to apply for a British Columbia identification card (BCID) and for the

Ministry to pay for it. The other piece of identification that we could not provide was a copy of my social insurance card. At our annual review a couple years back the worker we had at that time noted that I did not have a copy of my social insurance card and during this office visit I filled out the application for a replacement card. The application was left in the possession of that FAW with the understanding that the birth certificate in my welfare file, along with a welfare-issued cheque to the receiver general, would be attached to the application. The welfare office would mail this. Although I assumed this was done, no social insurance card came in the mail. This did not concern me as my card had been lost for the better part of a decade and the reciting of my social insurance number (SIN) had been good enough in the past. I just forgot about it. That is, I forgot about it until this appointment in April of 2001 when this new FAW asked for it. I explained to her the circumstances concerning the application of the replacement card and that the application was left with our worker at the time for her to mail in. Our new FAW informed me that the computer was telling her that a cheque was issued to me for the card and that it was my responsibility to produce it. I explained that no cheque was issued to me for this card and could she check this out. Furthermore, anticipating that she would find out that an error had been made in their records, I told her I would be happy to apply for the replacement card and could the Ministry produce a cheque to cover the cost.

The FAW replied to me by mail at the end of April 2001 to say that James' BCID would be paid for and a cheque for that was enclosed but that a cheque for my SIN card would not be forthcoming as it had already been paid for and that I needed to sort out the situation and produce the card (see Appendix 8). I contacted the Ministry responsible for SIN cards to inquire into this situation. The outcome of these inquiries was that no cheque for a SIN card was ever received and therefore no card was sent. I passed this information on to our FAW in the form of a voice mail message and I also let her know I would still be happy to apply for a card if welfare would pay the fee. I did not hear back from her and during the following months James was getting sick and eventually ended up in the hospital in Vancouver for weeks. The issue of the social insurance card was not on my mind, I forgot about it. At the beginning of September 2001, I received a letter from our FAW stating that I

was still responsible for producing this card and that if this were not done then our October benefits due out on September 26 would be withheld. I replied with a letter documenting this issue to this point and I included that if the responsibility was going to be put on me again that I would be appealing this decision (see Appendix 9).

When I did hear back from our FAW, it was in the form of a cheque for ten dollars payable to the receiver general along with the request that a copy of the card be submitted to her when it came in. I sent the application and the cheque away, received my SIN card, and forwarded it to our worker (see Appendix 10). The matter was settled. There was a huge amount of stress for me involved in this process. We lived with the threat of our benefits being stopped not to mention requests being made of me that I could not fulfill. This was and is an ongoing problem in my experience with welfare.

Welfare medical benefits and practices

In about 1997, a program called Schedule C was implemented by MSSH. This program was put into place as a result of ongoing requests of assistance for medical expenses and lobbying by organizations that deal with the disabled on welfare. Ongoing illness has ongoing expenses. The Disability Benefit Program does not meet many of our medical needs and expenses to this day. For as difficult as it can be living on these benefits, it was more difficult before we won our Schedule C in 2000.

The illness we have is very complicated and keeping one's health and battling illness is a complex matter that incurs expenses beyond the doctor visits and select prescriptions that our social service medical will cover. The medical coverage we get looks something like the following. We are allowed access to general physicians for acute care as well as health maintenance. We are also covered for access to some specialists and surgeons for some essential care although there are many restrictions to this category. Certain prescriptions are also covered though I must say that I don't always see the logic that is used in choosing what that will be. There are also dental and optical components to our coverage. For dental it is a yearly maximum allowable of \$500.00 per year for non-cosmetic, basic dental care. There are many restrictions as to what will and will not be covered and what types of materials can be billed

for to medical. The optical coverage is for one pair of replacement glasses each four years. Welfare has a set price that they will pay for lenses and a separate set price they will pay for frames. The last time I got glasses, a little more than four years ago, the amount welfare would pay for frames was \$27.00. It is difficult to find a frame for \$27.00 that will stand up to four years' wearing. Needless to say, I've spent a lot of time fixing my glasses. If you require new glasses before that time is up then you must make a special request in writing stating the specifics of your situation and then hope that you receive authorization to get new glasses. Like most everything to do with welfare, medical-related requests are a lesson in patience, something at which I've gotten quite good.

At first glance the list of medical coverage we get may seem complete and don't get me wrong, I'm grateful for this coverage but our medical-related expenses go far beyond this as they do for many if not most people living with illnesses on MSSH disability. Because of this reality, over the years, many requests for additional assistance with medical/health related expenses were submitted, denied, appealed, denied and taken to tribunal where more often than not the valid requests were decided in the applicants favour. After a number of years of this pattern being the norm, MSSH made some changes to their programs, the result of those changes were the Schedule C benefits. The basic premise of Schedule C is that persons collecting disability benefits from MSSH may apply for additional money to be paid monthly for approved medical-related expenses. Some of these expenses for one in our position might be dietary supplements, vitamins, purified bottled drinking water, excessive laundry expenses (caused by diarrhea, night sweats etc.), medical related transportation costs, etc. To apply for Schedule C a person had to fill out numerous multiple-paged forms explaining all aspects of one's illness and the expenses you were asking assistance to cover and then you had to show how these expenses were directly resulting from your illness. As well as the client portion of the application, there was also the portion of the application that a doctor had to fill out. This portion was incredibly long and involved, a barrier to getting the form filled out properly in itself as doctors often do not want to fill out simple forms let alone forms that will require a significant portion of their time, an hour or more. For these forms to be filled out the doctors

always billed a fee, ours was \$35.00 per form. This billing is not covered by our medical nor is it reimbursable from welfare, just another expense that must come from one's scant budget.

The process of applying for Schedule C was made to be very convoluted and difficult. The Ministry was looking for specific information put together in a specific way and if it was not done so it was a reason to deny the requests. This actually became the pattern that seemed to be the rule not the exception. How most all requests for Schedule C progressed was as follows. A person would get a Schedule C application kit from the Ministry, document and gather their portion of the application as well as the doctor's portion of the application, attach any other information that one might feel could assist in the Ministry rendering a favourable decision and then take it all into the MSSH office to which they are assigned. I believe that the Ministry had thirty days in which to respond to the initial application. Over 90% of these applications were denied. Once you received your denial then you could go back down to the welfare office, pick up an appeal kit. You had seven days in which to fill out and submit the appeal. The Ministry had approximately another fourteen days to respond to the appeal. The response was most always a denial. The next step was to apply for a tribunal to hear your request. This part of the process could take months but was one's best hope of getting the Schedule C benefits. How the tribunal works is that the Ministry chooses one person to sit on the tribunal, the applicant also gets to choose one person to sit on the tribunal. These two tribunal members choose a third person to join them and the tribunal panel is decided. The next step is submitting any additional positions or information to the tribunal as one might deem relevant and then a date for the proceeding needs to be set. Often easier said than done as not only do the three members of the panel need to be present but also a Ministry representative (often the office supervisor of the applicant's office) as well as the applicant and their advocate if they so choose to engage one. Once a date is set, often a couple months down the road, all one can do is to wait.

When the day of the tribunal is at hand, all parties gather at the appointed place. The tribunal panel reads through the mass of paper work generated during this process, then they listen to the Ministry representative speak to their reasons why they don't believe the requested money should be granted. Next is the applicant's advocate and then the applicant

themselves, explaining their reasoning why the request should be approved. The tribunal panel will then take the time to discuss the matter amongst themselves, review all documents and render a decision, which will be told to the parties at that time. If the Ministry wins the tribunal then the applicant has no recourse. If the applicant wins the tribunal then common practice at this time was for the Ministry to appeal this decision to a tribunal review board. A process where the decision of the tribunal is reviewed and either upheld or overturned.

This whole process is long and convoluted. The initial application was made to be difficult on purpose, in my opinion, in order to discourage applicants. Due to the fact that in order for the Schedule C application to result in a favourable outcome, it needed to be filled out in a very specific way, the details of which are not disclosed to the applicant. The advocacy department of an organization called the British Columbia Persons With Aids Society (BCPWA) took on the task of assisting members to negotiate the obstacle course that this process had become. This assistance included things like filling out the application forms in such a way that they not be returned time and again as had happened to many who took on this task themselves. The advocates would give tips to the doctors regarding sections which must be completed, they would assist with the appeal papers, the tribunal requests and finally they would accompany the applicant to the tribunal meeting in order to speak on their behalf.

We took advantage of the services offered at BCPWA and had them assist us in all steps of this process. The only unfortunate part was that so many people were after their help the wait list to get an appointment to have an advocate help was long. In our case, it was about a year. Our Schedule C application was filled out in 1998 and it took until 2000 to win our tribunal. We were some of the lucky ones; we lived long enough to get a final decision about our benefits. I know some people who did not fare as well, some people who died before their paper work had gone through the system. I feel angry that these people who had valid claims for assistance were unable to get the assistance that may not have stopped their death but might have made their lives a little more comfortable or even might have given them a bit more time on this earth. The needless suffering and stress caused by the Schedule C process angers me because, in my opinion, it is a result of our governments' efforts to look like they are helping those in need while their own unwritten policies put up roadblock after roadblock.

With the Schedule C process it was standard that all applications were initially rejected, they were appealed and denied, then they would go to tribunal and, because the Ministry could only control one third of the vote, over 95% of the applicants won their benefits. But even this runaround wasn't enough for our humane government; they had to appeal the tribunal's decision, a step that most always resulted in no change to the decision. It feels to me like something is wrong here, it leaves a bad taste in my mouth. It is unfortunate that I'm often left with a sense of disgust and fatigue when once again faced with negotiating with the Ministry's medical system. I often cannot find logic in decisions made by those who hold this power. Compassion is also not evident in many of the situations I've faced with welfare medical while struggling to come up for air in the midst of whatever medical situation we were in at the time. The naïve part of me feels that the powers that be couldn't understand the damage to my health that is caused by the way they handle many situations and decisions or it would be done differently. The tired part of me believes that they know full well the effect that stress has in shortening my life expectancy. My conflicting belief and pessimism have been shaped by my experiences with this system.

During the spring and summer of 2001, my husband was in the hospital about three times. The last time was for twelve weeks. He was very sick and we felt we were going to lose him. James has been very close to death four or five times before but he always seemed to come back. This was another one of those times although at the time, we didn't know that he was going to pull through. What the doctor's thought was wrong was that he had been taking a medication, Septra, that had depleted the portion of the white blood cells that are responsible for fighting infection (neutrophils) and as a result, his body had no ability to fight anything. Because of this, he needed a medication that would purge the Septra from his system so his body would have a fighting chance to get his white cell count back up.

His count got so low that they decided not to keep him in hospital because he could get dangerously sick from other people's infections and illnesses so he was sent home. This was good because he wanted to go home but they didn't send along the medication he required. He was given a prescription even though the hospital knew it was not covered by our medical plan and we could not afford the drug. He did need to take this medication but it was very

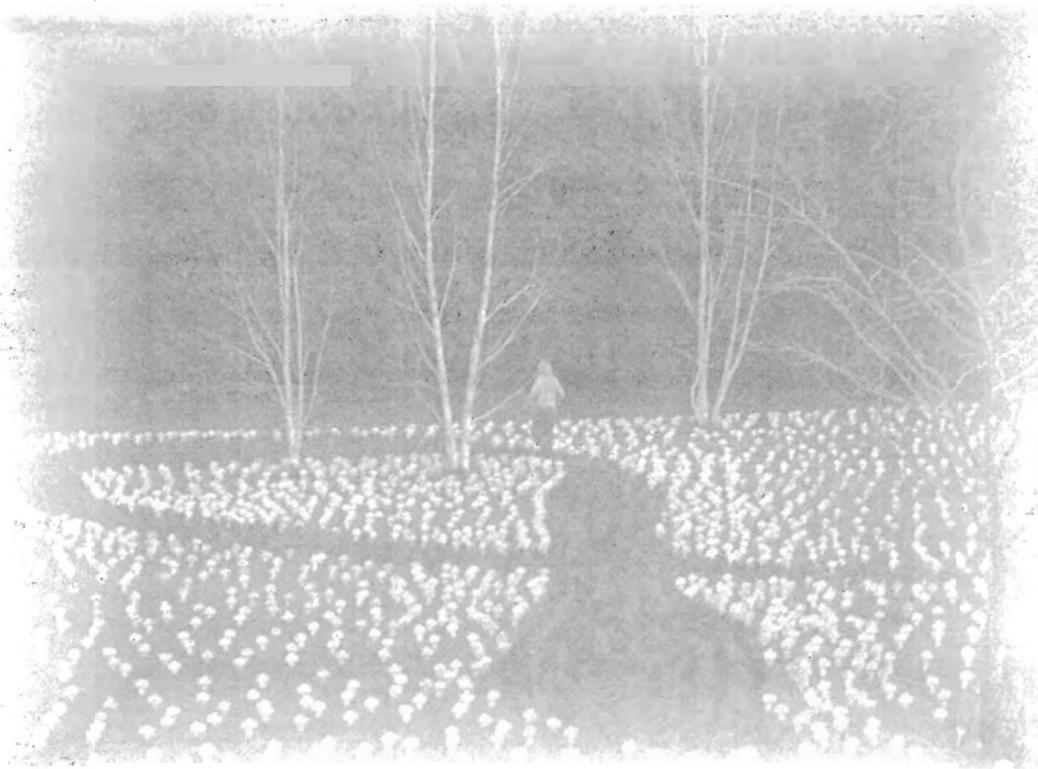
expensive. It was \$100 a pill and it was not covered by welfare medical. Jim also had sores in his mouth and throat from his low white cell count and he couldn't swallow. In the hospital, he had an antibiotic that he was taking to heal the sores and a lidocaine rinse to freeze his throat so he could eat. Welfare medical covered the lidocaine rinse and the antibiotic for his mouth but it wouldn't cover the pills he needed to stay alive. If he didn't get the white count problem solved he may have died. It took ten days to get this medication covered and in the end, it was a very simple process. I called doctors who supported his need for the medication. It was constant daily phoning to welfare to say, "He's getting sicker and I am afraid he's dying. Please give me some medication." It was a very traumatic time and I spent most of it trying to be strong for him and then locking myself in the bathroom sobbing because I didn't know what else to do. Finally, welfare got the right phone call from the right expert and they agreed to cover it. Unfortunately, this was not the first time we've had situations like that.

In the early 1990s, when Jim was in the hospital, he had probably seen a dozen doctors because they were trying to solve a problem around his bleeding disorder. I got a call one day from welfare after he had been in the hospital for three weeks saying, "Medical has contacted us. You have been seeing too many doctors. We think you are double doctoring and your medical is cut off."

I asked them what they meant. They said, "You have been seeing twelve doctors, they are accusing you of double doctoring". What they meant was they believed that we were going to different doctors to get different medications when all they had been prescribing were bags of platelets and immune system builders, things that would increase the platelet count, and antibiotics.

I tried to say, "Look, my husband is in the hospital, he is very sick and he needs these doctors." They just didn't want to hear it. They did not phone me and say, "What's happening and why are you seeing all these doctors?" They did not look at Jim's chart and see he has advanced AIDS. Maybe he was seeing all these doctors for a reason or even beyond that, the numbers that the doctors bill with will show if it is a hospital or doctor's office visit. Nobody did this. They saw the number of doctors, they saw the name, and they cancelled our medical. In the end it took many phone calls and three days to get our medical reinstated. It

was beyond any logic once again. That's why when I say it's a penalty system, it really is. You're guilty and you have to prove your innocence in just about anything.



Alex's scrapbook



Photograph 10: Wedding party



Photograph 9: Our wedding²⁴

My Wedding

²⁴ Photographs 9 and 10 by permission of the estate of Margaret Cooper.



Photograph 11: Brutus and I²⁵

Things that make me happy!



Photograph 12: Me and the critters



Photograph 13: My garden

²⁵Photographs 11, 12, and 13 by permission of Laura Cooper.

Laura's response

Alex's relationship with social services is undoubtedly a complicated one, given the depth of stigma that she herself associates with receiving welfare. From my earliest memories, our father was very vocal in his opinion of those who collected welfare. He believed that there was no reason for anyone to receive benefits, and those who did were just taking a free ride on the backs of working men and women. He lectured his children on what he believed to be the failures of socialism and the problems of a welfare state. While intolerant of alternative political views, he had always been a hard worker and demanded the same of his wife and children. He encultured his children in the belief that collecting welfare was not only a sign of personal failure, it also reflected badly upon the family in general.

Our mother was a very hard-working woman raised on a homestead in northern Saskatchewan. The second oldest of ten children and the oldest girl, she spent the first twenty years of her life engaged in domestic and manual labour. Never one to complain about work, she always took advantage of opportunities to generate income to assist in supporting her children and husband. From taking in borders and foster children, to knitting, sewing, and fixing small appliances, our mother's income-generating strategies in the home never seemed to end.

When Alex was in grade one our mother began working outside of the home, a practice that she continued until her retirement. During her years of labour force participation she was never in a position to earn a good wage, thus her retirement income was minimal and had to be topped up by a welfare supplement. When it came to governmental assistance, our mother was much more pragmatic and less judgmental about individuals in need. Regardless, the work ethic that was transmitted to us throughout our childhood and teenage years served to reinforce that personal failure and shame were synonymous with welfare assistance and poverty. Just as the stigma associated with HIV/AIDS needs to be framed as a social construction, so too does welfare stigma.

Certainly within our childhood home, not only was collecting welfare a shameful position to be in, but also persons on welfare were constructed as the other and seen as socially useless and deviant. We were discouraged from hanging around with kids from families on social assistance as they were seen as being bad influences on us children. Having parents that grew up in the 'dirty thirties', we were weaned on stories of their respective families' perseverance through poverty, without going on the dole. Life was constructed as being simply a matter of working hard enough because there would always be work to do, for no job was too menial to be tackled.

The value system embedded in the Protestant Ethic defined the way we were encultured to view our worth as labourers/workers and responsible family members.

A brief history of social assistance in Canada

Dennis Guest (1997), in his book, *The Emergence of Social Security in Canada*, suggests that the belief system of the Protestant Ethic is rooted in the historical development of social services. If a person/family exhibits positive traits of hard work and thriftiness they will be able to meet their needs. However, “if people are lax, improvident, and foolish, they are punished by their inability to obtain the goods and services they need” (Guest, 1997, p.5). In this case, the person seeking relief is subjected to stigmatizing and degradation. The institutionalization of this value judgment and its role in influencing public policy has been termed “a residual concept of social security” (ibid. p 4).

Historically, the English Poor Laws provide the roots of the response of British settlers in Canada during the colonial era toward those living in poverty. The poor were divided into unworthy (able-bodied persons) and worthy (educable children, sick, aged) of relief. Life for those deemed unworthy often included the workhouses where conditions were meagre and labour was hard (Chappell, 2001, Turner, 2001a, Turner, 2001b). While the colonial government saw the provinces as being responsible for servicing their own poor populace, there was no uniform mechanism in place for administering relief. Characteristic of residual care, in most cases the responsibility was relegated to charitable organizations while local government involvement remained minimal.

The residual concept of social security as it was practiced in Canada pre-1940 suggests that the individual (usually the head of household) would seek alternative sources of income or assistance in times of trouble, whether it was another job, help from family, savings, or a bank loan. Public relief was a last resort and was a “demeaning and stigmatizing experience because it was widely regarded as clear evidence of personal incompetence and failure” (Guest, 1997, p. 3). The associated norms and values became institutionalized and embedded in the structure of Canadian society. At the core of this laissez-faire political ideology, reducing government involvement in the social assistance needs of the citizenry was deemed desirable. Contradictorily, in this same time period, the government was increasingly being called upon to support the provinces in terms of health and welfare responsibilities though, “under the law, it did not have the power to do so” (Turner, 2001b, p. 84).

Throughout the early industrialization of Canada, poverty increased as more and more Canadians were left with few options but to work long hours at low-paying and often dangerous jobs. The formation of labour unions through the late 1800s and early 1900s provided the foundation for organized social movements aimed at improving the conditions facing working Canadians. With work-related injuries and deaths increasing, partly in response to dangerous mechanized equipment of early industrialization, labour unions in Ontario fought for protection and compensation for injured workers. This resulted in the Ontario Workmen's Compensation Act of 1914. This act became the forerunner for similar worker compensation plans that were in place in all provinces, except Prince Edward Island, by 1920 (Chappell, 2001).

Throughout the early 1900s, social reform movements continued to plague the federal and provincial governments in Canada. With rates of poverty increasing as levels of industrialization rose, the women's movement fought for attention to be paid to the deplorable conditions facing many women and children throughout the country. Mother's pensions and Children's Aid societies were in place by the 1920s throughout most of Canada. Similarly, given that many of those suffering in poverty were elderly, the federal and provincial governments agreed to a cost-sharing, means test assistance program. In 1927 the Old Age Pension Act was passed in Parliament; however, the responsibility for administering it fell to the provinces (McGilly, 1998; Turner, 2001b). While inroads were being made to accommodate those living in poverty, the role of government in ensuring a minimum of social assistance to all poor people in Canada remained non-existent. The rise in unemployment, and its associated health and social problems, throughout the dirty thirties began a shift in social services provisions in Canada from a policy of residual care to an "institutional concept of welfare" (Guest, 1997, p. 4).

The institutional concept of welfare is based on the premise that as a society industrializes and its populace becomes more centred in urban areas, there are costs upon the population that result from the industrialization process: "The society should not allow the costs of its progress to fall upon individuals and families, but should protect and compensate people who experience more than their fair share of the costs" (*ibid.* p. 4). In theory, institutionalized social services should reduce the stigma associated with welfare as the government takes on responsibility for caring for its populace who are uprooted by 'progress'. Guest (1997) suggests that: "It dispenses with moralizing about the shortcomings of the person in need and delineates instead clearly defined social responsibilities for the universal risks to human welfare that characterize life in an industrial society" (p. 5). Guest neglects to add here that persons who have been encultured through a socially constructed master narrative that has historically and

structurally justified and institutionalized moralizing and marginalizing of those in need, often conduct the administration of this policy. These persons are widely influenced by the values, norms, and possible judgments associated with their class, ethnicity, gender, and/or religion. As a result it is unlikely that all representatives of the government will administer its policy in a fair and unbiased manner. Furthermore, social assistance in Canada has moved between residual and institutional models of care and, thus, as a dynamic and fluid system, it is unlikely that those administering policy can change their individual biases to reflect the change in political and economic will. The philosophical roots of deserving and undeserving poor cannot be ignored as to how profoundly these have permeated Canadian consciousness and resulting public policy.

The 1940s brought forward an increasing institutionalization of social services in Canada. The Unemployment Insurance Act of 1940 was aimed at providing financial assistance to workers who, through no fault of their own, had lost their employment (McGilly, 1998). Seen as one of the costs of progress in a capitalist market economy, unemployment was to carry no stigma and thus benefits were to be awarded, without prejudice, based on work history. Initially shared by the provinces and the federal government, unemployment benefits became the sole responsibility of the federal government by 1941.

Influenced by Britain's Beveridge Report of 1942, aimed at dealing with post-war social reconstruction and poverty alleviation (Guest, 1997, p. 108), Canada's Marsh Report on Social Security was released in 1943 and laid out a social assistance plan that was based on Leonard Marsh's concept of social minimum. Marsh, a director of social research at McGill University (Turner, 2001b), defined social minimum as: "the realization that in a civilized society, there is a certain minimum of conditions without which health, decency, happiness, and a 'chance in life' are impossible" (Marsh, 1950 quoted in Chappel, 2001, p. 41). Marsh's report favoured government-sponsored social security programs that would ensure the minimum and thus, "reject the concepts of laissez-faire and worthy and unworthy poor" (Turner, 2001b, p. 85). Further defining the social minimum, Marsh writes,

What this minimum should be is a matter of definition. Certainly, however, it means the direct elimination of poverty. It raises the level of those families whose incomes are inadequate at the present levels or whose family needs are too great, to permit proper provision for healthcare or savings against risk of disability or unemployment. It prevents penurious old age and the necessity of parents becoming dependent on their married children in later life and straining the resources of these younger families. (quoted in Guest, 1997, p. 111)

Although a problematic concept is at the root of much debate regarding social services in contemporary Canada, the idea of defining a social minimum in the post-World War II years forced both federal and provincial politicians to consider what level of suffering constituted poverty, and to what degree the state retained responsibility for alleviating that condition. In 1944 the Family Allowance Act was passed through Parliament, and provided a small stipend to all Canadian mothers with children under sixteen. This allowance was seen as universal and a means test did not have to be undertaken to receive the benefit. Further, in 1951, the Old Age Pension Act was revised in an attempt to remove the stigmatizing means test associated with these benefits. The two-pronged system that emerged included the federally administered Old Age Security benefit that was a universal payment for which one did not have to prove need. Old Age Assistance was means-tested and paid for by both levels of government though administered by the provinces (Chappell, 2001).

In the 1950s, the Blind Persons Act (1951) and the Disabled Persons Act (1954) were passed into legislation. Both acts were cost sharing and the recipients were subjected to a means test. Rather than reflecting an institutional approach to services, both reflected a residual approach, reinforced by the means test. In the case of the Disabled Persons Act, two years after its implementation, less than one-seventh of the severely disabled in Canada were eligible for its assistance. Guest (1997) suggests that this is a case where “a policy of ‘helping those in greatest need,’ the hallmark of a residual approach, may become a method of severely rationing help rather than extending assistance to meet genuine need” (p. 138).

Complicating the stigma associated with poverty, under which many Canadians lived, was the way in which a person’s need was measured. This involved ongoing intrusion into one’s home by welfare agencies mandated to qualitatively assess a person’s level of need, including a review of both assets and budget. In emphasizing one’s inability to be in control of one’s own life or the lives of dependent family members, needs assessments reinforced shame and public humiliation for many. With these mechanisms still in place today, as evidenced by Alex’s earlier narrative, it is clear that the underlying philosophy of the residual approach to social assistance is deeply rooted such that it was never fully displaced during times when an institutional approach appeared to take precedence. The discrimination was not only aimed at the able-bodied. Policies that led to many disabled in Canada not passing the means test to receive assistance, thus being left to suffer in poverty, are still in evidence today in the climate of neo-liberalism.

Throughout Canada’s movement toward becoming a welfare state, the conflict between the residual and institutional models of social assistance continued to plague policy development

and implementation. In 1965, the Canada Pension Plan (CPP) was established to assist families with lost income whether it was from death, disability, or retirement. As a fully-indexed income security plan, it was mandatory for employed individuals to make contributions to CPP based on earned income, though there was a limit to the contribution for high income earners. While CPP would be important for many disabled persons in Canada, it would be so only if that person had been in a position to earn a contributing wage and then live long enough without disability to increase the portion of security payment they would receive once becoming disabled. For many disabled persons, CPP provided a minimum benefit that needed to be topped up by provincial welfare assistance.

As Alex suggested earlier in this chapter, many PWHA are young when they become too sick to continue working and do not have a lifetime of savings or an ample CPP claim to live on. Many are left to go on social assistance; a needs-based, means-tested provincially administered system of income support. Alternately, CPP has undergone many revisions since its inception in 1965 that have reflected political and ideological shifts in the provision of social assistance in Canada with varying degrees of impact upon disabled Canadians. Being deemed as worthy poor, the cost for many disabled Canadians has been high. These costs include: “extremely high rates of unemployment, violence and abuse, illiteracy, poverty, illness, social isolation and discrimination” (Bach & Rioux, 1996, p. 318).

From 1967-1996, the provinces (sans Quebec) received their federal welfare funding through the Canada Assistance Plan (CAP). The CAP was mandated to fund 50% of social services to the provinces and, based on need only, was intended to reduce the stigma associated with the means-tested plans. Regardless of work or residency requirements, the plan was aimed at expanding services to those in need in Canada. Alleged to be “one part of a federal plan for the ‘full utilization of human resources and the elimination of poverty’” (Guest, 1997, p. 146), the CAP also set up the provision for recipients to appeal decisions made by those administering the services. Referred to as “the apex of the creation of a universal welfare state in Canada” (Graham & Al-Krenawi, 2001, p. 411), CAP was to reflect a standardized and reliable service across the country.

Although a politically astute policy to bring together social assistance programs at both the federal and provincial levels, the problems of meeting standardized and non-stigmatized treatment of clients of the system were still present. Leaving the administration of all social services under the CAP to the provinces meant that the ideological and political influences on the administration of the CAP were subjected to constantly changing political and economic factors.

In many cases, people in need of social assistance were used as fuel for political agendas and treated with contempt by both the citizenry and the political leadership, regardless of political affiliation.

The administration of social welfare in its various forms was not seen as a threat to free enterprise and the accumulation of capital throughout the 1950s and 1960s. With an expanding national economy, and a stratified working class, social welfare seemed relatively secure as long as the times of fiscal crisis were minimal and were “resolved without excessive indebtedness” (Teeple, 2000, p. 48). It was not until the recession of the 1970s and the subsequent recession of 1981-82 that “fundamental cracks began to appear in the compromise characterizing the welfare state in Canada, with neo-liberals and most professional economists charging that Canadians [were] supporting one of the world’s most overgoverned and foolishly generous welfare states” (Francis, 1991, quoted in Kitchen, 2001, p. 236). Targeting social welfare enabled the corporate sector to blame the lack of economic growth and rising inflation on both the government, which implemented and serviced the transfer payments, and those Canadian recipients of these services. The government addressed the economic shortfalls “by cutting government and welfare services, restraining public sector wages, raising taxes, and increasing indebtedness” (Teeple, 2000, p. 49). Exacerbated by a political climate that began in the “post-World War II era..., a period recently characterized by the onset of globalism and neo-liberalism” (Coburn, 2001, p. 46), the belief that inequality of condition does not impact equality of opportunity in Canada placed responsibility for socio-economic standing solely on the individual. This did not consider the structural marginalization facing many Canadians, including the disabled. For this reason, a closer examination of social welfare in Canada, in the form of the administration of its health services, needs to be conducted.

Healthcare services

The administration of healthcare in Canada has undergone an interesting and ever-changing history and, like many other federal and provincial policies of social assistance, reflects varying degrees of stigmatizing and marginalizing policies and political agendas. During colonial times, healthcare was the responsibility of the individual. In the case of disabled persons, while seen as deviant, they were considered worthy of receiving charitable assistance in overcrowded poorhouses. Though attitudes became more compassionate throughout the 1800s with the development of institutions to retrain certain types of disabled persons for entry into society, they were met with resistance from the mainstream. Throughout the first half of the 1900s, disabled

persons were considered as having little to contribute to society and thus were seen as ill or diseased. The disabled rights movement that began in the 1960s has been focused on normalizing the existence of disabled persons by lobbying for equal access to that which is open to non-disabled in society (Chappell, 2000, pp. 321-323). While a lofty goal, the reality facing many poor, chronically ill, and disabled persons relying on social assistance in Canada paints another picture altogether.

In 1961, The Royal Commission on Health Services was appointed to review healthcare provisions in Canada and make recommendations for the delivery of healthcare across the country. According to Guest (1997), the work of the commission brought to the forefront many of the arguments that shroud the residual and institutional concepts of social assistance. Insurance companies, the Canadian Chamber of Commerce and some representatives of the medical profession, the most ardent proponents of a residual model of care, argued that freedom of choice and individuality were in jeopardy if a universal and government-administered healthcare system was mandated. Conversely, labour unions, farmers' organizations and consumer groups, those in favour of institutional care, argued "that a comprehensive health service should do more than meet sickness and accident costs: it should be oriented not only toward the prevention of illness, but also to the better distribution and organization of medical services" (Guest, 1997, p. 149).

In 1964, the Royal Commission of Health released its recommendations that included a national system of medical care insurance, similar to that offered under the Hospital Insurance and Diagnostic Services Act of 1958. Medical care insurance was to be operated at the provincial level with financial support at the federal level. Unlike the private medical insurance plans which served only a small portion of Canadians, the Medical Care Act (1966) was developed as a cost-sharing plan to which the federal government required the provinces to follow the following five criteria to receive funding:

1. provincial plans must be administered on a non-profit basis by a government agency or an agency designated by, and accountable to, government
2. plans must provide comprehensive coverage for all medically necessary services rendered by a physician or surgeon
3. plans must be universally available to all provincial residents on equal terms and conditions; they must cover 90% of the insurable population within the first year of operation and 95% within three years
4. all provincial plans must provide portability of benefits from one province to another or continued coverage when the insured resident is temporarily absent from his or her home province

5. insured services must be delivered in a manner ‘that does not preclude, either directly or indirectly, whether by charges made to insured persons or otherwise, reasonable access (Guest, 1997, pp. 150-151; McGilley, 1998)

For the first time in Canada the concept of a social minimum, introduced in the Marsh Report of 1943, included universal access to medical services and hospitalization for virtually all of the Canadian population. While positive in policy, it took three years before all the provinces signed the cost-sharing agreement with the federal government (Guest, 1997), thus delaying its implementation until 1968. While it was expected that the cost of delivery of both hospital and medical care insurance would be formidable, it far exceeded expectations, as high technology expenditures, hospital costs, and physicians’ bills “were consuming the largest portion of the healthcare budget” (Taylor, 2001, p. 423).

Also problematic with both the Hospital Insurance and Diagnostic Services Act (1958) and the Canadian Medical Care Act (1966) was that both pieces of legislation paved the way for the administration of cost sharing with the provinces and territories but did not create the systems of administration that would guarantee uniform access and delivery throughout Canada. Healthcare delivery was focused on medical specialists and hospital intervention, rather than prevention through reducing poverty. This created a total medical system that became cost prohibitive and virtually impossible to continue as per the philosophy laid down by the Royal Commission on Health in their 1964 report. Equal care to all Canadians became subsumed under ever-changing federal and provincial political and economic agendas.

Initially, the provinces were to receive from the federal government, “one-half of the national per capita cost multiplied by its enrolled population” (McGilly, 1998, p. 200). The incentive was for the provinces to keep their costs below the national average thus ensuring they would receive fifty percent or better. Those provinces that had medical care expenditures that exceeded half the national average would get less than half of their medical expenses covered by the cost-sharing program. Given the link between poverty and ill health, clearly not all Canadians were able to receive equal access to medical and hospital services, especially in the poorer provinces. The federal contribution to Medicare varied from 41% to 75% throughout the provinces (McGilly, 1998, p. 297). While in theory the plan for universal medical and hospital coverage appears sound, in practice it was plagued with inequality and abuse.

In 1977, the Established Programs Financing (EPF) was instituted to free the federal government from its costly commitment to paying half the costs of Medicare, and to attempt to equalize what the provinces could afford for healthcare. Because of the EPF, the federal

government began making block grants based on a complex equalization scheme aimed at providing a greater portion of transfer payment to poorer provinces. The block grant encompassed a cash payment called an equalization grant (not paid to the provinces with excessive wealth), tax points, and a residual grant, designed to balance out the payment. Reflective of growing neo-liberal philosophy that de-emphasized government involvement, this allowed the federal government to reduce its cash payment for programs over which it had no administrative control. The EPF mechanism of cost sharing allowed the provinces more control in that they did not have to reveal their hospital and medical expenditures to the federal government to receive their block grant (Guest, 1997; McGilly, 1998).

While the federal and provincial administration of healthcare has changed over the years, both hospitalization and medical care programs were merged into the Canada Health Act (CHA) in 1984. The CHA resulted, in part, from the situation of extra billing that was occurring throughout Canada that hampered the universal delivery of Medicare and hospitalization. In areas where extra billing was taking place, both doctors and hospitals were charging the patient beyond what was covered by the insurance plans. Believed by some to offset the growing cost of the delivery of medical services or to justly compensate medical professionals for their services, extra billing was also seen by others to have the potential to develop into a two-tiered medical system. Low-income and impoverished Canadians were in increasingly marginal positions when seeking healthcare where extra billing was the norm. Perhaps most problematic was the way in which extra billing undermined the very principles of socialized medicine which were at the core of the delivery of social assistance in Canada. It also served to reinforce the stigma associated with not being able to ‘afford’ costly medical services. This is also reflective of individual responsibility that is a core principle of neo-liberalism, where each person is accountable for his or her own self-interest. Any attempt on the part of government to reward those who do not acquire property or wealth to support themselves is seen to reward laziness or incompetence. Furthermore, “social policies (including healthcare policies) are totally meaningless for neo-liberalists as they are seen as a type of discrimination for those who do not get to benefit from them” (McGregor, 2001), primarily the affluent in any society.

The embeddedness of a neo-liberal political and economic ideology in the dominant master narrative in British Columbia can be found in medical care cutbacks. As the federal government cuts payments to the province, the provinces are not increasing their contributions to cover the reductions. This has been exacerbated by situations where extra-billing practices are the norm for many services. Somewhat different from British Columbia Medical, welfare

medical coverage often does not meet the amount billed by individual service providers, thus reducing the availability of practitioners for welfare recipients. As government cutbacks continue, more and more practitioners are not accepting welfare medical unless the patient agrees to, and can prove, that they can pay the additional charges for basic services before they are delivered, while other practitioners will not even consider accepting patients who receive welfare.

One can argue that evidence of the neo-liberal shift in Canada was indisputable with the announcement in 1995 of the Canadian Health and Social Transfer (CHST) to replace the CAP and the EPF. Under the CHST, a block transfer payment was established with the provinces that would amalgamate federal contributions for income assistance, social services, healthcare, and post-secondary education into a lump sum. While amounting to a reduced federal payment to the provinces, the trade-off was to remove the conditions under which the provinces should spend the transferred funds, beyond not being able to impose residence requirements on the recipients (Bach & Rioux, 1996). “Slashing federal cash transfers to the provinces reduced federal health spending from 6.18% of total federal spending in 1986 to 4.24% in 1992” (Fisk, 2000, p. 3). Continued cutbacks to social welfare in Canada have been justified by neo-liberals as reflective of the responsibilities of communities to “protect children and families and buffer them from the demands of globalized trade and markets” (Bach & Rioux, 1996, p. 324). The return to a residual welfare state once again calls into question conceptual judgments of worthy and unworthy poor and disabled. When one considers individual responsibility and self-interest, those who are disabled through their own actions (for example by contracting HIV) are viewed as not only a drain on the system but are also deemed as unworthy of its assistance. Hence, one finds the CHST opening the doorway to increased marginalization of vulnerable sectors of society.

Collins (1998) has called into question the degree to which the CHST will exacerbate the already problematic disbursement of social assistance in Canada. Under CHST, the minimum standards of assistance can no longer be monitored federally as a contingent factor of receiving the transfer payment. While the CHA maintains a minimum standard of care, though this is also questionable, there is no mechanism in place to ensure an equitable share of the CHST goes to provincial and territorial welfare programs.

Broadway (1995) (quoted in Chappell, 2001), and Collins (1998) discuss the potential that the CHST has for contravening the Canadian Constitution in that it may not guarantee accordance with the principles of horizontal and vertical equity. Horizontal equity requires “that Canadians ought to be treated comparably by the fiscal system regardless of the province in which they live” (Broadway, 1995, quoted in Chappell, 2001, p. 92). Vertical equity is a

“principle that the federal government should be concerned with national standards to reduce inequalities of income between the wealthiest Canadians and those who are least wealthy, and enhance equalities of opportunity for those most disadvantaged” (*ibid.* p. 92). As social programs are cut, in line with neo-liberal economic policies, levels of inequality in Canada will continue to rise, though in a free market economy, equality of opportunity is deemed a universal principle. The constitutional principles of vertical and horizontal equity that are paradigmatically fundamental to the welfare state are in direct contravention to neo-liberalism. According to McGregor (2001): “Nowhere in neo-liberalism is there a legitimate role for the welfare of the people, communities or societies nor for the state except to ensure that government enforces the rules and logic of the free market – economic profit, technological progress and growth and development” (p. 88).

Within the global neo-liberal political agenda, the welfare state in Canada, and in other nations, has been under constant attack for many years. Continuing reductions in federal support for healthcare and social programs, beginning in the 1970s and gaining momentum through the 1980s and 1990s, has increasingly displaced and further marginalized Canada’s poor and disabled. Contradictory to the principles of individualism, free market, and decentralization that define neo-liberalism (McGregor, 2001), Medicare in Canada is seen as promoting a not-for-profit enterprise. It is argued that Medicare defies free and open trade and, as such, promotes unfair trade practices in these times of globalization. At the level of individual lives and deaths in British Columbia, neo-liberal economic policies are having profound and devastating consequences for many disabled and low-income persons. Alex’s story of living within the constraints of social welfare in British Columbia exemplifies how both HIV/AIDS and welfare are socially constructed to encompass historically and politically-institutionalized marginalization and stigma such that agencies of the state are permeated with judgment and guided by the politics of blame.

Social assistance and welfare disability in British Columbia

The early days of Alex being unable to return to work due to complications associated with her HIV raises many issues in understanding the life circumstances for one living with the constraints of a long-term catastrophic illness for which there is no cure in sight. Clearly, Alex states how she defined herself through her work, and the degree to which this value was encultured within her childhood home and was reflective of the master narrative. In our family, work was more than a means to an end...it was how we established our value as members of both

our home and our community. Losing this ability to work, perhaps for the rest of her life, was a very traumatic and marginalizing experience for Alex. This feeling, however, was exacerbated when she was faced with entering into a system of welfare that reinforced that she was no longer in control of her life. The day-to-day uncertainty of HIV, coupled with the ongoing intrusion of welfare agencies, would define her world.

The meaning behind the loss of work for disabled people is an area of inquiry that sheds considerable light on how and why social assistance becomes, for many persons, a system of degradation and marginalization (Freedman & Fesko, 1996; McReynolds, 2001; Vachon quoted in O'Del, 1993). Often not cognizant of the many losses that persons seeking welfare assistance have already faced in their lives, and as Alex's story has revealed, many see those on welfare as taking from the system, being too lazy to work, or as a drain on society. Rather than easing day-to-day living, welfare in British Columbia guarantees that the disabled person lives below the poverty line and has their life open to an 'annual review' to ensure that the disability is still there. There is no option but to accede to the review or risk having welfare support immediately cut off. (See Appendix 11 for a copy of the British Columbia Benefits Eligibility Review annual report for 1998 for James and Alex. Note page 3 of the review that lists the areas of their lives open to government intrusion.)

When Alex was forced to give up her paid employment she also gave up the hope for a 'normal' life, in terms of how she had been encultured to believe normalcy was maintained. Research has revealed that, for many PWHA, remaining a part of the paid workforce is fundamentally important in how the person associates working with hope for a future, and in seeing their life in terms of living with the disease rather than dying from it (McReynolds, 2001). What Alex's story reveals is that many of the FAWs whom she has come into contact with have not communicated to her an understanding of the psychosocial factors of living with HIV/AIDS. Their treatment of her contributes to her infiltrated consciousness and subsequent loss of agency. I am curious of the degree to which the master narrative has influenced the picture that many FAWs hold toward the clients whom they are mandated to serve. Over the years I have heard Alex tell many stories of traumatic and degrading experiences with welfare and, as evidenced above, of the few kind and humanistic individuals that she has also encountered.

The embedded marginalization and stigma of the welfare system is a multifaceted and complex phenomenon. The FAWs who face people asking for assistance must mediate between their own bias or attitudes toward those seeking help, the current political and financial agenda that they are to enforce, the burnout factor as a result of an ever-increasing client load, and the

attitudes and/or financial issues of the clients themselves. While the CHST does not provide a minimum standard of treatment for administering assistance, there is an ethical responsibility to administer the policy of the welfare office without prejudice.

Alex has been on welfare disability through political and economic changes such that her well-being is almost ‘held hostage’ to current social constructions that define those on welfare. This lack of power over her own life was reinforced in 1998 when James and Alex were left with no option but to sign a consent form giving MHR the right to access information in any areas of their lives deemed relevant to the receipt of their welfare money. Important to note in the document that they had to sign is the section that lists the examples of places where MHR might need to access information, and that this list was not exhaustive. James and Alex signed over their basic right to privacy and protection from the intrusion of the government into many elements of their lives, a right that most of us take for granted. (See Appendix 12 for a copy of the request for consent and the signed consent form.)

Reflective of neo-liberal policies, Alex has experienced continued welfare reform that is increasing the challenge of meeting daily needs and ensuring a limited quality of life. As the definition of ‘disabled’ is under review by the current provincial Liberal government under the leadership of Gordon Campbell, many vulnerable persons, such as Alex, are increasingly finding their lives being thrown into turmoil, not knowing whether or not they will be deemed able-bodied and cut off of welfare benefits.

Regardless of the impoverished positions of those in need, neo-liberal economic policies target for reduction the socially, politically, and economically unpopular programs, such as social assistance, (Chappell, 2001). In June 2001, the Liberal government redesigned the Ministry of Social Development and Economic Security. The new Ministry of Human Resources (MHR) emerged and “began a redesign of income assistance in British Columbia, including a significant shift from a culture of entitlement to a culture of employment and self-sufficiency. It laid the groundwork to replace British Columbia Benefits with the British Columbia Employment and Assistance program, aimed at helping more British Columbians leave assistance for employment and lead independent lives” (Coell, quoted in British Columbia, Ministry of Human Resources 2001-02, p. 1).

In the language of the new MHR, the report identified that “Persons with disabilities who want to and are able to work are not getting the supports they need to get and maintain employment” (*ibid.* p. 5). While the MHR culture shift is to “employment and self-sufficiency”

the categories of those needing continuous assistance and supplementary assistance are aimed at disabled persons.

Continuous Assistance will be available to eligible individuals who are not expected to gain independence through employment to ensure these individuals get the ongoing support they need. This will include persons with severe disabilities and those with persistent multiple barriers to employment.

Supplementary Assistance will provide health assistance to clients with disabilities and other eligible clients. Other programs and services include emergency social services, childcare subsidies, bus passes, hostels and emergency shelters, and user fees for continuing care and for drug and alcohol facilities. (*ibid.* p. 6)

What the above descriptions fail to provide are the ever-changing criteria that one must meet to remain eligible for the assistance, or to address specifically what degree of support will be provided. The reality experienced by those receiving continuous and supplementary assistance does not necessarily reflect what is quoted above.

Considered a major change in policy is the '*Employment Strategy for Persons with Disabilities*'. This reflects a general trend emerging from the 1996 First Ministers' meeting, where "persons with disabilities were identified as a priority area of joint policy reform" (Disability WebLinks, retrieved July 15, 2001). The resulting focus for the provinces and territories was to develop a multilateral framework for employability assistance for people with disabilities. Thus, the general trend emerging throughout Canada can be seen in the policy changes in British Columbia with regard to the disabled. In British Columbia, the MHR is to provide services to prepare disabled persons to either become fully self-sufficient through employment or, for those deemed unable to become self-supporting, to engage in volunteer activities at the community level (British Columbia, Ministry of Human Resources, 2001, p. 8). While in theory this plan seems optimistic, the reality is much different.

Research has shown that, while many disabled persons in Canada have made significant strides in entering the allegedly non-disabled workforce, there is still considerable discrimination and marginalization facing them. Many employers are unwilling to make the accommodations needed to create an inclusive work environment for disabled people thus causing their workforce representation to be low (National Council of Welfare, 1990). In 1994, Alex's employment with a women's HIV/AIDS support and resource organization was terminated due to extended illness. (See Appendix 13 for a copy of the termination letter to Alex, citing ill health as the reason.) Even though the organization was mandated to assist HIV-positive women, she was not offered a

leave of absence until her health improved. Given the stigma attached to being disabled, in a general sense, coupled with the fear and marginalization associated with HIV/AIDS specifically, one needs to question what the government's position might be on the intended employability of PWHA who have been absent from the workforce for a number of years.

Another area of significant change is the 'streamlined appeal process' which will come into action alongside of the new Employment and Assistance Act and Employment and Assistance for Persons with Disabilities Act. Under this process, the appeal Tribunal Committee will not resemble the panel that was assembled to hear Alex's Schedule C appeal. Under the new ruling, the Appeal Tribunal will be made up of a Chair and Vice Chairs who are appointed by the Lieutenant Governor, and regional Appeal Panel members, appointed by the Minister of Human Resources²⁶. Nowhere does the tribunal accommodate advocates for those on welfare. As Alex says, "They have found a way to silence us again. I can't believe that the tribunal process does not have a voice for the client. That is so sad."

On January 17, 2002, the British Columbia Government announced additional changes to the welfare act to be implemented throughout the year. James and Alex received notification on March 18, 2002, of the changes being implemented on April 1, 2002 (see Appendix 14 for the changes to the disability benefits for level 2). Critics of these changes, including community-based advocacy and lobby groups, have been very vocal about the lack of social justice associated with the new "culture of employment and self-sufficiency"²⁷. Under the existing British Columbia Benefits, disabled persons are categorized as either Disability Benefit I (DBI) which suggests non-permanent status, or Disability Benefit II (DBII) suggesting permanent status. In the past, DBII, once established, was accepted as permanent in that the individual did not have to continue to prove disability, thereby did not have to live with the stress of being cut off or living on reduced benefits as a DBI.

With the implementation of the new Assistance for Persons with Disabilities Act in the fall of 2002, the DBII designation is no longer considered permanent. Status will be under review

²⁶ For additional information on the Government-issued specifics of the Tribunal refer to <http://www.mhr.gov.bc.ca/tribunal/background.htm>

²⁷ The information and statistics for the following changes have been compiled from the PovNet Legal Services Society, and the BC Coalition of People with Disabilities websites. These can be accessed at the following addresses. <http://povnet.org> , <http://www.lss.bc.ca> , and <http://bccpd.bc.ca>

and a narrower definition of disabled will be applied²⁸. To qualify for disability benefits a person will need to prove that they are directly and significantly restricted in their ability to perform the tasks of daily living. Although the clear definition was not revealed when the change was made public in 2002, the implications for PWHA can be catastrophic. If a person loses their DBII status, their monthly support and shelter cheque will drop from \$786 to \$607 (if a DBI) or to \$510 per month (if assessed as employable). Couples who are both DBII receive \$1,329, which will be reduced to \$972 if the couple is assessed as DBI. While the government's rationale is that it is cheaper to live as a couple than as a single, Alex and James' experience with stretching their welfare money suggests otherwise. Additionally, if one loses the DBII status they will lose their extended medical, bus pass, access to basic dental, and the exemption allowance of \$300 that a DBII person may earn per month through volunteer activity. If reduced to a DBI, any extra income earned will be deducted dollar for dollar from one's cheque. In Alex's case, if she is deemed employable, and cannot find a job on Salt Spring, under the new Act she will have to move from the island, as Salt Spring is considered an area of low employment.

Further complicating the entire process is the uncertainty around reinstatement. If a person's disability designation is reduced, they must reapply for a reinstatement at the higher level. If, and when, this is approved, they will begin at the bottom without enhanced medical coverage or any other additional supplements to their benefits. In the case of Alex and James, then, this would mean that the Schedule C money that they fought for years to obtain would be gone. Under the new Act, Schedule C section 2.1(1) of the British Columbia Benefits program has been abolished. On April 2, 2001, MHR announced the new nutritional and medical supplement that will likely replace Schedule C. This allows for up to \$300 per person, per month. Being defined as a nutritional supplement, it does not allow for the wider-ranging health needs that were available under Schedule C, thus it is questionable as to what one needs to prove to be eligible for the maximum amount (see Appendix 15 for a news release pertaining to supplemental benefits).

After years of being within the welfare system and fighting for benefits over and above the basic DBII designation, as of July 2002, Alex and James receive a total of \$2,004 per month for shelter and support. See Table 1 for their monthly budget.

²⁸ While there has been considerable critique over the narrowing of the definition of people with disabilities by many NGOs in support of disabled persons, the MHR responded, through two Letters to the Editor, to the allegations that people would lose their benefits and/or be under the constant threat of having their disability designation reviewed. These letters can be viewed at http://www.mhr.gov.bc.ca/editor/Min_editor_DB.pdf and <http://www.mhr.gov.bc.ca/editor/Cheema-Coell.pdf>

Amount	Expenses
\$675.00	rent for home including hydro
\$20.00	welfare deduction for previous security deposit
\$100.00	rent for garage/storage/workshop space attached to home
\$60.00	car insurance monthly payment
\$90.00	bank loan payment
\$35.00	Telus, home phone
\$32.00	Telus mobility
\$70.00	Starchoice satellite
\$25.00	Imagen internet service
\$120.00	clinic fees, Royal Oak Clinic
\$45.00	purified bottled water
\$25.00	household cleaners, bleach etc.
\$120.00	laundry costs inc. wash/dry/soap/softener
\$100.00	car, gas/oil/parking not including repairs
\$15.00	household garbage and recycling
\$120.00	vitamin/mineral/supplements
\$30.00	pet food and supplements...not including vet costs
\$322.00	food...and all other expenses including entertainment, car repairs, vet expenses, presents, clothing, not covered medical user fees, non-prescription medications, personal hygiene items and anything else that is needed
\$2004.00	Total

Table 1: 2002 Monthly budget

As for assets, before the restructuring of British Columbia Benefits, a person on disability benefits was allowed to have a vehicle for daily transportation. For a DBII, the value of this was not required to be included in the total assets for a couple which are limited at \$5,000. Under the new Act, the car is included in the allowable assets of \$5,000. As of April 1, 2002, if the assets exceed the \$5,000 limit the cheque can be immediately cut. Earlier in this chapter, Alex wrote of her frustration at the FAW who suggested she sell her wedding rings rather than grant the additional \$35 to help with an outstanding hydro bill. Under the new asset designation, a worker could force them to part with these rings, or reduce their assets in some manner, or risk having their cheque cut off (see Appendix 14 attachment for a list of the changes to the asset limits for Disability Benefits Level 2).

There is considerable research that examines the poverty which a person living on welfare faces. Problematic, however, is the lack of consensus regarding what poverty is, how necessities are measured, and whether or not there can be a universal definition of poverty. Given that the concept ‘poverty line’ is a social construction in and of itself, the context within which it is being defined must be considered. Furthermore, poverty lines are highly political concepts that are often paraded about at election times to garner support either for or against welfare reform. Low-income cut-offs (LICO) are a set of measurements published by Statistics Canada that are often used by researchers as representative of the poverty line. While Statistics Canada emphasizes that LICO and poverty are different measures, they do provide an indication of characteristics relative to the poorest income categories in Canada (Fegelli, 1997). Using LICO, the National Council on Welfare (2001) has calculated that a single person with a disability who was living on welfare in British Columbia in 2001 would have a total welfare income of 52% of the poverty line²⁹. *The Canadian Fact Book on Poverty, 2000*, suggests that any Canadian family spending more than 63.6% of its after-tax income on food, shelter, and clothing, would be living in difficult circumstances (p. 17)³⁰. Clearly when looking at the monthly budget for Alex and James one finds that the ‘difficult circumstances’ suggested above should read ‘impossible circumstances’.

²⁹ The entire report can be obtained at http://ncwcnbes.net/htmdocument/reportelfinc00-01/WI-2000-01-ENG.htm#_Toc2735441

³⁰ Accessed at <http://www.ccsd.ca/pubs/2000/fbpov00/chapter2/pdf>

Non-basic supplemental benefits

As of March 31, 2002, Home Support Services were no longer allowed under MHR and one had to apply for the services through the Ministry of Health. If a disabled person was receiving home care support it would be cancelled. Prior to moving to Salt Spring Island, Alex and James relied on the services of Home Support when they were living in Vancouver. These services were vital to their well-being since there were numerous times when neither James nor Alex was well enough to cope with daily living requirements. Upon moving to Salt Spring, these services were lost. While home support is supposed to be a portable service throughout the regions of British Columbia, as stipulated within the Ministry of Health's Continuing Care Policy Manual, the reality is often very different.

During the fall of 2001, I recall a time when both James and Alex were sick with nausea, diarrhea, and vomiting. While Alex had requested home support assistance, she had yet to hear back from the coordinator. Alex was too sick to properly care for herself and with James' health condition being so severe, any energy Alex had was aimed toward providing minimal care for James. As James' health deteriorated, he ended up being put in hospital in Vancouver. While they were in the city, I went over to the island to get things ready for James to come home. Entering their house almost broke my heart. I could see the aftermath of what they had lived through in the weeks that they had been sick without home support assistance. In talking with Alex about this she recounted to me the struggle that each moment brought. She wondered if it was worth it to keep going as her own health continued to deteriorate. She did not know how she would be able to continue to care for James when they were both so very sick at the same time.

Throughout this time, Alex was continually trying to get some level of home support reinstated. After numerous calls to an overworked Ministry of Health home support coordinator servicing the Gulf Islands, James was approved for personal assistance for a few hours a week. What this meant was that the bathroom could only be cleaned if James would bathe while the worker was there and the kitchen could be cleaned only if James was well enough to eat while the worker was there. There was no provision for assistance to Alex for housecleaning, cooking, laundry or personal care.

There is a vast amount of research that supports the need for many disabled to remain in their homes thereby enabling them to live with dignity and in control of their own lives. The continued claw back of home support services by the government is increasingly compromising independent living for British Columbia's disabled population. Reassessments of current levels

of care are constant for disabled people³¹. The absolute uncertainty under which many disabled people live is contributing to increased ill health. There is no lack of data supporting the link between increased stress and increased ill health. In the case of HIV/AIDS, elevated stress levels are directly associated with weakening the immune system, thus creating a life-threatening situation.

Additional cutbacks, as referred to by Alex earlier, include dental coverage. During the late fall of 2001, Dr. Burdge³² of the Oak Tree Women and Family HIV Care Unit in Vancouver wrote a letter to the dentist James had seen on Salt Spring providing documentation stating the absolute need for his teeth to be pulled out and be replaced with dentures. Given that the condition of his teeth had deteriorated substantially in the last ten years because of his HIV, it was believed that some of his intestinal problems were related to this. The local dentist concurred with the assessment and took on the task of seeking approval through the welfare system. Unfortunately, James became very sick, was hospitalized, and the process was put on hold.

James was released from hospital in Vancouver just before Christmas 2002 and saw the local dentist in early January. Upon receiving verification that James' white cell count and platelets were up and that his immune system was strong enough for the procedure, the dentist started the paperwork process for approval of dentures (see Appendix 16 for a copy of this letter). Because James had an ongoing problem with his platelets, he was referred to a dental surgeon to have his teeth removed under general anesthetic. The dental surgeon began the approval process through welfare for the removal of his teeth in the late spring and James received approval on June 28, 2002. This approval arrived a few days before the new policy was implemented that would not have allowed for the surgery to take place with full coverage, meaning that James and Alex would have had to pay the difference over and above \$500. Given that James has had ongoing problems with getting enough nutrition into his body, it was imperative to his health that any barriers to increasing his nutrient intake be removed. With the approval in hand, the dental surgery took place on July 10, 2002.

Unbeknownst to Alex and James, the dentist who had begun the process of filing for approval for the dentures had left the office at the end of May 2002 without having sent in the approval forms. On June 13, 2002, a new dentist in the office who took over James' case saw him for a pre-surgery check-up. It was at this time that James discovered that his paperwork for

³¹ For additional information on the impact of Home Support cutbacks refer to <http://bccpd.bc.ca/commalert/homesprt.html#critical>

³² Dr. David Burdge has formally consented to having his name appear in this dissertation.

denture approval had not been submitted by the previous dentist, but had lain in his file for months. The new dentist faxed the paperwork that day and the office suggested that approval could be obtained and the dentures made within four to six weeks. This was of specific concern to James and Alex as his being without teeth for months would only exacerbate his already nutrient-deficient condition.

In June 2002, MHR released a new policy for dental coverage which removed any option for dentures under the DBII \$500 yearly maximum. Additional dental beyond the annual limits would no longer be covered unless services were needed to relieve pain³³. Given that James' dentures were not associated with pain relief, merely with enabling him to obtain adequate nutrition from his food to improve his health, they were not covered under the new policy. On June 28, 2002, the dental office notified Alex of the new policy and that MHR was trying to process the backlog of requests. If their request was not approved by 4 p.m. that day it would not be approved. This presented a predicament in that James and Alex needed to come up with over \$2,000 for the dentures and, knowing this would take months to save, were unsure of going ahead with the removal of his teeth. The dental surgeon's office gave them until July 8, 2002 to decide if the pre-approved surgery would go ahead.

Hearing this, the local dentist assured them that it was necessary for his teeth to come out and to not delay the surgery. If they could come up with the lab fee of \$700, she would donate her time on a day off and she would find a way to have the remaining costs covered. Feeling assured that all would be okay, James went ahead with the surgery.

On July 12, 2002, James saw the local dentist for a surgical follow-up, at which time the dentist laid out James' and Alex's portion of the cost for the teeth. James had another follow-up appointment on July 15, 2002. On Sunday evening July 14, the dentist phoned Alex at home to tell her that she had been fired. The employer provided the rationale that the dentist was doing charity work and that it was not acceptable nor in line with the operating procedures of the clinic. What was perceived as unacceptable charity on one hand could mean the difference between life and death on the other. James was once again deemed unworthy and undeserving and Alex, as his primary advocate, was dealing with unbearable levels of stress that continued to diminish her health.

Another impact of the new policy changes of MHR is the Employment and Assistance for Persons with Disabilities Act, implemented in the fall of 2002. As discussed earlier, the

³³ This information was obtained from a Government Fact Sheet that can be accessed at <http://www.mhr.gov.bc.ca/factsheet/2002/dentalserv.htm>

narrowing of the definition of disabled, for the purposes of welfare, means that many persons who are currently classified as DBII will lose their designation and their benefits. For persons with HIV/AIDS, this poses a complicated scenario because of the uncertainty and variability of day-to-day health. The current drug combination therapy has, for some infected persons, reduced the detectable levels of HIV in the bloodstream, such that, while the drugs remain effective, the person may experience a relatively healthy condition. For some, this has allowed either a continuation of, or a return to, work. Problematic, however, is that once one has begun a regime of highly toxic treatment, one's life is controlled by a pill timer; facing a future that will likely never be free of a complex drug regime. Complicating this are the numerous side effects that also diminish quality of life over time, and in some cases can be directly debilitating. As the HIV becomes resistant to one set of drugs, and the HIV levels in the blood increase, a new regime is started in the hopes that health will improve. With the new MHR disability policy, it is likely that a person receiving benefits would have them cut off as health improves and they return to work. While this is not problematic, in and of itself, when health declines, as it will, the person's benefits will not be reinstated at the level before cut-off. Any supplements that they have fought for will be lost as they begin with the basic disability benefit, as per the assessment. The uncertainty that this poses can have, for some, life and death consequences.

In 1999, Dr. Burdge suggested to Alex that she should put some serious thought into beginning anti-retroviral therapy, as her viral load was increasing and her T cell counts had been steadily decreasing. For intervention to be effective, it was stressed that Alex should begin treatment as soon as possible. Given that drug treatment often begins with side effects, Alex chose to delay the start of the drugs so she could care for James, who was quite sick himself at this time. Early in 2002, Alex had agreed to start treatment, and waited for the approval from the federal government for the drug regime, which took two months. Once approved, she began on the drugs but, after five days, was having an extremely adverse reaction and had to stop the regime. While waiting for approval for the next regime to be processed, the new MHR policy changes were announced, at which point Alex became afraid of the impact these would have on her and James' lives. While the changes were slow in being released by the government, Alex believed that the changes would not be good for them.

Under the new classification, Alex knew that some of the areas that had classified her as DBII were being removed. Her experience in dealing with a bureaucracy like welfare reinforced the belief that the new definition of disabled as it pertained to HIV/AIDS would be based on medical measures such as viral load and T cell counts, not on the day-to-day qualitative

measurements of health levels of the individual. Alex knew many persons whose counts suggested relative health but in reality those persons were not well. Many suffered from extreme fatigue and any of a number of illnesses associated with HIV and thus were not employable. She felt the full weight of MHR control over her life and health to the point that she made a decision to delay taking the AIDS drugs and wait until the full disability definition was made public before considering drug therapy again.

While at first I had difficulty understanding her reasoning because she was becoming increasingly weaker and more fatigued and I just wanted her to get better, I eventually came to see the complexity of factors and stressors impacting upon her decision. If her health was to improve on paper and she be deemed employable, she would lose whatever security had been provided by welfare, albeit at a minimal or less than minimal standard. At least on welfare she and James were guaranteed food, shelter, basic medical and dental. If deemed employable, she would be gone from the home, thus leaving James without home support care as these services had been drastically reduced and were to potentially be cut off. Also, based upon whatever work she might find, James' welfare support would be threatened based on her potential earning capacity. However, due to her own health, and the side effects of the drugs, it was not guaranteed that she would be healthy enough to work continuously. There would be no guarantee of steady income. With HIV/AIDS, medical costs are continuous and difficult to plan for and, as the syndrome changes so fast, she would need to earn a substantial amount of money to cover all contingencies on her own.

What I need to reinforce here is that the new regulations being implemented were making Alex afraid of becoming healthy and as she said, "It is like an axe over my head, I'm waiting for it to fall. There is a part of me that feels like just stopping the fight and letting it take its course." She knows that the anti-retroviral therapy is not a sure thing and that there is no cure in sight. Furthermore, hoping for health and hoping for a future is something that she has been unable to do since 1986. As she suggests, "If I had any faith that these programs were being done in a humane way I wouldn't be so afraid. I know that my best interest is not in their heart. The next election is what is most important to them. They don't give a shit. Part of me just wishes that those making these decisions would have to experience the implications of their decisions."

Beggars can't be choosers

This chapter was extremely difficult for both of us to write. In critically examining the influence that MHR has over James' and Alex's lives, she said: "It pops my little bubble of

illusion. The illusion being that in this aspect of my life I have some control. I created this illusion by avoiding welfare at every turn.”

Throughout this chapter we have shared tears and frustrations, anger and hopelessness, at the inhumane way in which much of the administration of social assistance occurs in British Columbia. In going through the above brief chronology with Alex, of her history with welfare, she expressed how tired and depressed it made her to revisit these events. On August 1, 2002, the day before her 37th birthday, we decided to end this chapter. Both of us had reached a limit of the amount of reality we could be immersed in and needed a break. Alex needed to care for James and I needed to make a birthday cake.

Over the years of teaching anthropology and engaging students in discussions of structural marginalization, I have encountered many who believe that people on welfare should accept what they get without complaint. The ‘beggars can’t be choosers’ line that many of us have heard throughout our lives is often applied to those on welfare. This belief is embedded within an oppressive master narrative and communicated in a number of ways. Whether through the media, or imbedded within institutional structures and policies that administer to welfare recipients, or in the rhetoric espoused by political leaders seeking votes, by medical or dental practitioners servicing welfare clients, or within the general public at large, there is a deeply-rooted belief that those on welfare are deserving of the suffering in their lives. Nowhere is this made clearer than in the literature on the relationship between poverty and HIV progression.

Research has revealed that socio-economic status has a clear impact on the length of time a person can survive with HIV/AIDS (Gillies & Tolle, 1996; Hogg, Strathdee, Craib, O’Shaughnessy, Montaner & Schechter, 1994; Zierler, Krieger, Tang, Coady, Seigfreid, DeMaria, *et al.*, 2000). Those with greater income have a longer life with greater levels of health. Those in poverty are sicker and tend to die faster. Given that welfare disability maintains persons below the poverty line, Alex has often questioned whether it is part of a larger plan to cut spending by hastening the deaths of those with HIV/AIDS due to the way in which their cases are managed. As she writes earlier in this chapter, “welfare is based on a system of penalties” and perhaps the penalty for contracting HIV is to suffer, not only ill health leading to death, but also marginalization on an ongoing basis due to an entrenched societal belief that beggars can’t be choosers.

This chapter was written during the spring and summer of 2002; therefore, many of the events were unfolding as we were writing, and the reality became like a crushing weight. We had little, if any, distance from the events. Many days, we would not be able to work on the

dissertation as Alex was too exhausted from battling ill health and depression as well as being a caregiver to James, who was very sick. While the days would be spent trying to find solutions to the seemingly impossible situations they were facing regarding welfare's medical and dental decisions, writing this dissertation seemed of minimal importance in the scheme of things. Witnessing their daily struggle made me question even more the degree to which the objectivity of positivism has contributed to the coldly impersonal forces that are controlling Alex's and James' lives and deaths.

In critiquing a positivist tradition that would maintain that academics are obligated to write of another's suffering in an impersonal manner, and that we can remove ourselves from the influence of another's pain and write free of bias, I suggest that this writing is exploitative, abusive, and self-serving and does not bear witness to another's life as lived. The ethics of ethnography in the twenty-first century imply that we need to reposition the voice of the subject as central and call into question forces of representation and legitimization, while self-reflexively looking at our own power over the written narrative. I believe this cannot be done unless we open ourselves up to the weaknesses of both our subjects and ourselves, and in doing so become, as Ruth Behar (1996) would suggest, vulnerable observers. I would be remiss, and even dishonest, if I asserted that the events, which occurred during the writing of this chapter, did not profoundly affect my perceptions and analysis. In raising these difficulties in fieldwork, Behar writes:

Our methodology, defined by the oxymoron "participant observation," is split at the root: act as a participant, but don't forget to keep your eyes open. Lay down in the mud in Columbia. Put your arms around Omaira Sánchez. But when the grant money runs out, or the summer vacation is over, please stand up, dust yourself off, go to your desk, and write down what you saw and heard. Relate it to something that you've read by Marx, Weber, Gramsci, or Geertz and you're on your way to doing anthropology. (p. 5)

Behar's quote above suggests that the anthropologist has physical distance from the subject of study, and in doing so ends up distancing herself from the emotional aspects of doing fieldwork. In the case of this research, Alex and I do not have the physical distance referred to by Behar. The emotional distance is perhaps easier for me to obtain than it is for Alex as I am not the one living with a terminal illness. Having said this, however, I cannot ignore the pain and sorrow that washes over my body in waves when I witness her suffering and empathize with her fears. The intimate relationship that has developed between Alex and me throughout this research in many ways parallels what Frank (1995) calls for when listening to those whose narratives we record, we must "listen for ourselves. The moment of witness in the story crystallizes a mutuality of need, when each is for the other" (Frank, 1995, p. 25). Clearly, Alex and I, as collaborators on

this project, are recognizing a “mutuality of need” that goes beyond the dissertation itself, and in doing so, are each finding voices that have up to now been silenced.

Throughout this chapter, Alex and I looked at the administration of social welfare in Canada and British Columbia that has historically, politically, economically, and medically defined the lives of those who are its recipients. We have laid a foundation that challenges the rhetoric of the dominant political ideology embedded in the master narrative that suggests that welfare recipients, including those who are disabled, are being provided with their basic minimum without judgment or prejudice. The “culture of self-sufficiency” referred to by British Columbia’s Minister of Human Resources, Murray Coell, needs to be critically analyzed as to whether it truly reflects an ardent attempt to address the needs of disabled welfare recipients or if it is merely political rhetoric aimed at justifying spending cuts to programs that service the most marginalized populations in British Columbia. If Alex’s narrative is seen as ‘evidence’ of the ‘culture of self-sufficiency’ in action it leaves no doubt that we are deeply into a time of residual care as opposed to one of institutional support for impoverished and disabled persons.

In terms of linking this collaborative narrative work to policy and practice, I believe that putting a human face on what it means to live with a chronic illness in the times of neo-liberal cutbacks is necessary. The British Columbia government’s policies for administering welfare for those who are disabled reflects the push toward self-sufficiency. The language of policy suggests, “we will implement new strategies to support persons with disabilities to move in and out of employment, as they are able...We want to assist people to have the motivation and the skills they need to get a job and lead more fulfilling and independent lives” (see Appendix 14, pg. 1). On paper this seems quite reasonable to one who has no experience with chronic illness. The reality, as evidenced by the earlier illness narrative, suggests a vast gulf between policy and practice. For many disabled persons with HIV/AIDS the qualitative indicators of ill health may not reflect more quantitative indices employed by welfare. Alex cogently explores the difference between what blood work suggests about a person’s HIV and the reality of lived experience. Narratives such as Alex’s give depth of meaning to living with chronic illness that is not available in medicalized reports. Biomedical reports intentionally remove human suffering and depersonalize the story, often in the quest to objectify and thus validate the case study. Unfortunately, the lack of recognition of the important perspective provided by subjective illness narratives is a thread that runs throughout the biomedical master narrative.

Two very important points are raised in Alex’s narrative that merit review here. Firstly, her decision to delay anti-retroviral therapy while waiting to see how the British Columbia

government would define the characteristics leading to the self-sufficiency of disabled, brings to the fore the fear of losing the safety net that she had fought so long to be able to provide for her family. The practical implications of such policies suggest that they have the potential to be stress inducing, thus further compromising one's health. Secondly, Alex's experiences with paid employment as an HIV-infected woman also suggest that the potential employers of those with HIV need to be educated or sensitized to diminish the stigma and discrimination that accompanies the diagnosis. It is not as easy as the policy suggests to find stable and secure employment for chronically-ill persons. The necessity for leniency may not be part of the employer's operating procedures. Illness narratives that explore the problematics of securing safe employment for HIV-infected persons go beyond an understanding employer. The compromised immunity of many with HIV suggests that the paid work situation must be one where the employee is granted scheduling flexibility, without prejudice. In practical terms, this means that the delicate balance must be struck between protecting one's decision whether or not to disclose HIV status coupled with a work setting where co-workers are aware of the threat they may pose to one with compromised immunity. Whether or not this can be achieved, in a generalized sense, in the climate of self-sufficiency and the politics of blame is yet to be seen. While there are employment situations where HIV-infected persons are welcome and supported, one cannot presume that this is the case overall as evidenced by Alex's narrative. In the vague language of the policy changes of MHR (see Appendix 14), the answers Alex requires from the Ministry are not forthcoming. From a practical health sense, improving the dialogue between disabled persons and government agencies responsible for policy creation is essential to one's overall health. Illness narratives may be one mechanism of bridging the gap between policies and their practical implications for PWHA or other chronically ill persons. Were this to come about, MHR disability benefit changes may actually work toward self-sufficiency rather than create continuing levels of unbearable stress for many relying on it for survival.

CHAPTER IV: MEDICAL CONSTRUCTIONS AND IMMORAL MARGINALIZATION

*Time is perpetual motion
Bound by no firm rule
Pace is but its whimsy
Ebb and flow its tool*

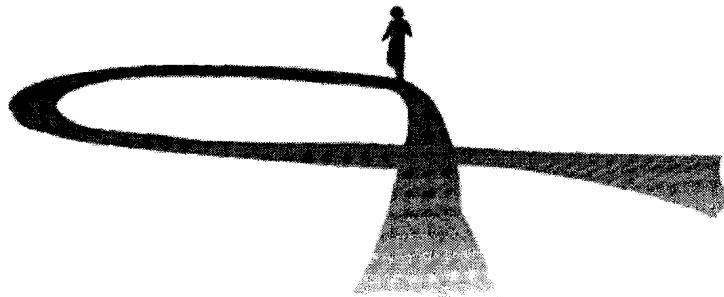
*Time flows in not one direction
Its' capriciousness eternal
Thriving on our disillusion
Its' motives seem infernal*

*We find ourselves in life perplexed
By the speed that time can fly
Or those moments that it creeps along
To revel in our cry*

*To me time seems the enemy
That grazes on optimism
Fragmenting my desires and dreams
Like light through a prism*

*Some see time as my friend
Since my illness lies in wait
But this infliction is insidious
So for me... time is too late*

Alex Keating, August 28, 1987



Alex's story

When I do public speaking, most of the medical and health discussions centre on my husband James' health and my care-providing role. I would guess that is because my role as care-provider for my family has dominated my adult life. This is due in part to the continuous and life-threatening nature of the illnesses that have plagued James for the past fourteen years. But more than that it has also been a self-defence mechanism. Focusing on James and his battle for life and health enabled me to not focus on my own health issues. I believe it is a common thing for a woman's health issues to be put on hold when her family has a need. In this way I am no different than others. Where I may differ from some is that my family's health crisis not only left many of my needs unaddressed, it also became a conscious way to avoid my own critical health issues. It's easy to put off blood work or a Pap smear when you think that your husband might die. I am not saying that I exaggerated James' health situation in order to avoid my own. I didn't need to. He faced death at least once if not twice a year for 10 years. The crises were there, I just used them as a reason to avoid certain health concerns of my own. What I find interesting when looking back is that not only did I avoid going for the tests or treatments that I needed but also I did not talk about my own health situation in much detail when I was doing a public presentation. I would use a small general phrase like "I was unwell for awhile" or "I had some cancer problems" but I wouldn't go into detail. On occasion, students or participants would ask me a direct question about my health. I would answer these questions but would still not go into much detail. For the purposes of this dissertation I've agreed to talk more about my own health situation. With this in mind I guess a good place to start would be somewhere between the time I was infected with HIV and when I was diagnosed HIV-positive.

The physical symptoms were not the first effects of HIV I had to battle. My emotional and mental struggle came first. Once I realized I had most likely contracted HIV, a sick and heavy feeling grew in the pit of my stomach and stayed there for months if not years. At that time, the only way I could get a handle on that feeling was to go into denial. Denial can be a very effective coping mechanism as long as you don't allow yourself to stay there too

long. I almost did stay there too long. It took me years to get past this stage of denial. I was angry at my stupidity in not protecting myself and I was fearful that I was dying. Over the next couple of years, watching friends of mine getting sick and dying exacerbated my fear. It seemed to drive me deeper into that place of "if I ignore it it's not true."

It was during this time that I had my first scare with cancer. In 1987 a small lump about the size of a pea had come up on my outer right calf. This little lump became red and sore, which led me to see my doctor. This general practitioner (GP) decided I needed a biopsy and did so that day in her office. The biopsy was sent away to the lab and a couple of weeks later I was contacted for an appointment at the Cancer Control Agency of British Columbia (CCABC). I had an initial appointment with one of the physicians there at which time they told me there's a possibility of cancer cells from that growth and I was scheduled to come back for surgery. Many of the details of this time period are hazy. I don't remember all the specifics; I am just left with the general sense of what transpired. I know I was admitted to the CCABC for surgery and that I was there for a few days. The release form I was required to sign prior to surgery stated that I was giving the surgeon permission to remove as much tissue from the side of my leg as he deemed necessary. When I woke up after this surgery and was able to see the incision I was shocked. This all started over tiny lump the size of a pea but what I was left with was a six inch-long scar. The surgeon had felt it necessary to remove the tissue from an area six inches long and four inches wide and right down to the bone. I don't recall the actual diagnosis regarding the tissue they removed. I know there was no follow-up required other than caring for the incision.

During all this I was still in my state of denial and never informed the doctors at the CCABC that I believed I was HIV-positive. Looking back at this I feel ashamed. I am aware that medical personnel use universal precautions in order to protect themselves and their patients. I am also aware that medical personnel regularly come in contact with people who are undiagnosed but are infected with HIV. That being what it is, I still feel shame. I've had to forgive myself for this as I've come to realize that I was not yet ready to put my fears into words. To do this would make it real.

My decision to be tested for HIV was not initiated due to ill health; it was because I desired a more intimate relationship with James, the man I was then dating. James was HIV-positive and I knew in my heart that I was HIV-positive. I felt a need to confirm the status of my diagnosis before James and I went further in our relationship. This was very important to me as I knew an HIV diagnosis after James and I had been together longer would be something he would blame himself for. I could not allow this; I knew he did not infect me.

This is what motivated me to break through this barrier of fear I carried for the previous three years. I was tested at the Simon Fraser University health unit, the unfortunate details of which have been discussed previously. The circumstances of this testing resulted in my not seeing a doctor for a few years, even though I had begun experiencing symptoms of my HIV.

How the HIV began to manifest itself in my body was with fevers and night sweats. I also began experiencing headaches that would last for days and my fatigue level started to grow. When I finally felt it was time to address my health issues I went to a new doctor. It would have been sometime in '91 or '92. This physician gave me a complete physical that included new blood tests for HIV and a Pap smear. My HIV test once again came back positive and I was also diagnosed with hepatitis C. My Pap smear results came back with abnormal cell growth, a situation, the doctor assured me, was nothing to worry about as many women have abnormal cell growth results. It seemed this doctor was unaware of the connection between cervical cancer and HIV in women. The assurances regarding my Pap results were the only encouraging dialogue I got from him.

He proceeded to explain his version of the facts of my life to me. That I didn't really have one to look forward to. I was told to expect this disease of HIV to progress rapidly and that life expectancy was a few short years, maybe as little as two. I was also told that I should consider myself a nonsexual being, which was the only responsible thing to do. The fact that I was married and monogamous didn't seem to register with this doctor. It was like all he could see was the stereotype of a 'promiscuous woman', my reality did not seem to make an impression on him. In retrospect what I find interesting is that he never really talked about the hepatitis C. Hepatitis C is also considered a terminal and, at that time, untreatable illness,

yet this doctor did little more than tell me my diagnosis. It was like the HIV blinded him to everything else. Sadly I would find this was a thread that would run through much of my medical future as well as my husband's.

During the same time period I began to experience recurrent respiratory problems, chronic bronchitis, as well as bouts of pneumonia. Each time one of these illnesses occurred they lasted longer and my fatigue level increased. I began to find I was unable to recover fully. Time came for me to have another Pap smear done. The results from this were also abnormal. This led to my seeing a gynecologist who performed a colposcopy. The results from this procedure showed possible cancer cells so a cone biopsy surgery was performed. The doctor responsible for this asked for no follow-up other than further Pap smears. There was no correlation made between the cervical cancer and HIV by this doctor either. But why should he because female-specific AIDS-defining illnesses had not yet been addressed by mainstream medical. The only AIDS-defining illnesses that appeared in the definitions had been based on male subjects.

Although by this time I had withdrawn from school, I was still working. As the periods of ill health increased, fulfilling my work responsibilities became more difficult. I never really seemed to get my feet back under me after that surgery, minor though it was. It eventually got to where I was off sick more often than I was at work. Although I was a good employee who worked hard, it was getting to where I was unable to guarantee my presence from day to day. This caused me great shame and sadness as my ability to do an efficient and hard day's work had always been a matter of pride for me. I remember feeling that this job was my last link with a normal life. Knowing I would have to quit, at least for a while, was the beginning of a serious downhill slide, emotionally and physically. Quitting this job required my approaching welfare for assistance that compounded my feelings of worthlessness and shame. The combination of my fear of the HIV, of cancer, of hepatitis, as well as my ill health and being on welfare, all contributed to my shame and sadness. Not having the outside contact work provided added to the shutting down of my world.

For the better part of a year I did not see any doctors. I kept my contact with my family to a minimum, turned off my telephone, didn't reply to the answering machine and saw

no friends. As my world shut down, my depression and hopelessness increased. Knowing what my death might look like exacerbated the fear that I was dying and it wasn't pretty. I didn't want to be there. I didn't want to be in my own skin, in my own life, so I began to look for a way to not be present. If I was going to die I wanted it to be fast and painless. Where this search led me was to try to shut down my mind and feelings with drugs and if this happened to hasten my death, so be it. It's not that I wanted to die or commit suicide, I didn't. I think it was that I believed I was dying already and I was afraid of what that death would be, how long it would be dragged out. If I could numb some of the pain I was feeling or shorten how long I lingered on, that was OK with me.

Clearly my thinking was a little off kilter. Although I dabbled with pot, alcohol and such when I was younger and would party with my friends, this was different. I went straight to one of the hardest drugs there is, the one guaranteed to allow your mind some downtime. I started using heroin. At first I would use it once in a while. But my desire to shut down drew me back more often. Before I knew it I no longer felt I had a choice. Although using this drug continued to allow me periods of nothingness, my use was no longer motivated by desire but by need. When I didn't use, I got sick. That I found myself using this drug left me absolutely ashamed. If I thought I wanted to keep the world at bay before, my desire was twice as strong now. I wanted nobody to see me in my weakness and shame. I became a prisoner of my own sickness of spirit as well as body. I continued to use heroin for a couple of years but around the time I went to the women's retreat I found an addiction doctor who was able to help me start down my road to recovery. I will struggle with this addiction for the rest of my life, even if I never use again. That's the nature of this addiction. Shortly after the time I went on the woman's retreat, I again came in contact with the medical profession. I had found an infectious disease doctor I would keep until the present day.

In 1994, Oak Tree Clinic Women and Family Care Facility opened its doors. It was the first of its kind in western Canada and was a breath of fresh air. It was based on a female model of healthcare delivery, not on a male model. This clinic not only had infectious disease doctors but pediatric infectious disease doctors, nurses, dietitians, pharmacists, a social worker and child care when mom was getting medical attention. A couple of years after they opened

their doors, a gynecologist joined their staff. This clinic was located in a hospital so there were lab and x-ray facilities on site. In the reception area they offer hot and cold beverages and snacks. It was a kind of one-stop shop in HIV-related healthcare for women and their families.

Only once before had I seen an infectious disease doctor and that was at some point right after my HIV diagnosis was reconfirmed. This was a less-than-successful interaction that led me to believe infectious disease doctors had nothing to offer me. This first infectious disease doctor was considered one of North America's best in his field, that being the study and research of HIV/AIDS. My appointment with him lasted all of 15 minutes during which time he took few, if any, notes and asked very few questions about me or my health. He told me about HIV/AIDS and offered me treatment in the form of the drug AZT. When I informed him that I had no desire to take this drug, he informed me he had nothing more to offer me and I should come back when I was prepared to start drug therapy. Needless to say, I didn't go back to this doctor. But at this new clinic it was different.

The approach at this women's HIV clinic is to focus on the whole person. An average appointment with your doctor is scheduled for 45 minutes but they'll give you more time if needed. Dr. David Burdge, my infectious disease doctor at this clinic, has done more than just try to get me to take drugs. I have very strong feelings about HIV medications, which have not only been influenced by my readings but also by what I observed of those around me who were taking these pills.

Early on in the battle against HIV, it was standard procedure for an HIV-positive person to take only one drug at a time (monotherapy) and in massive doses. Doses were 4, 6, or 8 times as much as they would be today. In the mid- to late-1980s I watched a multitude of friends down handfuls of HIV meds in hopes of a reprieve. What most of them got was seriously toxified by those handfuls of poisonous pellets which I believe hastened many deaths. Almost all of the people I knew who were living with HIV in the mid-to late-1980s, who were on the high-dosage monotherapy, are dead and have been for many years. For me this is powerful evidence of the toxicity of these drugs and the fact I didn't want them.

Fortunately David was a doctor who saw more than just pills as a way to heal someone. Although he did express his belief that I would benefit from HIV drug therapy he also agreed with me that if I believed these drugs would kill me, then they most likely would be harmful. He also made it perfectly clear he was willing to help me stay healthy in whatever way I chose. This was a great relief to me, a doctor who was not trying to push pills down my throat. A doctor who was willing to listen to my perspectives and ideas and give them merit, not just dismiss them. He is one of the few doctors I have ever come across who seems to believe that the individual is the expert and the doctor is there to offer advice and support whatever decision the patient makes. It's not that he isn't clear in what he would like you to do; he does so in a direct but gentle way. It is rare that I've come across a doctor who was sure enough of who he is and what he had to offer that he didn't always need to be right or obeyed. David's ability to say, "I don't know" made a huge impression on me and opened the door to my trusting him, a decision I have never regretted. Since I was unwilling to try HIV medications at that time, there was very little David could prescribe to improve my health. I was willing to take some prophylactic medications so these were prescribed. I began taking Septra (which I took for a short time) to prevent pneumocystis carinii pneumonia (PCP) and Acylovire to prevent the zoster sores (cold sores). I also incorporated multivitamins, B injections, rest, a better diet and a reduction of stress to my healthcare regime. Beyond that, what David offered me was a monitoring of my health situation and someone who would listen and care. In my opinion, that was as important as any medical advice or treatment I could be given.

Since this women's HIV clinic did not yet have a gynaecologist on staff I had to go elsewhere for this care. I had been plagued for many years by pain in my pelvic/abdominal region. Although I had expressed this to a number of doctors over the years, it was always dismissed as simply 'female problems.' Having grown up with that as an explanation for most of my gynaecological problems I had learned to live with this kind of pain as normal. What I finally came to realize in my late 20s was that pain is not a normal state. What I believe led to this revelation was that the explanation for my pain had been shifted from being a "female thing" to being an "HIV thing."

I remember seeing this one male gynaecologist sometime in 1994/1995 because of the abdominal pain I was having. This doctor had me in the stirrups and was examining me internally. He was so rough with me that I was crying. He told me to stop exaggerating. At one point I cried out in pain so loud that my husband James heard me from the waiting room and came running in. When James entered the examining room the doctor demanded he leave. Fortunately for me, James, seeing what was going on and the pain that I was in, bundled me up on the spot and walked me out of there. Later, in my general practitioner's office I was able to see the letter this gynaecologist wrote as follow-up. In this letter he referred to me as "that poor unfortunate woman" and "a victim of my own imagination." Since this doctor could not find a reason for my pain he stooped to using derogatory phrases and calling me a hypochondriac. I couldn't believe it. His inability to say "I don't know" had been turned around and put onto me. Once again I felt dismissed, degraded and invalidated. I still had no answers.

When I saw the new gynaecologist at this clinic, it was the first time I have ever seen one who was knowledgeable on HIV-positive women's gynaecological needs. She examined me and ran a Pap smear, which once again came back abnormal. The difference this time was that this doctor was aware that cervical cancer was considered an opportunistic infection in women with HIV and she was concerned. I was referred to the Women's Health Centre where a colposcopy was performed. The results of this were that cancer cells were found in my cervical tissue and a cervical biopsy was again necessary. This frightened me terribly. Cancer is such a frightening word. Many of the women in my family and my mother's family have had cancer problems. My fear of this kept me away from this gynaecologist for the better part of two years. Although I would go to the women's HIV clinic to see David or with James when he would see David, I did not want to see the gynaecologist. I believe it was that I was afraid and did not feel I could deal with a serious cancer diagnosis on top of everything else, so I chose denial again.

During this time finding reasons why I couldn't proceed with the necessary treatments was easy. James was very sick a number of times during this period. He had a bleeding disorder, Idiopathic Thrombocytopenia, (ITP) which could not seem to be brought under

control. Every few weeks we found ourselves at the emergency room with him bleeding from his nose, mouth, rectum or somewhere. Or else it was that his lungs had filled with blood and he couldn't breathe. I remember the first time his lungs filled with blood it took them a couple of days to realize what was happening. Initially all they knew was that the X-rays showed a huge mass in his lungs. We spent two days believing his lungs were full of KS, a cancer associated with HIV. Once the doctors were able to ascertain it was not cancer but blood, he spent a couple of weeks in the hospital receiving platelets and allowing the blood to be reabsorbed and was discharged. During these couple of years James also had multiple systemic infections that took him to the brink of death and required from one to three month stays in hospital. With everything that was going on it was easy to be in denial of my own health problems. Eventually, with David's gentle prodding and my husband James' expressed concern I did eventually make another appointment with this gynaecologist and have her book surgery. The surgery was done at University of British Columbia (UBC) hospital and didn't require my staying overnight. Although no cancer-related follow-up was deemed necessary, this gynaecologist made it clear she intended to keep an eye on me.

The pain I had complained about for years was still present. On those occasions when I would see this new gynaecologist I would tell her about it but she could never find a cause. Eventually she scheduled me at UBC hospital for a laparoscopy. The results of this were that a small lump was found on the outside of one ovary that needed removal. I kept putting the doctor off as I was terrified of the possibility of cancer once again but eventually I agreed, so another surgery was scheduled. This time I was to be at UBC hospital for a week. I was left with a five-inch scar just above my pelvic bone. They were able to remove this small lump and not harm my ovary, for which I was grateful. The pathology of this growth was benign. I had once again been lucky.

The one thing I tried to avoid through all my years of living with HIV, up until 2002, was getting blood work. I did not want to know my immune system counts and I did not like how I was sometimes treated while getting blood drawn. Between the early 1990s and 2002, I probably had blood work done half a dozen times. I guess this was another one of my forms of denial but for me it was easier not to know my counts and face the discrimination. The

discrimination I am talking about is from the medical staff involved in drawing the blood and the treatment I would receive as a result of my having injection drug user (IDU) on my medical chart. Many of them did not care that I was no longer using drugs or why I had started using, they just saw a disposable drug addict and behaved accordingly. These medical personnel would usually assume that I got HIV from sharing needles and would often seem disbelieving when I corrected them. For some reason I often seemed to get the phlebotomist who believed that if you had injected drugs then getting blood would not bother you, even if they had to stick you four or five times to get the blood. I remember one time telling this lab technician that she was hurting me and I will never forget her answer, she said, "Stop complaining, you should be used to this."

The lack of regard for my well being that I felt from many of these medical people left me sad and ashamed that they felt this was the treatment I deserved. As poorly as some medical personnel have treated me does not compare to the treatment that James has received. He too has a history of IDU and although it is not always necessary for medical personnel to know this fact, James is very honest about it and informs them. He does not want to hold back any information that may assist in diagnosis or treatment, even if the result of his disclosing could be substandard or down right abusive care. Although some people may find it hard to believe, the fact is that there are many in the medical community who behave as though people with a drug use history are taking up valuable space and resources that a more deserving person should be accessing. There have been multiple occasions that if it weren't for the forceful intervention on James' behalf by a specific doctor, certain health concerns would have been left uncared for, to the detriment of his health or possible death. This is no exaggeration.

These discriminations have been happening from the beginning of our health struggle and have continued right up until James' last hospital stay two years ago. Fortunately not all medical personnel are judgmental or ignorant. All of us have aspects about our person or our history, which could be judged by others, these judgments should not dictate the care we receive from our medical system. Unfortunately, people often let their bias dictate their

actions. All that I can do in these instances is refuse to accept the action and demand better care, even if that means lodging a complaint or requesting a change of medical personnel.

The other aspect that kept me from having regular blood work done was that every time I did have blood drawn for lab work, my counts would have dropped. Although the immune system of people living with HIV can go up and down, mine never did. Each time I would have blood drawn my immune system would be lower. I would be more afraid and would avoid my next blood work for months or years at a time. I'm sure this is frustrating for my doctors, especially David, because for periods during this time I would also avoid him. But he was great. He never got down on me for the choices I made. He would simply pick up from wherever we were and move forward. For this I was grateful since I know that had he chosen to berate me I would have stayed away. But that was not David's way. He would express his desire for more consistent blood work but he would also listen to my reason for not wanting blood work done and he seemed to understand.

Through all this time my fatigue level increased and the night sweats became more common and intense. I would run low-grade fevers that would last weeks at a time and headaches were almost a daily occurrence. My respiratory problems continued to increase in intensity and frequency and I began to feel run down. Then the AIDS-related illness, peripheral neuropathy (nerve damage in the extremities), began to plague me. It started fairly mildly with my hands or feet going to sleep and feeling numb for no apparent reason. Initially this would last for a few minutes. After a while the numbness would stay for hours but would eventually go away.

The next phase of this illness was that I got some mild pain in my feet and fingers and they would often feel cold, like my circulation was poor. This pain would come and go but my hands and feet always felt cool. I began to feel very frightened as peripheral neuropathy can advance to the point where one loses the use of one's arms and legs. For me this thought was devastating as the ability to use my hands is a big part of my well being. Also, the thought of being unable to walk was beyond my comprehension. But my peripheral neuropathy, for a long time, did not seem to advance. Through the use of some pain relieving medication and much frustration I lived with it.

What I have found frustrating during my time living with HIV is that most of my doctors act like I should expect to feel like crap. They would say things like "you have HIV what do you expect?" It seemed like every ailment from a headache to an ingrown toenail was being blamed on my HIV. Yes my advancing HIV has always been responsible for much of my illness but not for all. It seemed like I was expected to just accept the deterioration of my body. I felt the emphasis was directed away from those things a person who expects a long life might focus on.

For example, I've been plagued with reoccurring staph infections in my body since about 1993. For about six or seven years it was quite severe. I would have infections erupt from under my skin for no apparent reason, some of these infections lasted up to three years. I have scars all over my body ranging in size from 1/4 inch to 1 1/2 inches across. The worst affected areas were my legs, arms, and hands. At one point a number of my fingers became infected at the same time, the ring fingers of each hand seem to be affected the worst. For more than two years I had constantly weeping sores on these fingers that required my hands to be bandaged. At one point it got so bad that I had to have a drain tube put into the knuckle joints of each of these two fingers that stayed in place for a few weeks. During this time I was going to the hospital emergency room daily to receive intravenous antibiotics, as the oral antibiotics had not seemed to help. I was also consuming major doses of ibuprofen sometimes as much as 3000 milligrams a day. Having these infections on my body where they could be covered was bad enough but having them in plain view on my hands affected me greatly. I had to wear bandages on my hands for so long that I forgot what it was like without them. I also felt great shame over this. It was as if I was the infection. I felt a part of me was so putrid it was pushing its way to the surface for all to see. I know this may sound silly to some but I guess it was just a continuation of the condemnation and punishment I inflicted upon myself and felt from others resulting from the stigma of HIV.

Due to the bandages and the pain in my hands I was unable at times to take proper care of my personal needs. During a stretch when I was spending a lot of time sick in bed my cat Samantha would sleep with me. Unfortunately she felt the need to sleep around my head and on occasion knead at my hair, which at this time came halfway down my back. During

this time I was unable to properly brush my hair each day and the result was that a small knot formed at the back of my head. Over the course of the next few weeks, with my inability to properly hold and use a brush this knot grew. I seemed unable to ask for help with this. Even though at this time I had a home care worker coming into my house once a week to help clean, I couldn't ask her to help with this. I felt so ashamed and saddened by the fact that I could not take care of my own most basic needs that I allowed this knot to get out of control. Eventually I had to cut out this tangle which meant removing a large chunk of hair about two feet long, as the knot was against my scalp. I don't know if it was pride, ego or just plain fear but I know it left me defeated. In my defeat I could not let anyone in.

This had always been my way and to some degree, still is today. When things would get tough and I was struggling I would shut people out. I didn't want anyone to see me if I wasn't together. Still to this day very few people see me when I am unwell. It's interesting how so many people are always saying to me "you're looking so well" or "it's hard to believe you're ill". What I rarely hear is "you look sick". That's because people almost never see me when I am sick. I guess it's one of the few things I can control in my world where so much of my control has been taken. So many people don't understand this, including some members of my own family and others who have been present when I am publicly speaking and discuss this topic. Maybe for some you have to live it to understand.

Back to my fingers, when they did finally heal I was left with a large amount of scar tissue and hardened protein, especially in my ring fingers. This hardened protein resulted in the ring finger of my right hand being unable to bend at the top joint and both ring fingers having difficulty with other bending movements. Also, due to this hardened protein, my ring size on these two fingers has gone from size 6 1/4 to a size 9 and my hands in general look beaten up. In discussing this with David he suggested I see a plastic surgeon regarding the joints of my ring fingers and referred me to one who specialized in hands. This doctor had an initial appointment with me and told me to come back when my infections had been gone for one year. When this year had passed I returned to see this surgeon, by this time he seemed unwilling to do the surgery. His position was that I had so many other concerns going on that my hands should be the least of them. It was like fixing the fingers of the dying woman was

frivolous. Needless to say my fingers have never been fixed, I am still left with scarred up misshapen fingers.

Some of the other problems I have with my extremities are arthritis and joint deterioration. These problems began about the same time as the peripheral neuropathy. These ailments have continued to worsen over years to the point where some of my joints seem frozen and are immovable. This causes my joints to seize which is very painful and interferes with my ability to walk or use my fingers. It also seems that the ibuprofen I had taken in the past had interfered with my body's ability to heal the skin infections, so these anti-inflammatory meds are not available to me for pain relief. I have therefore had to move to a stronger narcotic-based pain reliever, which I try to use as little as possible. Fortunately I have not found these narcotic-based pain medications to be a problem for me. If they were to become a problem I would be in trouble as I would no longer be able to take them and would be without pain relief. I also now have poor circulation in my extremities that exacerbates the numbness and cold feeling I get as a result of the neuropathy.

During the latter part of the 1990s my husband James was very sick more often than not. He was spending from 4 to 8 months a year in the hospital. There are many times we were not sure if he would be leaving the hospital alive. This again made it easy for me to not focus on my own health situation. And by this time I truly did not want to focus on my own health situation because I was getting scared again. As I had stated earlier my CD 4 count (immune system helper cells) had been on a steady decline and was now getting dangerously low. In the past I had always believed that focusing too much on the numbers was dangerous. I know so many people that, as the numbers declined, their belief in their health declined. I've always believed that one can will themselves to be sicker if they truly believe that's what will happen. I think this position was in part behind my desire to not have blood work drawn too often. I also believe that when it comes to the numbers, the CD 8 count (suppressor cells) is more important. It seems those people who live with HIV for many years and stayed relatively healthy have high CD 8 counts. Even if the helper cell counts are low, high suppressor cells counts seemed to keep opportunistic infections at bay. Early on my CD 4 count was dropping rapidly but my CD 8 count was decreasing very slowly.

By the end of the 1990s my CD 8 count had also begun to drop rapidly and this frightened me. My fatigue had become extreme. No matter how much I slept I did not feel rested, and I was sleeping a lot. By now, not having a headache had become a blessing that did not happen often. My night sweats were so severe I would, at times, have to change the bed sheets in the middle of the night. Then I started wrapping myself in a flannel sheet to absorb the night sweats so I could dispose of the sheet halfway through the night and crawl back into a relatively dry bed. I seemed to be constantly battling bronchitis with the odd dose of pneumonia thrown in. I seemed to have constant ear infections and because of these, was always on antibiotics. These antibiotics were hard on my intestinal tract and caused diarrhoea, so I was always afflicted by this. I seemed to feel a general sense of unwellness, something I couldn't define.

With all of this going on David once again began talking to me about starting HIV medication around 1999. He said that since he knew it would most likely take me a long time to get to the place where I could take these pills, he was going to start the discussion now. He told me he had great concern for my future health if things continued the way they were going. We also discussed how much time I had to make this choice before my immune system got so low it would be very difficult to turn around. He knew how I felt about HIV meds. He knew that I believed they were poison and he acknowledged that yes, they were very toxic. We discussed the issue of quality vs. quantity and I would have to decide if I felt I could still have a quality life while taking these medications. I assured him I would give the matter some thought that might take me a while, something he seemed to expect.

Over the next couple of years James continued with his life-and-death battles and I continued to get sicker. Our world once again seemed to be getting smaller and more full of fear. As the neighbourhood surrounding the co-op in which we lived grew more violent, our windows became barred and covered with drapery that almost never opened. Our home seemed to become gloomy and dark. I believe all these factors contributed to the growing depression and sense of hopelessness that had begun creeping in again. The last time James was in hospital while we were still living in Vancouver was a very difficult time for us both. He had to fight so hard to stay alive that I was grateful he was able to hold on to a strong spirituality

in the core of his being. I believe this is what gave him the courage to eventually make the choice to live. I remember him saying, "If this is what my life is going to be, always in hospital and so sick, I don't know if I want it." It was like our lives were closing in on us. We were both beginning to fall into a depression that I wasn't sure either of us could get out of. Our lives seem to be comprised of one health crisis to the next with little breathing room in between. When one crisis would pass I would find myself filled with the anxiety of anticipation of the next.

James had expressed to me that he did not want to spend any more time in hospital and that the next time he went down he may choose to just let God take him. Although this broke my heart, I had to accept whatever decision he would make. We had talked numerous times over the years about quality of life and quality of death. I had always been a firm believer in the position that a person has the right to choose to end his/her own life when the quality has reached the point that is unacceptable to them. I still believe this but it is easier to believe it than to participate in it. I knew I would do whatever I could to help him find that desire to stay around but I also knew if he chose to die I would do what I could to make it all right and to help him.

And then things took a turn. We moved out of the city to a peaceful and vibrant little island. Within days of our move I saw a change begin to take place in James. He seemed to have a sparkle back in his eyes and a lifting of his spirit. He was focused on creating a life for us and was able to laugh again. As this transformation happened for him, I too was able to laugh again. Within weeks of moving to Salt Spring he told me this was the closest he had felt to home since he left Newfoundland more than twenty years before. Maybe this was part of the healing for him.

Interestingly enough, about six months after we moved to the island he again became very sick with a multitude of systemic infections that seem determined to take his life. But suddenly he wasn't ready to go. He was once again in hospital in Vancouver but this time he was saying, "I have too much life to live, and I'm not ready to die yet." He was probably the closest he had ever been to dying from this illness with hospital-assigned doctors who just wanted to discharge him and send him home without solving the problems he was having.

Another one of those situations where the doctor in charge of his case attributed all his ailments to the progression of his HIV and felt James should just go home and accept it. In other words, go home to die! This was not acceptable to James.

The twelve weeks he was in this hospital were probably his most difficult hospital stay ever as it seemed he had to fight for every bit of care he eventually received. Although he had some real low times emotionally he was able to focus on the plans for his life back at home. By the end of these 12 weeks, he had decided to follow David's advice and start taking HIV medication. I had such strong feelings about these drugs, I did what I could to stay out of his decision. My feelings were so mixed about his choice. On one hand I was grateful that he was choosing to live, on the other I was afraid of what the toxicity of these drugs could do to him. Fortunately he tolerated these medications very well. When he started this treatment his CD 4 count was 4, counts in a normal healthy individual run between 500 and 1500. Since he had waited so long to start (17 years since his infections with HIV) and had allowed his immune system to get so low, it took a while for the turnaround to begin. But eventually it did and his body's systems began to get stronger. He did have to be in hospital once more in the fall 2001. He was there for about twenty days but was released a couple of days before Christmas. Since then he has not been in the hospital. This is probably the longest hospital-free time we've had in 10 years.

As James' health improved I had to re-evaluate my own health situation. When James and I married I promised him he would never be alone again; I needed to keep this promise. If he was going to continue getting stronger then I needed to get stronger as well. By fall 2001 my CD 4 count was down around 100 and my CD 8 count was in the three hundreds. I was not in a healthy way. As 2002 began I had an appointment with David at which time I let him know I was willing to start HIV meds. The next step was to decide which medications to take. As David was aware that I had strong feelings about taking HIV meds, a regime that incorporated the least number of pills and the fewest dosages per day would be best. With this in mind he suggested the drug Trizivir, a single pill that contained three medications. These are AZT, 3TC, and Abacavir. I think David was aware that getting me to agree to this choice might be a challenge as it contained the drug AZT, the one drug to which I had the strongest

feelings of disdain. But, I trust David and he assured me that the dosage at which this drug would be administered to me would be relatively safe, or at least no more harmful than any other HIV drug.

The Abacavir was known to have a possible side effect of causing an itchy rash for some people. In about 4% of the people, Abacavir had more severe reaction; they would run fevers and their throats would close making breathing difficult. I was told this happened in such a small percentage the chances were minimal it would affect me this way. If I did notice an itchy rash I could use an antihistamine to alleviate the symptom, which often take two weeks to begin and should go away by six weeks.

This single pill regime only had to be taken two times a day. This twice a day dosing of certain HIV medications was a vast improvement over how it used to be. In the past persons may have had to take medications up to six times a day on exacting schedules. Being able to take your meds only two times a day, although on just as exacting a schedule, made HIV medications accessible to more people. By that I mean if you are not going to take every pill at exactly the same time every single day, then you may as well not start them. Adherence to the complicated pill regimes was one of the biggest barriers to these medications working as they were designed to. So, I agreed to start this medication.

The pills arrived via courier in mid-March of 2002; it took me until the beginning of April before I could bring myself to put them in my mouth. Taking them felt like a defeat to me. I started these pills on a Friday. On Monday, James and I decided to go for a walk to the beach. We had been walking for less than five minutes when I began to feel nauseous. My body started feeling hot and my skin was red and burning. I then began to sneeze continuously, where I could barely get a breath in between. Next I started to vomit but my sneezing continued so I had a very difficult time breathing and not choking. I was really frightened. We were so close to home but I couldn't move. I started to feel weak and could no longer stand so I found myself lying at the side of the road with my face on the cool grass trying to get control. Once the vomiting had subsided and the sneezing had slowed down I became more aware of my surroundings. The look on James' face made my heart hurt. He was so afraid and didn't know what to do to help me, as there was very little that could be done.

So he did the one thing he could do, he sat down and comforted me. I must have been there for forty minutes until I was strong enough to stand up.

The walk back to our home, which should have taken no more than four or five minutes, took about half an hour. I would take two or three steps and have to stop. To me it seemed like hours. By the time we got home I was having trouble breathing, my lips had gone numb and I was breaking out in a rash. I called the pharmacist from the woman's HIV clinic at the emergency phone number I had been given in case something like this happened. She was great. She was able to calm me down and had me take a specific type of antihistamine. I was told to give it a half hour and call them back but if I got worse to go to the hospital. Fortunately the antihistamine eased the symptoms and I fell asleep. When I did not call the pharmacist back, she called me. I was asleep but James assured her I was somewhat better. She wanted to be sure that I would not take even one more dose of the HIV med that had caused this reaction, to do so could be life threatening. With Abacavir, getting the mild rash reaction is nothing to worry about but if you are one of the few who have the more severe reaction then you can never take another dose of this drug. To do so could kill you. To be sure, I had no intention of taking this again. Someone from the Women's HIV clinic called every day for two or three days just to check on me, this I appreciated.

This experience made me wonder if I was wrong in deciding to start HIV drug therapy. When I went back to see David a few weeks later he was worried that the allergic reaction might make me decide not to try a different drug. On that note he was not far off base. I was hesitant to try again. Through our discussion I decided to give it one more try and a new drug regime was planned. This plan consisted of the three drugs Nevirapine, 3TC and D4T, all in separate pill form. I would only have to take one of each pill two times a day, 9am and 9pm. Although it was a simple regime it was exacting, the pill has to be taken at the same time every day for as long as you take them.

It took a couple of weeks for the new pills to arrive, which was just fine with me. As it was it took me until August to build up the courage to begin taking the new pills. It's not that I was afraid of another allergic reaction, I wasn't. I was afraid of starting pills that I would most likely have to take for the rest of my life. As I said before, these pills felt like a

defeat to me. I was also worried about the toxicity, let's face it, they are poison. I have now been taking this combination of drugs for more than a year and have very few side effects from them. The side effects I do have, though not life threatening, they are debilitating. The D4T has increased the neuropathy a hundred fold. My neuropathy now goes up both legs to mid-calf and to just below the elbow in my arms. My hands go numb from just holding a book, to the point where I can't hold it any more. I also get pain, which is some times throbbing and some times shooting, from my fingers to just above my wrists and my hands almost always feel cold.

With my feet it is much worse. My feet and lower legs have a constant tingling sensation that will turn into total numbness on a regular basis. When my feet and/or legs go numb, walking is difficult. I also get shooting pain through my feet and into my lower legs that can be so severe that it makes me jump from the pain. There is a general, milder pain in my feet at all times and for the past seven or eight months I have been totally numb in my toes, though this has now spread to the ball areas of my feet as well. Also, for the past seven or eight months I have had a sensation like there are pebbles under and between my toes and under the balls of my feet; this sensation never goes away. Walking can be difficult at times and I can be a bit unsteady as well. It can also be very painful to step on the smallest thing from an edge of a carpet to an apple stem, it seems at times the smaller the item I step on the more it hurts. Lastly, my feet, like my hands, always feel cold even though if someone was to touch them they feel a normal warm temperature.

Since I had a milder form of neuropathy from my HIV before I started the D4T, just stopping this drug would help with some but not all of the symptoms. This is not the option I have yet chosen. If I were to stop the D4T it would have to be replaced with another drug. HIV like any other virus mutates and the chances for mutation increase the more you change medications or if you miss doses. Mutating HIV scares me. I believe one of the reasons why my HIV may have progressed so slowly for so many years is that I was infected so long ago, before too many drugs had been introduced into the pool of the virus. I believe that the more the virus mutates the more virulent it can become. Although I have been told there is no proof of this, the fact is that some strains of HIV are more virulent than others. When looking at

other disease organisms out there like tuberculosis or the flu, they seem to be mutating to more virulent strains all the time. Why should the HIV virus be any different? There is also a strain of HIV out there today which is resistant to the drug AZT at the time people get infected with it. A sure sign the virus pool is changing in ways that will negatively impact those being infected. Also, a new drug will have its own side effects to contend with and I'm not sure I want to go there until I sort out the ones I've got.

What I am doing for the neuropathy is I've become part of a double blind study of the drug L-Acetylcarnitine. Even though it's a 50/50 chance I may not get the drug, it's worth it to me. L-Acetylcarnitine is a drug that many people I know who have suffered from neuropathy have used with great success in relieving their symptoms. It is also a very expensive drug that I would have a hard time affording every month. The cost would be about \$120.00 a month for the minimum needed dose. If this study can prove that there is benefit it may go a long way towards getting L-Acetylcarnitine as a Pharmacare-covered medication. I have been with the study for three months now and I feel no benefit. I feel it is likely I am on the placebo, as I know in my gut L-Acetylcarnitine would help me. I look forward to the time when my six months' commitment to the study is up so I can try what I know to be L-Acetylcarnitine and see if things get better. I hope that it does since the neuropathy getting even worse could result in my stopping the HIV meds; my fear of not being able to walk or use my hands is strong.

I believe the self-esteem and body image I carried played a part in the choices I made years ago that led to my HIV infection. To those around me I always seemed so self-assured but inside I was the fat little girl who was so afraid of being unloved that she wouldn't ask a man to wear a condom to save her life for fear he might leave her. These self-held beliefs affect how we see ourselves and how we present ourselves to the world around us. Though HIV is transmitted through a number of body fluids, not all of which are sex-related, it is considered a sexually transmitted disease. Living with HIV has its own challenges when it comes to building a healthy self-esteem and positive body image. For me, not having a very strong sense of self-esteem when I was infected made it a greater challenge to find myself after infection. I was always a girl who carried extra weight on my body and as I became an adult this did not

change. The fact that I carried this weight in a well-proportioned way made it OK. I am grateful that for the past few years of my life I have been able to say that I truly like who I am and feel good about the way I look. Sure there are things I would like to change about my person but I am content with where I'm at. I must be honest though that lately I've had some things going on that are causing me a bit of anxiety. For the past eight or nine years my weight has always been very stable, changing by five or six pounds at most.

Between mid-June and mid-August of 2003 my body weight dropped 33 lbs although I was not doing anything to encourage this. This was OK with me as I have always been overweight and a few pounds off made me feel healthier. From September into December I seemed to stabilize at this new weight. But this does not seem to be so. I'm not sure how much more weight I may have lost but I'm losing body mass. James has been expressing concern over the past month about my continuing to lose weight but I didn't think I had lost any. Then a couple weeks ago he told me where he was noticing the changes in my body. I snuck off to my bedroom where I found myself standing in front of the mirror. As I looked at my body I could see the changes he was talking about and didn't understand why I couldn't see it before. The lower part of my buttocks and the inner part of my upper thighs seem to have reduced. I've also noticed that my breasts are going. I began to feel afraid and so very sad. I've seen what HIV and the different drugs can do to a person's body. Body mass comes off where you don't want it to and on where you don't want it to, a lose/lose situation. I could again see that part of me who was so unsure of her body. I have become so afraid that if I continue to lose weight and mass the way I am that my body will become unattractive to me. I fear the effect this might have on my self-esteem.

Self-esteem is a fragile thing for most of us. I know that mine is. This weight loss is also making the progression of my illness very real. You can make the numbers of your blood work seem negligible as they are only numbers but when it's looking back at you from your mirror it's hard to ignore. As of now the doctor has not come up with any concrete reason as to why I am dropping this weight but he is keeping an eye on it. I too am keeping an eye on it. For the past few weeks I seem to have spent more time in front of the mirror looking at my body than I have in the past year. This might be part of why I am so afraid but I can't seem

to stop looking and speculating as to what will happen next. The only thing I know for sure is that I have to find a way to be OK with whatever the future holds for me. I am very lucky as I have a husband who loves me as I am and thinks I am beautiful no matter what happens to my body. For this I am truly grateful. I just need to see myself through his eyes.

Throughout this dissertation James has been spoken about a great deal. Although he is a big part of this story, Laura's and my words about him portray a very limited view of his life. With this in mind James was asked if he wanted to speak for himself in the dissertation. He agreed and his writing is what follows.

James' story

My name is James Richard Keating. I was born in Burien, Newfoundland in 1962. I grew up on the Avalon Peninsula in and around the St. Mary's area. In 1964, one brother died in a house fire. By the time I was 3 or 4, my younger brother and I were put into foster homes. Members of the family adopted my two remaining brothers. Between the age of 3 and 16 years old I was moved around between seven different foster homes, as well as some short stays in Christian orphanages. I had no contact with my mother or father during these years.

When I was 16 I ran away from a foster home to go to Halifax to try to find my mother as I had been told that I might find her there. I found her easily in the phone book and arrived on her door. She seemed pleased to see me. After I had been there two or three weeks I was told I would have to pay rent and my portion of the bills in order to stay. Since I had a grade 9 education, no job skills, no life skills, and no money I had to leave her home. I went to live at the Salvation Army and stayed there several months. Once I did find some employment I didn't go back to my mother's house, as I didn't really feel welcome there. I stayed in Halifax about a year working odd jobs but things weren't going really well for me. So I got a job with a traveling carnival show and worked for them until we got to Leamington, Ontario. There I got a job at an onion and tomato farm and worked for the season. Then I moved to British Columbia in the fall of 1979.

When I got to British Columbia I didn't know anyone and didn't have a job so I found myself living on the street for the first couple months. Then I met a friend from New Brunswick whom I shared an apartment with. I began working in restaurants and bars and continued

doing this work off and on for a number of years. I also did occasional work at a Vancouver West End youth centre for several years. Between 1979 and the mid-1980s I would find myself with a job and an apartment and sometimes without a job and on the street. I never really had anything steady.

By 1981, my mother moved to Vancouver. I contacted her but found there was no room for me in her life or in her home. Around this time I started using hard drugs and became addicted very quickly. At the beginning I used the drugs to numb the guilt and pain associated with what I had to do to survive on the street. I lived in the Downtown Eastside of Vancouver for many years of my addiction. The use of drugs left me feeling lonely and lost. I did not feel like I was worth anything, not worthy to get ahead or live a good life.

I found out I was infected with HIV in March 1984. This was not a shock as many of my acquaintances had died from this new threat to our already risky behaviours. I had become addicted to heroin in the early part of 1981 and by the time HIV started to show its effect on my group of friends, my risky behaviours had most likely already led to my infection. I did have a blood transfusion in 1982 that could also have infected me with HIV. I don't know which.

When I first got diagnosed I was told that I would most likely die within six months because I was an IDU and living on the street. I felt like I wanted to commit suicide but as a Roman Catholic it wasn't an option for me. I spent the next few years in a daze, doing drugs and feeling worthless. I had a few relationships but none that seemed to last long. In 1986 Ally and I met through a common friend and would cross paths on occasion for the next couple years. In 1988 we met for a drink and went on our first date. We dated several times over the next year and, by summer of 1989 Ally and I were living together. In February 1990 we were married. We knew that both of us were HIV+ and we decided to share our lives together.

Our lives together have not been easy. There have been many issues to overcome along the way. I was HIV+ and hooked on heroin. I thought the heroin would alleviate some of my fear. Later in my life I found out this was not any way to live and over the next few years there were lots of ups and downs. The addiction was very hard on my self-esteem and I found it hard to be motivated to change my life for the better. Our lives as they were could not have been easy on Ally.

Life was unsettled and we moved around for a few years. Then we settled into the co-op near Commercial Drive where we lived for nine years. Even though our living situation had settled down, life became

a roller coaster as I began to get very sick. I was in and out of hospital many times each year for stays that ranged from weeks to months. This went on for the better part of a decade and my times of wellness were an unexpected gift.

In the summer of 1998 my sister-in-law Laura was going to a spiritual ceremony in South Dakota and she invited Ally and I to go along. I didn't want to go but Ally did. It took some convincing but I finally agreed to go and support Laura. By helping out around the camp and getting to talk to some of the elders and the community who were there I began to realize that something was missing in my own life. For many years my life had been a haze of HIV, death and addiction. I did not feel like I was living, but just existing until death came.

My nephew Jesse was also at this ceremony and he suggested I go to a spiritual meeting with him. The way of prayer I found at this meeting was foreign to me as I was brought up Catholic. In the Catholic religion that I knew, I did not find much forgiveness or absolution for the choices I had made in my life. This led me to believe that I was unforgivable and that hell and purgatory awaited me at my death. I went to this meeting and I found a way of prayer that showed me I was forgivable and that I had to forgive myself. I also came to believe that if I did not find a way to begin living and enjoying life I would not make it many more years. Through this process I came to understand that I was a person of value, not only to those around me but also most importantly to myself.

Over the next two and a half years I spent more time around ceremony and made friends who shared these same beliefs. This made me more aware of my life as it was, and my life as I wanted it to be. For one of the first times ever I began to feel I was worthy to be happy and to have a good life. Even though I was still quite ill and going into hospital frequently during this time my growing spirituality allowed me to focus on something more than dying. It allowed me to look forward and see life.

For years we had talked about moving away from the city but never found a place we connected to and that felt right. On New Year's Eve 2000 we went to Salt Spring for a spiritual meeting. One of our friends casually said we should think about moving to Salt Spring. Before the weekend was up Ally and I had decided that it would be a good move for us. It just felt right. We went back to Vancouver and gave two months notice that we were moving.

Some people have asked, why Salt Spring? Because on Salt Spring it is the closest I have felt to my home of Newfoundland since I left there in the late 70s. What is familiar to home is that it is a small rock surrounded by water and cliffs. It is a small community that is a community. The violence of the city isn't here and that is reflected in the warm and trusting nature of those I have met here. That is reflected in our community newspaper that has a crime section of one paragraph a week. Maybe two paragraphs in the summer. What I have found here is a place of peace and tranquility. A place where I can heal some of the damage I have done to my body and soul over the years. Over here I have not only been able to stay away from drugs but I have lost the desire to cut myself off from the world by using drugs.

We live on the same amount of income as we did in the city. We are also able to have in-home help as we did in Vancouver, but our living expenses are substantially more over here. The quality of life that we get for our dollar is substantially more rewarding. It is worth the investment in my life.

My first year living here was difficult as I was still very sick and spent a lot of time in the hospital. At one point during that year I dropped 60 pounds in two months and ended up in hospital in Vancouver for several weeks. I felt like a bone rack. The doctor who was overseeing my case at the hospital told me it was HIV wasting disease. He said that I should stop taking up needed space in the hospital and go home and accept I was dying. This was unacceptable as I finally had a desire to live with my HIV not to be dying from my HIV. I was not ready to die. So I fought this doctor and he was forced to run tests and find out what was wrong. It turned out it was a water-borne parasite and easy to treat. After five days of antibiotics the diarrhea stopped and my body stopped losing weight and began to absorb nutrition again. This allowed me to begin gaining back my body weight.

The year before I was sick with this intestinal parasite I was in St Paul's Hospital with multiple systemic infections and was gravely ill. At that time David Burdge, my infectious disease doctor, convinced me that it was time to start taking the HIV drugs that I had said I would never take. My CD4 count was at 4 and my white blood counts were so low they were non-existent. At this time my body was so sick that death was a real possibility, so I made the decision to listen to David's advice and start taking the drugs.

I had been taking the HIV drugs for almost a year and was beginning to respond to them when I was infected with the intestinal

parasite. Once the parasite was under control the drugs were able to continue their work at strengthening my immune system and lowering my viral load. My weight came back to normal and I started putting on muscle mass.

What helped me get stronger was to begin building a garden at our home and planting it. I spent much time at the beach watching the eagles and playing with my dog Marley. Since I smoke marijuana, I decided to grow a couple of plants for myself. This inspired a greater love of gardening. A friend on Salt Spring told me about the government's legal marijuana for medical use program. This interested me and I decided to apply for a license to possess and grow my own pot. Ally and I were granted licenses by the federal government and have held those permits for the past two years. This has taken away the fear of getting busted for possessing or growing illegal pot that I use for medical reasons.

Just over two years ago we moved to our present address. We now live on six acres that we share with our landlord. We have a small house with wood stove, an attached workshop and a large 25" x 35" garden space. Our landlord has also signed the papers necessary to make our growing marijuana on her property legal. I am very grateful to her for making it possible for me to grow marijuana legally since a property owner's signature is necessary to get a license.

The fact that we now have a large garden allows us to grow all sorts of vegetables and flowers. There is nothing like caringly tending this garden all season then sitting to eat this food I have grown with my own hands. My garden requires a great deal of time and physical work to prepare and maintain. This has helped me regain my physical strength and has also helped me to mentally find a sense of peace and tranquility. I have a tendency to be very fast about things when I'm feeling well. Gardening food and marijuana helps me to slow down.

My spirit has also continued to get stronger because of the animals in my life. Marley has been at my side for 11 years and has been able to give me what I need when I need it. Happy to walk when I want to walk and content to sleep when I need to sleep, his gentle, goofy, loving nature has seen me through much and is a big contributor to my present health. I now have a new puppy that is a year old and who has brought much life and laughter into my home.

Volunteering at the Annual Kwantlen First Nation Pow Wow in Fort Langley, British Columbia is important to me. I have done this for the last three years. The friends I've made and the respect I've gotten

from this involvement is something I'm grateful for. I've also been involved with a local AIDS support group here and have volunteered to help with the activities that this group has undertaken. This volunteer work and my ongoing participation in spiritual ceremonies have given me a greater sense of well-being and self-worth. These things have led me on a path of wanting to become a valuable person in my community.

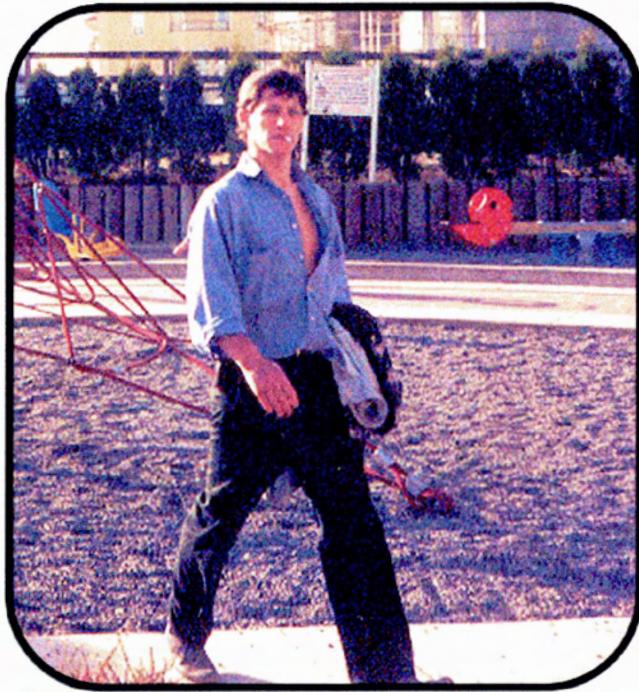
Today my physical health is good. I am able to get in four or five good hours of physical activity a day, four or five times a week. This is amazing considering my health two years ago. My CD4 count is now at 230 and my viral load is undetectable. My ITP is under control since my platelet count is almost normal. I have not been in the hospital for more than two years.

This is what Salt Spring and the personal changes I've made have done for me. They have opened my eyes and let me see there is a life after HIV. I have lived with this illness for at least twenty years and this is what I've learned. This disease can kill you long before it finally does. It also has the ability to bring out your very best. The last four years are my proof. I moved away from an unhealthy way of life to a place of peace and health. My personal health followed and my world has opened up and is becoming more complete. I can now see a future.

I would like to acknowledge my wife; she has been by my side for the last 16 years. Ally was there from the start, she found out early what she was in for and has been my rock. As the years have passed, my relationship with the rest of her family has evolved. I am sure that the knowledge of our illness and possible loss of a sister and a family member could not have been easy to accept. Through our love we are both soldiering on. I am thankful for the strength I have gotten from Ally and her family.

As I continue to heal I will make every effort to share the lessons I've learned with those who want to listen. I think this dissertation is a way for me to give back to those who have struggled with HIV and continue to struggle in overcoming this pandemic. I, like many, wish for a cure and I am going to fight to live until that time.

Early in my life I lived through the school of hard knocks. Born, abandoned, institutionalized, bounced around, discarded, and alone. My adulthood was dazed, confused, bewildered, longing, found, embraced, loved and finally, once again, alive.



Photograph 14: James Keating, Vancouver, 1988³⁴

³⁴ Photograph by permission of Alex Keating.

Alex's scrapbook



Photograph 15: It's all legal now.³⁵



Photograph 16: See how our garden grows

³⁵ Photographs 15 and 16 by permission of Laura Cooper.

Laura's response

Biomedicine has shaped the way in which most North Americans have come to understand HIV. From its earliest perception as a gay plague, to its present metamorphosis as a manageable chronic terminal illness, the shifting sands upon which societies have come to know HIV provides a good metaphor for its master narratives. Of further interest is the ease with which the master narratives change from a North American context to a global one. While portrayed as a global pandemic that has infected more than 40 million men, women, and children worldwide, HIV in North America is still a highly-stigmatized disease that is associated with risk groups and not risk behaviours. Given that a ‘cure’ is not likely in the present tense, the ability of biomedicine to overcome HIV/AIDS is minimal. Thus, rather than HIV/AIDS becoming a success story for biomedicine, it continues to mystify the scientific community and outwit researchers, regardless of the economic benefit of pharmaceutical companies. To this end, blame is often placed upon individuals who contract HIV, thus lessening the responsibility upon the scientific community to effectively ‘cure’ the virus. The stigma of blame that is attached to contracting HIV also becomes embedded within the dominant narrative. As Sontag writes: “It seems that societies need to have one illness which becomes identified with evil, and attaches blame to its ‘victims’, but it is hard to be obsessed with more than one” (1988, p. 16).

Critical interpretive medical anthropology (CIMA) provides adequate theoretical frameworks from which to address HIV as a social construction that reflects political, economic, religious, moral, ethnic, geographic, media-centered, and gendered influences. It allows for one to trace the creation of the master narratives of communicable diseases and how causality and blame are assigned. To examine biomedicine as a socio-cultural construction, the historical roots of anthropological theorizing of the role between health/illness and culture will be brought to the fore. In doing so, the emergence of anthropologically-informed master narratives in which biomedicine is dominant and other forms of healing are homogenized under the labels of folk wisdom, or magico-religious practice will be explored. Once this foundation is laid, it then becomes possible to apply CIMA to examine the embeddedness of biomedicine within master narratives and juxtapose Alex’s story against this to reveal how her life is constrained and enhanced through biomedicine. Also it will give voice to the struggle that she has undergone to counter the marginalizing and alienating stigma of having HIV.

Historical trends in anthropology's understanding of biomedicine

Byron Good (1994) provides a thorough overview of the history of anthropology's interest in medicine with a focus on the emergence of biomedicine as a dominant mode of practice within the Western world. In terms of a master narrative, biomedicine has achieved a critical position as expert knowledge that often usurps other forms of knowledge and healing practice. As a result, non-biomedical healing knowledge is often diminished in terms of acceptability and availability to ill persons. Support within the wider social and political body for alternative medicine is often compromised. As Good (1994) deconstructs the culture of biomedicine, he challenges the commonly held belief that disease is of the scientific domain and therefore is taken to be a 'natural fact'. Further, Good writes that, "it takes a strong act of consciousness to denaturalize disease and contemplate it as a cultural domain" (p. 2).

Anthropology's role in medicine, as evidenced by historical analysis, has shifted over the years from tacit, unquestioning acceptance of biomedicine as factual and universal and thus maintaining the characteristics of a master narrative to the contemporary critical analysis of biomedicine as another form of ethnomedicine; culture bound and specific.

Critical discussion regarding the historical positioning of biomedicine as a multi-faceted cultural system is fundamental for providing a foundation from which to challenge the 'fact' that disease is "paradigmatically biological" (Good, 1994, p. 2). Given its current near-global hegemony, biomedicine constructs both disease and the "diseased person", thus lending itself to critical anthropological analysis and understanding.

The advent of the scientific revolution from the fifteenth century onward opened the doorway for a radical shift in the perception of the human condition. The method of scientific inquiry rested upon two key assumptions or rules: "*empiricism* (scientific questions are answered through scientific research) and *objectivity* (research must be replicable and controlled for bias)" (Baer, Singer & Susser, 1997, p. 33). "Philosopher-mathematician René Descartes (1596-1650)...most clearly formulated the ideas that are the immediate precursors of contemporary biomedical conceptions about the human organism" (Lock & Scheper-Hughes, 1996, p. 47). Descartes perceived the rational mind as that of a higher order, capable of an objective evaluation of nature, while the body was of nature and ultimately knowable by the rational mind. The separation of rational mind from the body created the core elements of Cartesian dualism with the body being viewed as analogous to a machine (Hatty & Hatty, 1999, p. 3). The dichotomous structure of human existence did not accommodate recognition of spirit or soul as fundamental elements of personhood, and like a machine, the body was ultimately and objectively knowable.

In the quest for professionalism, objectivity and positivism in science became cornerstones for the scientific method. By employing Descartes' reductionism as a method of inquiry, the human body (machine) was reduced to its smallest possible unit of analysis to the point that one objectively-derived phenomenon could be explained by another objectively derived phenomenon. Replacing religious explanations with the 'higher order' of objective 'truth' put into motion the domination of man (scientist) over medieval cosmology (belief) (Cooper, 1993).

Cartesian influences permeated biomedicine such that physical reductionism became one of its central tenets (Hahn & Kleinman, 1983, quoted in Rhodes, 1996, p. 167). While it is suggested that "this perception of the body remained inherent in philosophical, scientific, and medical discourses until the latter part of the twentieth century" (Hatty & Hatty, 1993, p. 3), my research into HIV/AIDS has revealed an ongoing presence of physical reductionism within biomedicine into the twenty-first century. While Alex's narrative does reveal that there is a movement within HIV/AIDS care toward a more holistic model of health promotion, there is still a predominance of physiological reductionism within biomedicine.

Consideration of a critical medical anthropological perspective on the philosophical and methodological roots of biomedicine requires that one engage in an analysis of the influence of Western (capitalist) economic and political systems. With a goal of the scientific revolution being to provide empirical evidence (fact) to counter the stranglehold on the production of knowledge held by the church and religious clergy (medieval cosmology), the link between sixteenth century European capitalism and contemporary biomedicine cannot be overlooked. According to Baer, Singer & Susser, (1997) "biomedicine as an outgrowth of this development provided an ideological rationale by downplaying the roles that political, economic, and social conditions played in the production of disease" (p. 209). Deeply imbedded in the belief system of the scientific method was the concept that axiomatic conclusions could be discovered about natural phenomenon. This served to highlight the primacy of scientifically derived knowledge from other forms of knowing. Concomitant with this "discovery" was the application of Darwin's principles of natural selection to the adaptation of human groups.

The resulting evolutionary theory, hand in hand with biomedicine, created socio-cultural, political, and economic systems that profoundly impacted the colonial world. Many academics of the day held to the discriminatory beliefs embedded in evolutionary theories, while advancing their medical theories on disease and the rationale for hierarchy of races. James Hunt, physician and founder of the Anthropological Society of London (1862) supported polygenicism in that he believed that not only were "races of men distinct and permanently unequal," but also that the

“intellectual inferiority of the Negroes could only be humanized and civilized by Europeans” (quoted in Singer & Baer, 1995, p. 16). Interestingly, Hunt is also cited in the journal, *The Anthropological Review*, which was set up by polygenists to promote their views (*ibid*, p. 16). Though Hunt had a minimal direct effect on medical anthropology, it is important to note the socio-cultural context within which anthropology as a discipline was growing. The burgeoning reliance on positivism reflects the ahistorical and uncritical perspective from which many academics viewed the ‘accomplishments’ of Western society.

The Eurocentrism and racism that was embedded in much academic theorizing of the late 1800s is exemplified by examining the work of Hunt’s nephew, W.H.R. Rivers, who studied ethnomedicine during the Torres Strait expedition of 1898. His resulting theory on indigenous medicine separated Western practices from all other expressions of healing and medicine undertaken by indigenous peoples. In doing so, he set a standard for grouping non-Western medical systems as ultimately homogenous and in the domain of magico-religious practice. Western medicine, by contrast, was perceived as natural, scientific, and “categorically different from all other pretenders to the title of medicine” (Singer & Baer, 1995, p. 7). Rivers created a conceptual model detailing three worldviews: magical, religious, and naturalistic, followed by corresponding beliefs about disease and the resulting practices or behaviours for treating disease. Though conceptually a very important model for envisaging cross-cultural understanding about disease, Rivers acknowledged that only magical and religious worldviews were associated with culture thus the naturalistic worldview was not considered when analyzing “native medicine.” The naturalistic view presented phenomenon as subjected to natural laws, and these were associated with the West. He does acknowledge evidence of “empirical, and ostensibly naturalistic, curing practices” among native groups but chose not to regard these as such, preferring to remain within the magical or religious domains of explanation for “primitive” peoples (Wellin, 1977, pp. 49-50).

Good (1994) calls for us to “denaturalize disease” and nowhere is this more necessary than when conducting historical analysis of the spread of colonialism around the globe. The process of diffusing people, culture, and technology from Europe to the colonies led to the global spread of allopathic medicine. Anthropologists played an important role during these years for they provided ethnographic knowledge of native populations that facilitated colonial expansion. Good (1994) refers to the historical merging of medicine and religion as part of the colonial process in the “new world.” In this sense, Christian-based religious systems became “tools” of the colonizing forces. If the scientific revolution effected the separation of church (belief) and

science (knowledge) it was colonial expansion of the 1800s that brought them together to serve the political, economic, and socio-cultural needs of Britain.

Baer, Singer & Susser (1997) provide an interesting discussion of the emergence of biomedicine as a global system by referring to its application to the diseases that were both caused by and threatened colonial expansion. Medical personnel, including medical missionaries, accompanied merchant marines and settler populations to the New World, while establishing medical outposts in indigenous communities. While Baer writes of the suppression of indigenous healing systems by treating indigenous diseases with biomedicine, he fails to adequately address the direction of transmission of diseases from the explorers, missionaries, and colonists to indigenous populations. Many of these diseases were airborne and outside of the realm of indigenous healing strategies. The widespread death of indigenous populations threatened the survival of the colonies (Baer, 1997) but perhaps not so much due to the fear of colonists contracting indigenous diseases. Rather, the rapid decline in sources of cheap labour to extract resources for shipment to the “motherland” must also be considered in the face of supporting evidence. Public health missions were synonymous with the spread of western-based economic, political, and religious ideological systems. Many colonists believed it was their responsibility to bring civilization to undeveloped nations and to improve the standard of life in the colonies. Seen as the White Man’s burden, this practice was adopted and practiced without question.

Jared Diamond (1997), in his book, *Guns, Germs, and Steel*, recounts how disease was one of the most powerful weapons in the arsenal utilized against the colonies. In many cases diseases were transmitted by missionaries whose work involved carrying both medicine and religion to the indigenous peoples in an attempt to “convince the natives to give up false beliefs and take on a set of beliefs that [would] produce new life and ultimate salvation” (Good, 1994, p. 7). Indigenous healing systems were rendered useless by the powerful air-born sicknesses of which the people had no cultural explanation. In many areas entire populations succumbed to disease.

The role of smallpox in facilitating the colonial take over of Native lands and resources from indigenous peoples in British Columbia provides an excellent example of Good’s suggestion that one must ‘denaturalize’ disease and see it as a cultural domain to fully and critically understand the complexity of biomedicine. Along the Fraser River in British Columbia, two-thirds of the indigenous population died from contact-related smallpox in the 1800s, regardless of the knowledge of immunization against this disease that was held by the colonizing forces. With

a weakened native population, colonial encroachment into non-ceded indigenous lands was simplified (Carlson, 1996).

Patrick Tierney (2000), in his book, *Darkness in El Dorado*, provides a contemporary example of the alleged genocide of indigenous peoples in South America by anthropologists, social science researchers, medical researchers, missionaries and journalists in an attempt to achieve academic fame, conduct biomedical studies, convert, and acquire resources. Though Tierney's work is highly controversial and under close scrutiny by the American Anthropological Association, he alleges that many of the people who brought sickness to the Amazon basin during the past 50 years knowingly risked the lives of indigenous peoples in the quest for medical knowledge, or to test medical and social scientific theories. The rationalist belief in 'common good' as opposed to individual right to life, does not merely result in collateral damage in the quest for cure, rather it is rooted in racism and ethnocentrism common to many Western-based research paradigms within biomedicine and in some areas of anthropology.

Physical reductionism is a powerful concept that must be deconstructed to enable the researcher to look at understanding the diseased body not as a natural target of invaluable biomedical processes, but rather as a construction, by humans, that is influenced by social, political, gendered, economic, religious, and scientific factors. "Biomedicine...objectifies the patient and the disease, constituting both decontextualized and asocial objects of the medical gaze. Disease is thus entified and treated as a dimension of human biology rather than as socially produced misery or human suffering" (Good & Good, 1993, p. 82).

In discussing the early history of the social context of anthropology and medicine, Singer & Baer (1995) make an important connection between Britain and America (p. 18). Samuel Morton, a polygenist, founded the American School of Anthropology. Like Hunt in Britain, both men were physicians who espoused an anthropology based on racial determinism. Though the relativists were mounting a campaign to counter the racial determinism of the evolutionists, "the micro level focus, however much an advance in some regards, failed to fully confront and eliminate earlier tendencies" (p. 18).

While the positivist school was advancing and making inroads in medicine, politics, and economic systems, in both the Western world and in the colonies, the evolutionary and ahistorical perspective being promoted was not without notice or criticism. From a public health perspective in Europe, the industrial revolution was creating massive upheavals in all sectors of life such that poorer classes of peoples were doomed to lives of misery and suffering. Similarly, in the

colonies, indigenous lifeways were being eroded, and the international traffic in human beings was increasing.

Rudolf Virchow, a German physician and clinical pathologist, became intensely interested in the causes of epidemics in the 1840s, after documenting a typhus outbreak in Upper Silesia in 1848. The minority Polish population was dying by the thousands, much of their demise being complicated by famine and poverty. Virchow looked beyond naturalistic explanations of this epidemic to a more complex explanation that included social and political factors (Singer & Baer, 1995). His work, “in addition to demonstrating the social etiology of compromised health, including powerlessness, insist[ed] on the understanding of contradictory social forces that obstruct reform” (Taylor & Rieger, 1985 quoted in Morsey, 1996, p. 26). Though surprisingly absent from Good’s (1994) discussion on the history of illness representations in medical anthropology, Virchow has been credited with formalizing the relationship between medicine and anthropology by helping to develop the “first anthropological society in Berlin” (von Mering, 1970 quoted in Baer, Singer & Susser, 1997, p. 15). Further, Virchow has been linked to the famous quote, “Medicine is a social science and politics is nothing more than medicine in larger scale” (quoted in Singer & Baer, 1995, p. 20). He also wrote that “once medicine is established as anthropology, and once the interests of the privileged no longer determine the course of public events, should physicians become supporters rather than opponents of the existing social structure” (quoted in *ibid*, p. 20). Unfortunately, Virchow’s recognition of the political nature of biomedicine did not infiltrate dominant anthropological theory for many years though many of his ideas are as applicable today as they were when he was alive.

Virchow makes an interesting point about the relationship between physicians and social structure. In the context of HIV/AIDS research, one must acknowledge the privileged relationship between many research and clinical physicians, and the powerful pharmaceutical companies that often fund AIDS research. Similarly, the controversy over the discovery of the HIV retrovirus, between Gallo and Montagnier (Maggiore, 1997; Schilts, 1987), is a telling reminder that the ‘alleged’ objectivity of the scientific method is a powerful socio-cultural construction. The very foundations of biomedicine are both political and economic and have a profound impact on how illness and disease are represented within master narratives.

While Virchow called for a critical political economy perspective in medicine and anthropology, he also influenced Franz Boas through their affiliation with the Berlin Ethnological Museum in the 1880s (Baer, Singer & Susser, 1997, p. 15). Both men were committed to

“scholarship and the scholar’s social responsibility” (Singer & Baer, 1995, p. 21), though Boas did not integrate the political economy perspective of Virchow into his theory and methodology. Committed as he was, however, to spreading his critical perspective on racist evolutionary thinking, Boas impacted many anthropologists who followed in his stead.

Forrest Clements and Erwin Ackerknecht, researching disease among non-Western peoples in the first half of the twentieth century, were both influenced by the theoretical school of Franz Boas. Clements utilized a “culture trait” approach to “classify disease-causation concepts among primitive peoples” (Wellin, 1977, p. 50). Attempting to record the worldwide distribution of traits, he also sought to record relative time frames and the path of spread in each trait’s diffusion. Clements believed that behaviour related to sickness and healing were important parts of culture, thus, made “effort[s] to reconstruct the paraphernalia of healers” (Rubel & Hass, 1996, p. 114). Clements concluded in his 1932 monograph, *Primitive Concepts of Disease*, that “a society can be characterized by the disease cause most prominently reported for it” (*ibid*, p. 114).

In critiquing Clements’ classification system, Wellin (1977) makes mention that years earlier Benjamin Sapir had raised the question, “How [are we to] inject a chronology into this confusing mass of purely descriptive fact?” (Sapir, 1916, quoted in Wellin 1977, p. 51). By laying out the conceptual and methodological problems and weaknesses of “charting spatial distribution of traits and in making out temporal inferences from them” (Wellin, 1977, p. 51), Sapir provided Clements with a framework for improving or altering his methodology. It is noteworthy that Clements did not adhere to Sapir’s concerns.

Good (1994) adds an important dimension to the critique of Clements’ trait classification system. Referring to Rivers, Clements, and Ackerknecht as writers in the empiricist tradition, he notes their use of “embarrassing evolutionary language” (p. 29), and that they ranked illness representation “according to a hierarchy of increasing rationality” (*ibid*, p. 29). As an outgrowth of earlier evolutionary theory, the medical knowledge of non-western peoples was seen as a “kind of proto-science elaborated in primitive theories of disease causation, primitive surgical practices, and primitive knowledge of pharmacological properties of plants and minerals” (*ibid*, p. 29). While Clements’ attempt at large-scale classification has been noted (Wellin, 1977, p. 51), it has also been suggested that he, Rivers and Ackerknecht “unwittingly contributed to biomedical hegemony by bracketing biomedicine off from ethnomedicine. They accepted biomedicine at face value, not as a subject for social science” (Baer, Singer & Susser, 1997, p. 15).

Though primarily an ‘armchair’ anthropologist among non-western people, Ackerknecht is noted as having shaped medical anthropology as a “modern sub field of the discipline” (Wellin,

1977, p. 51), and is seen by Clements as “the ‘father’ of medical anthropology” (quoted in Singer & Baer, 1995, p. 23). Widely influenced by the Boasian tradition of Ruth Benedict, Ackerknecht believed that indigenous healing practices could only be understood within the cultural context of which they are a part. He “sought to develop a systematic cultural relativist and functionalist interpretation of what he termed ‘primitive medicine’” (Baer, Singer & Susser, 1997, p. 15). The work of Ackerknecht, while in the empiricist tradition (according to Good, 1994), clearly sought to adopt ideological concepts from the relativist school.

In tracing the ‘history’ of medical anthropology, the different genres of study and intellectual interest cannot be clearly demarcated. The theories and methodologies that have emerged in the past 120 years are best understood as complex networks of influences and perspectives and not necessarily lending themselves to one-dimensional definitions. Good’s presentation of Ackerknecht as being empiricist and Benedict as being relativist is a clear example of this. Ackerknecht’s ‘embarrassing’ language and system of classification, while empiricist by Good’s definition, clearly did not define the totality of his work. Though Ackerknecht, refers to himself as being widely influenced by a Boasian tradition, of Ackerknecht’s influence, Wellin (1977) writes:

By focusing on the importance of the *culture whole* in shaping the society’s medical elements, directing attention to the *patterning* of medical belief and behaviour, and by emphasizing the *functional interrelationships* among the parts of the medical pattern between the latter and the total culture, his orientation stimulated the development of medical anthropological inquiry within the mainstreams of social-cultural anthropology of the 1940s and the early 1950s (p. 52).

In discussing the influence of relativism in medical anthropology in the earlier part of the twentieth century, Good (1994) suggests that while relativism provided the main alternative to empiricism, the majority of relativist theory and research was being conducted in psychiatry and not in medical areas (p. 31). Ruth Benedict, a psychological anthropologist and student of Franz Boas, called for a culturally relative view of illness. She challenged the universalizing of naturalistic explanations of disease. Benedict attempted to trace patterns of behaviour within a culture such that one could know the culturally determined (bound) manifestation of psychiatric illness (Benedict, 1934). While Benedict has had a profound influence on anthropology in general, the culture-bound nature of her psychological theories has created gross overgeneralizations. These have led to homogenizing populations, particularly with her development of the national character concept.

Much of her work was being conducted in the years around World War II. The influence of the global political and economic relations on Western academia during this time must be critically examined. Benedict's patterning of personality as reflective of a national character was politically appropriate for the times in that it alleges to allow one to know the *other* as a complex of culture-bound traits and behaviours, including culturally-rooted illnesses and psychoses. Her ethnographic analysis of Japanese national character, *The Chrysanthemum and the Sword*, was particularly important given United States – Japan relations during World War II. The Office of War Information commissioned this ethnographic analysis in 1944 (Benedict, 1946). While Benedict did not go to Japan to conduct her study, she did interview many Japanese who were living in the United States, some of whom were living in relocation and internment camps. A groundbreaking study in its day, Benedict's research was to provide a relativistic overview of "how your enemy looks at life through his own eyes" (1946, p. 5). The relativism that guided Benedict's research was intended to counter bias and open a window into the world of the other. In terms of Benedict's contribution to medical anthropology, her focus on the role of relativism in denaturalizing illness cannot be understated. The role of relativism however also tended to ignore political and economic factors that influence illness and disease.

While there are many theoretical movements impacting the development of medical anthropology, Hahn and Kleinman (1983, cited in Hahn, 1993), have suggested that the central theories can be best understood on a continuum. They would place environmental/evolutionary theories at one end, cultural theories at the other and interactionist theories as the merging point in the middle. While I find continuums too simplistic to accurately portray the complex field of discourse that exists in medical anthropology, the opposition between evolutionist theories and cultural theories needs revisiting.

In reformulating the early history of medical anthropology, one clearly benefits from placing the theoretical changes, in part, as responses to the socio-cultural milieu in which they were developed. Evolutionism promoted racism, classism, sexism, and other forms of ethnocentrism. It became the justification for much of the colonizing and genocidal policies on behalf of the 'mother' land. Compounded as this was by the unparalleled human suffering resulting from industrialization and emerging capitalism, the relativists found much fuel to fire their theoretical work. Benedict, as well as other proponents of the American School of Anthropology, found fertile soil for their theorizing among those academics who recognized the inherent flaws of the ahistorical nature of evolutionary theories. As a reactionary practice, cultural relativism often neglected the macro political and economic processes that clearly impact

both culture and individuals at the micro level. Furthermore, in the years after World War II and with the emerging Cold War, criticism was being generated among many who recognized the need to factor in global political and economic processes as primary sources of influence on cultural phenomenon. Adding to the complexity of the academic field was the growing reliance on biologically-based theories, particularly the influence of environmental factors on the occurrence and dispersion of disease.

Medical ecology

Environmental and ecological theories in medical anthropology developed in an evolutionary sense, though not necessarily with the unilineal constraints of the nineteenth century evolutionists. The influence of the American cultural school caused much theorizing in the medical arena to focus primarily on cultural factors to the relative exclusion of environmental and ecological ones. In response to this, as much as from the effort to return anthropology to the scientific side of social sciences, environmental and ecological theorists attempted to merge the biological with the socio-cultural. Wellin (1977) refers to the “root source of the ecological orientation [as] essentially a ‘scientific revolution’...in evolutionary biology that erupted along a broad front of biological disciplines during the 1940s and laid the necessary theoretical foundations for dealing with human evolution and adaptation as the complex interaction of cultural and biological factors under given environmental conditions” (p. 54). Adding to this, Alexander Alland (1970, quoted in Hahn 1995), a key figure in medical ecology, posited an interrelationship between environmental and medical factors in any society. Regardless of its complexity, this was critical in understanding a society’s adaptive strategy. By bringing biological and environmental variables to the forefront of analysis, medical ecology presents itself as holistic and multidisciplinary in that it takes a systems approach while drawing on relevant theoretical concepts from many fields of analysis (McElroy 1996).

From a global environmental perspective, the ecology school clearly reflects the influence of technological innovations in the 1960s and 1970s to more comprehensively measure human-induced global change. The first satellite images of ‘spaceship earth’ in the 1960s, as well as later images of development-related environmental degradation, provided fuel for theoretical critique on the finite potential of growth. Taken from the realm of being seen as a natural result of the evolution of ‘mankind’, the limits to growth theorists looked to the cultural and environmental consequences of the global spread of Westernization. Medical ecology was a

'natural' outgrowth of this movement, as disease, once again, came to be seen as primarily biological, albeit with recognition of the confluence of social and cultural conditions.

Brown, Inhorn & Smith, (1996), in the essay, *Disease, Ecology, and Human Behavior*, responds to Hahn's (1995) allegations of apolitical theorizing in medical ecology by noting the merging of cultural and political ecology. While acknowledging the validity of the criticism, Brown, *et al.* (1996) suggest, "it is important to note here that adding the dimension of political ecology to microsociological studies reveals the 'unnatural history' of many diseases" (p. 188). Relying on 'evolution' as a key concept, medical ecologists remind us that they envisage the evolution of disease, as opposed to illness, resulting from the process of change over time. Using the Darwinian concept of natural selection as the primary driving force for evolutionary change, Brown *et al.*, (1996) see disease as a crucial factor in evolution for its links to mortality. They suggest that disease shapes "both human biology and culture" (p. 191). The resulting ecological view rests upon the foundation that ethnomedical systems are developed as, primarily, rational responses to adaptive strategies.

Good (1994) suggests that ecological and rationalist theories, in conjunction, support an empiricist paradigm in medical anthropology that views human adaptive responses to disease as processes of natural selection and common sense. "The very common sense quality of this paradigm hints at its role in reproducing conventional knowledge about the role in the individual in society" (p. 41). Central to Good's perspective on ecological theories is his argument that by seeing disease as primarily biological and illness behaviour as being driven by adaptive instincts, the role of folk beliefs are diminished in the overall analysis of medical systems (p. 44).

A second main argument raised by Good (1994) pertains to the "analytic primacy given to individual choice and the implication that illness representations and ethnomedical systems are ultimately derived from the rational, instrumental activities of individuals" (p. 46). The belief that scientifically-derived theories, such as medical ecology, are using a value-neutral framework for analysis does present the potential for non-critical and biased theorizing regardless of the complexity of the society or medical system under study. One is left to question the assertions by Brown, *et al.* (1996), that merging medical and political ecological theories can adequately enhance accurate representation. Also important here is the basic premise that individuals always act in a rational manner intended to increase reproductive fitness, a key element in the process of natural selection.

The ecological paradigm does provide important elements for improving on the critical perspective from which to understand illness and disease representations. Inhorn and Brown

(1997) have clearly shown the value of an expanded ecological medical anthropology in the research of infectious diseases. They suggest that infectious diseases play primary roles as agents of selection and that human action influences the distribution of infectious disease. The origins of the suffering induced by infectious diseases must be “analyzed from both micro- and macro-sociological perspectives, including the political-economic one” (pp. 53-54). This can clearly be seen in the global AIDS pandemic. While drugs do exist that may prolong life in those infected with HIV, they are not readily available to many impoverished and infected persons living in Africa, or other developing nations around the world. HIV as an agent of natural selection may have more to do with politics, classism, and racism rather than any naturally occurring phenomena.

The reintroduction of sociological concepts to medical analysis serves to create a greater potential for a holistic analysis, though not from a value-neutral perspective, as has often been suggested. Secondly, an ecological approach does raise awareness of the complex, heterogeneous relationships between humans, both individuals and groups, and their environment. This relationship is complicated, however, by a myriad of influential cultural, political, economic, and spiritual forces.

Inborn and Brown (1997) remain committed to a biomedical characterization of infectious disease at the epidemiological level, and while they do acknowledge the main criticisms by the critical medical anthropological school (CMA), remain steadfast in their belief that “applied medical anthropologists must be equipped to work within the biomedical paradigm if they hope to be effective in improving infectious disease control programs or healthcare delivery” (p. 54).

CMA: The political economy of medical anthropology (PEMA)³⁶

As with any form of discourse that provides central concepts from which interested parties can formulate their research ideas, PEMA provides a theoretical foundation that results in a diverse body of scholarship. Gaines (1990), in his critique of CMA, has identified what he refers to as its five variants. They are: 1) Marxist political economies; 2) cultural critique of medicine school; 3) dependency theorists; 4) Gramscian school and hegemony; and 5) the critical

³⁶ The use of both PEMA and CMA appear throughout the readings; however, CMA is the more recent of the two labels. Baer (1997) explains that CMA, as a label, was questioned by Morsy (1989) who prefers PEMA. Baer suggests that CMA and PEMA are virtually identical. It is questionable as to whether or not there is a discernable difference between the two, reflecting a paradigm shift, or if it is a matter of convention. I will be using the terms interchangeably.

theorists (Gaines, 1990, quoted Baer 1997, p. 1566). While Baer (1997) carefully exposes the weaknesses of Gaines' classificatory system by citing the work of researchers that falls into more than one of the listed categories, it remains clear that CMA does not provide a simple analytic strategy from which to engage praxis. Regardless of theoretical complexity (or perhaps because of it), the central emphasis to this orientation is analyzing power and powerlessness as they function at multiple levels for people living with HIV.

In understanding the historical antecedents to PEMA, Morsy (1996) notes the influence of Virchow in Germany in the nineteenth century, among others, who called for attention to the link between poverty, social suffering, and disease. Rather than seeing disease as solely biological, or inherently cultural, PEMA suggests, "the relevance of culture is not restricted to ethnomedical conceptions, it extends to issues of power, control, resistance, and defiance surrounding health, sickness, and healing" (Morsy, 1996, p. 23). The connection between class inequality and human suffering that compelled Marx to theorize on the inequalities of capitalism is inherent in the explicit political agenda of CMA (see Hahn 1995, p. 74).

The influence of Marxism in rooting PEMA in "the historicity of conception" (Singer & Baer, 1995, p. 59) must not be understated. As dialectic, this tradition seeks to "controvert claims of scientific objectivity and ethical neutrality by explicitly acknowledging that both anthropology and medical knowledge are socially informed products of particular historical and cultural contexts" (Morsy, 1996, p. 25). This argument forms a core from which CMA develops its analytical framework for re-examining the "guiding conceptions that have shaped the nature of understanding in medical anthropology" (Singer & Baer, 1995, p. 60) and their links to master narratives.

In reacting to the ecological school, CMA makes explicit the lack of attention to the role of power relationships in sickness and healing studies. The criticism suggests that "human populations do not interact directly with their environments; rather, populations are organized by societal rules, backed by consensus and/or force, which differentially allocate control over material hazards and material resources" (Hahn, 1995, pp. 71-72). CMA, then, takes sickness and disease from the apolitical and ahistorical realm of natural selection and adaptive strategy, and reconceptualizes it in the analytic framework of historical, political, and economic factors acting upon individuals and groups within a society. In this context CMA lends itself to a critique of biomedicine as a product of historically emergent Western capitalism rather than as a paradigm of objectively-derived truth aimed at universalistic explanations of scientific phenomena. Singer & Baer (1995) add a further dimension to illuminating the hegemonic positioning of biomedicine in

relation to anthropology by recognizing that the key ideas that gave birth to medical anthropology were widely influenced by biomedicine. Given that biomedicine is a politically and economically powerful medical system, it undoubtedly represents the values and beliefs of the dominant class, those who control access to medical resources (Singer & Baer, 1995).

As has been shown previously in this chapter, earlier anthropological perspectives studying illness and healing have fallen prey to a separation of biomedicine from all other arenas of healing, labelled in a rather homogenizing manner as ethnomedicine. As a reaction to the apolitical nature of these theories, CMA does hold biomedicine, as a social construction, as one of its primary focal points. Given the hegemonic position of global capitalism, the absolute authority vested in biomedicine within a capitalist system, the functioning inequalities within the institution of biomedicine, and the often-uncriticized link between pharmaceutical companies and “objective laboratory research,” it seems logical that political economy as a theoretical perspective would emerge to challenge the more conventional theories of disease.

Gaines (1991) has expressed the concern that some CMA researchers have focused too intently on capitalism as an explanatory factor in disease to the exclusion of biological and ecological factors (cited in Baer 1997). In response to this allegation, Baer (1997) cites numerous examples of CMA utilizing environmental concepts in its search for the causes of disease and further posits, “Human health is affected by an environment which is the product of the dialectical interaction of natural and socio-cultural forces” (p. 1567). Epidemics of infectious diseases have plagued humanity for hundreds of years and that these epidemics have biological and environmental components is not necessarily being called into question or discounted within CMA. The focal points for analysis are the complexity of forces, both social and biological, that impact upon the unequal progression or regression of epidemic diseases among a population. Within this analytical framework, then, one finds biomedical rationale for epidemic disease as limited in their explanatory potential, though reflective of dominant Western master narratives.

As this dissertation is exploring the socio-cultural construction of HIV/AIDS and its impact upon one woman’s life experience, the political economy of this epidemic must not be ignored. Looking at the history of AIDS in North America, one finds a disease that is poorly defined within biomedicine. Paul Farmer (1992) is an anthropologist and medical doctor who was writing on AIDS in Haiti and among Haitians living in the US in the 1980s. He exposed the necessity of factoring in racism, political and economic ideology, moralizing, belief, faith, and biomedicine to obtain a more clear understanding of HIV/AIDS in any community or country. The marginalizing he identified was derived mainly from master narratives disguised as common

sense knowledge about AIDS and was supported by the biomedical community, including public health officials, to all who would listen. It fueled a carefully orchestrated ‘blame the victim’ scenario aimed at Haitians. Targeted as a ‘risk group’, Haitians were fired from jobs, evicted from housing, harassed, and encouraged to leave the United States for fear that being Haitian meant having AIDS.

Farmer (1992) carefully lays out a complex analysis that exposes the likelihood that the direction of disease was not from Haiti to the United States but visa versa. Poverty and unemployment led Haitian men and women to sex trade zones in their home country that serviced sex tourists from the United States and other countries. Economic impoverishment in Haiti, due to foreign-owned development initiatives, left many Haitians with little choice but to immigrate to the United States in search of employment. Some of those who emigrated arrived with HIV/AIDS, became sick and, in many cases, died. The master narrative emerged to fuel public hysteria, in part, by poor science on the part of some members of the biomedical community, and by an uninformed and overzealous media. Farmer’s study resulted from his extensive medical work in a small, relocated Haitian community. He merged a critical medical anthropology with a critical interpretive anthropology to arrive at a comprehensive understanding of how macrostructural political, economic, and biomedical processes collectively constructed the risk group ‘Haitian’, and how those infected organized their own lives around personal beliefs and meanings attached to their HIV/AIDS status.

In terms of levels of analysis, CMA is well suited for deconstructing the complexity of political and economic factors surrounding this global pandemic. AIDS exists at multiple levels: global, national, regional, local, and individual; thus, understanding the complex flow of influence between these levels is essential to understanding AIDS. While epidemiological evidence strongly suggests that HIV causes AIDS, there is a minimal likelihood that the biomedical research community will discover a cure in the near future. With over 40 million HIV infections to date, AIDS will continue to be a central feature in many peoples’ lives and deaths around the globe. Governments, private and public sector researchers, drug companies, global organizations, non-governmental organizations, educational institutions, and community-based health organizations are but a few of the institutions in the international community that have a vested interest in HIV/AIDS.

In attempting to gain an understanding of the political economy of HIV/AIDS, Wolf suggests it is “the changing product of an ongoing compromise between socially opposed and continuously contending forces (e.g., classes, genders, ethnic groups, sexual orientation groups)

rather than the imposition of powerful upon the powerless or a mystical achievement of human complementarity across social groups" (quoted in Singer, 1998, p. 23). It cannot be stated strongly enough that AIDS is political, at virtually all levels. From the earliest days of AIDS, multiple voices have been competing for position, including those of 'authority' and those in resistance to authority. The interplay between hegemonic and counter-hegemonic forces in this pandemic bears strong evidence to the desire of infected persons to wrest control over their lives back from the often dehumanizing and impersonal bureaucratic political and biomedical institutions that are determined to control both their living and dying.

Alex Keating's life, before AIDS, was political. Fiercely independent, she supported those causes that appealed to her sense of fairness and justice. After her HIV diagnosis, her life spiralled down a path of powerlessness. Being female in the mid-1980s, when the majority of community support organizations in Vancouver were oriented to homosexual and bisexual males and not heterosexual women, complicated her situation. The majority of biomedical research and drug testing was still aimed at understanding HIV/AIDS through the opportunistic infections common among infected men. In her narrative she speaks of gaining her 'life' back through becoming political. By learning the language of biomedicine, she was able to communicate with biomedical practitioners in a manner that left many uncomfortable. She opted out of AZT, a move that she believes saved her life but cost her the care of one of the leading AIDS doctors in Canada when she refused his offer of AZT. Later Alex determined that all of this doctor's patients that she knew about were taking AZT. One is left to question the efficacy of a treatment regime that is contingent upon one drug, one drug company, and a life-threatened client load. Alex often wonders what threat she posed to this medical authority by questioning the efficacy of AZT. Lock and Kaufert (1998) suggest that individuals who "challenge institutionalized power bases can be perceived as a serious threat" (p. 6). Treichler (1989) adds to this discussion by suggesting that:

To challenge biomedical authority – whose meanings are parts of powerful and deeply entrenched social and historical codes – has required considerable tenacity and courage from people dependant in the AIDS crisis upon science and medicine for protection, care, and the possibility of a cure. These contestations provide the model for a broader social analysis which moves away from AIDS as a lifestyle issue...and requires us to acknowledge and examine the multiple ways in which our social constructions guide our visions of material reality. (p. 35)

In discussing CMA, Good (1994) suggests that it "forcefully poses the question of when illness representations are actually misrepresentations which serve the interests of those in power, be they colonial powers, elites within a society, dominant economic arrangements, the medical

profession, or empowered men” (p. 57). In applying this to Alex’s experience with HIV/AIDS, as a socio-cultural construction, her social body has been medicalized in a way that defines her as a dying woman, though her biomedical relationship with death changes as the definition of HIV/AIDS grows to encompass more ‘opportunistic’ infections. Interestingly, though Alex has had common colds throughout her entire life, she no longer gets a simple common cold; rather it becomes medicalized as potentially another AIDS-defining opportunistic infection. Virtually every illness she encounters is filtered through her HIV/AIDS status to the point that, within a biomedical frame of reference, she becomes HIV/AIDS not Alex Keating, an HIV-positive woman. The language and culture of biomedical institutions and government welfare agencies demand that she be subservient and grateful for the expertise and assistance of these powerful and impersonal bureaucracies.

Critical interpretive medical anthropology (CIMA): Contextualizing the illness story

In discussing illness representations, Good (1994) has chosen an interpretive approach that is informed by critical theory to address “the difficulty of joining political economy and interpretive perspectives, of integrating historical and global perspectives with rich cultural analysis in our ethnographic writing” (p. 63). Preceding CIMA, the emergence of an interpretive perspective in anthropology is traced to Arthur Kleinman’s work in the late 1970s (Good, 1994). Kleinman’s writing is oriented to a meaning-centred approach that grants primacy to the illness narratives of individuals and those in close contact with them. Kleinman (1988), in differentiating between illness and disease, writes, “I mean to conjure up the innately human experience of symptoms and suffering. Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability” (p. 3). Conversely, disease is the taxonomic category through which the practitioner has filtered the individual’s illness characteristics, coupled with other biomedical indicators of “an alteration in biological structure” (p. 5). Kleinman defines sickness as “the understanding of a disorder in its generic sense across a population in relation to macrosocial (economic, political, institutional) forces” (p. 6).

In imbedding the illness narrative into the larger understanding of one’s relationship to their health, one is encouraged to place symptomatic explanations within a complex network of social relations and cultural understandings. Attempting to regain a more holistic understanding of illness, disease, and sickness, interpretive theorists have challenged the influence of Cartesian reductionism on biomedical understanding and definition of the body (Kleinman, 1988; Lock &

Scheper-Hughes, 1996). The “normative conceptions of the body in relation to the self and the world” are integral to how one perceives illness and the meaning attached to symptoms of sickness (Kleinman, 1988, p. 12). Calling for a more comprehensive network of understanding of the body in relation to illness, many have analyzed the construction of the body within the language of biomedicine, seeing the body as a multi-faceted, dynamic political agent.

The analysis of the body as a cultural construct is central to Lock and Scheper-Hughes' (1996) discussion of CIMA. They theorize that understanding the complexity of the body is conversant with three levels of analysis: the individual body; the social body; and the body politic. The individual body encompasses the “lived experience of the body-self”; the social body “refers to the representational uses of the body as a natural symbol with which to think about nature, society, and culture”; and the body politic “refers to the regulation, surveillance, and control of bodies (individual and collective) in reproduction, and sexuality, work, leisure, and sickness” (p. 45).

Good & Good (1993) have explored the social construction of the medicalized body as a critical starting point in a student's education at Harvard Medical School. Beginning with an analysis of how the anatomical body is presented and following through the application of symptoms to a narrowly defined physiological diagnosis, they trace “the experience of learning medicine” (p. 90). By dissecting the body (cadaver) to an anatomical structure, the students are taught to see the body as hosting a medical problem needing a medical resolution. The process of “objectively” reconstructing the body, anatomically, is a very important step in developing the medical gaze (Good, 1994).

Good & Good (1993) continue to examine the language of medical school. They engage in a very compelling discussion as they make clear how the language opens up a new world to the student doctor. She learns to collect patient narrative explanations of symptoms, but reduces those symptoms to a few lines on a medical chart, devoid of the meaning that the ill person attaches to the symptoms. Learning to write and speak in medical school “authorizes the medical student as it constructs the patient” (Good 1994, p. 77). A patient's own illness narrative is often seen as a subjective, non-expert, emotional perspective on the medical condition; therefore, it does not warrant entry into the medical chart. Furthermore, Good reveals how the patient is constructed by the order of questions asked, and that the student doctor is evaluated based on the written report. In this sense the person becomes reformulated as a patient for treatment (p. 77). The process of medicalization “inevitably entails a missed identification between the individual and the social bodies and a tendency to transform the social into the biological” (Lock & Scheper-

Hughes 1996, p. 48). Alex's narrative exemplifies this when she writes of telling a doctor about her persistent pelvic and abdominal pain and having him reply, "What do you expect, you have HIV." Alex's subjective illness experience is denied value in its own right and is reduced to the biological diagnosis of HIV.

Lock & Kaufert (1998) raise an interesting and pertinent point regarding the medicalized body. Using Foucault's concept that biopower creates a "domain of expertise, constitutes its own objects of analysis to which it then responds" they suggest that, "bodily states are labelled by experts as diseases; certain behaviours are defined as deviant, unnatural, immoral, opening up the way for systematic and legitimized attempts of medicalization of both body and behaviour" (p. 7). Clearly, the indoctrination in medical school (Good, 1994; Good & Good, 1993) prepares the student doctor to work within the domain of biopower, a critical component within the master narratives of biomedicine and capitalism (Foucault quoted in Rabinow, 1984, p. 263).

Alex Keating's story provides an interesting opportunity to look at these ideas in an applied context. The medical chart of her husband James shows his former injection drug use. He has a bleeding disorder, called ITP, which requires the transfusion of clotting agents when his platelet count falls too low. There was a time in the mid-1990s when James was having difficulty finding a haematologist who would order the requisite transfusions on a regular basis. During this time, blood and blood product were in short supply due to the "tainted blood problems" and the crisis at the Red Cross in Canada³⁷. After trying multiple ways to get a haematologist to order the necessary treatment for her husband, Alex took him to the emergency room and refused to leave until he was treated. At some point during the night, a sympathetic nurse spoke with Alex and told her that the real problem in getting the treatment was influenced by his history of injection drug use and was complicated by the HIV and hepatitis C. Within the clinical narrative, James was seen as a terminally ill man and being held morally responsible for his medical condition (Good, 1994, p. 83). The consulting haematologist allegedly did not want to "waste an expensive treatment on a dying addict."

The medical construction and subsequent treatment of both Alex and James Keating as diseased bodies have been at the core of their relationship with the biomedical community since

³⁷ Throughout the 1980s and into the early 1990s the Canadian blood supply, administered by the Canadian Red Cross, was seriously infected with both HIV and hepatitis C. As a result of many persons being infected after receiving blood products, the RCMP convened a task force to examine evidence and lay charges of criminal negligence and common nuisance against the Canadian Red Cross, directors and former chiefs of the Canadian Red Cross, and a pharmaceutical company. Those charged were cited for failing to properly screen blood donors, failing to properly test blood and warn the public about the risks associated with various blood products (CBC News Online Staff, 2002).

their respective HIV diagnoses. While they have worked very hard to assemble a biomedical and complementary healthcare team to meet their health needs in a holistic manner, they still struggle to ensure humanistic treatment within many biomedical institutions. Alex is very pragmatic about her and her husband's biomedical needs and will do what ever it takes, including meeting the indignities of being defined biomedically as a diseased person, to ensure that these needs are met. This life and death struggle is an identity-constituting element of their relationship with the biomedical communities (Kaufert 1998), as exemplified by James' need for transfusions to combat low platelets, for without these he would eventually bleed to death.

Foucault (in Rabinow, 1984) refers to the subjectification of the individual as one of three modes of objectification in his analysis of the politicization of the relations between body and social institutions. In the process of becoming a subject, the person remains active in self-formation. Linking this concept to both Nelson's (2001) ideas of restoration of agency and Frank's (1995) theoretical discussion of illness stories as healing mechanisms, Foucault's subjectification mode "entail[s] a process of self-understanding...mediated by an external authority" (in Rabinow, 1984, p. 11) through which self-understanding is achieved. To move beyond the chaos of chronic illness, the deprivation of opportunity, and the loss of power that results from the surveillance of the political body that is congruent with HIV, subjectification addresses the nexus of power that remains with the individual and that is fundamental in building towards a counterstory.

Resistance to the hegemonic control by biomedical and economic institutions upon which Alex and James rely is central to Alex's illness narrative. Abu-Lughod's (1990) suggestion that "where there is resistance, there is power" (p. 42) clearly reorients the relationship with hegemonic sources of power that enables one to see resistance not only as a form of power in and of itself, but as a possible avenue for the restoration of agency. Alex has often commented that it is the very struggle with doctors and welfare workers that keeps her going. Furthermore, as a guest lecturer in university classrooms, and a sensitization workshop facilitator for doctors and welfare workers, telling her story allows her to confront the medicalization of her 'body' that attempts to define her as a powerless woman with a catastrophic terminal illness. Of fundamental importance here is that she can recognize the external sources of power that seek to constrain and define her life, and work both within and outside of these institutional settings to retain some semblance of personal power.

Alex has been able to assemble a biomedical care team that was willing to accept her earlier decision not to take any powerful and toxic AIDS drugs, yet still provide prophylactic

treatment as needed. I believe this exemplifies the power that Alex herself possesses in decision-making about her health and thus reflects her agency. Also, her current care team's acceptance of her resistance calls into question the over-generalizing tendency to group all medical practitioners as cogs in the wheel of hegemonic medical institutions. As Lock & Kaufert (1998) suggest, "biomedical knowledge is complex, often not standardized, and always open to contestation from both within the profession and outside" (p. 16).

Applying the analytic categories of CIMA to Alex's experience with HIV/AIDS is useful for portraying the complexity of factors that collectively, though not equally or consistently, influence the socio-cultural construction of her as a diseased body. The categories allow for the meaning she assigns to her living and dying to exist on a level separate from the medicalizing definition of the biomedical community, yet facilitate an understanding of the influences between the different bodies. Important to note, however, is that while the generalized definition of these categories provides the reference for analysis, the complexity of factors that contribute to understanding the "three bodies" of Alex Keating are constantly shifting.

As Alex describes her life 'in the beginning', she believed herself as closer to death, though the biomedical indicators of HIV/AIDS showed minimal progression of the virus. Her individual body was dying. The consciousness of her social body was infiltrated by the stigma of the dominant narrative; thus, went into hiding. Her political body was powerless over those controlling forces that marginalized her very existence. Eighteen years later, with a consistently high viral load, and having experienced numerous AIDS-defining illnesses, she describes herself as more alive than ever.

Ethnographic illness narratives

Arthur Kleinman's intention in the 1970s was to bring forward illness narratives as a means of studying the "subjective experience of illness" (Ezzy, 2000, p. 605), and to look at the multiple influences that shape the telling of the story. Profoundly impacted in the 1960s through his experiences with critically ill persons while in medical school, Kleinman learned the "difference between the patient's experience of illness and the doctor's attention to disease" (1988, p. xii). Learning to talk with ill persons about their illness and to witness their experience became a foundation for much of Kleinman's writing on the value of narrative as a healing strategy.

The function of these narratives for healthcare providers is equally important. They act as a vehicle to mediate between the personal experiences of suffering and pain and the external

world of socio-cultural interpretation and treatment of both the ill person and their story. Narratives become “an essential resource in the struggle to bring experience to conscious awareness” (Ochs & Capps, 1996, p. 23) and in so doing, have a direct link to one’s agency. They provide the willing listener, especially those in healthcare provider roles, with a “window on the ways illness can permeate lives and relationships and on the way the experience affects thinking and decision making” (McLellan, 1997, p. 1619).

When a person becomes ill this happens within socio-cultural and familial contexts such that there are many influences on how an individual may be impacted by their biomedical diagnosis and their personal relationships, among other variables. Nelson (2001) refers to biomedicine’s control over one’s disease experience as part of the master narrative through which ill persons become constrained and their personal and contextual experience becomes subsumed. Research conducted among fourth-year medical students’ first-person narratives of stories of those infected with HIV have revealed that the ill person’s story is often reconstructed in the transmission (Marshall & O’Keefe, 1995); thus, may reflect “the way in which individual meanings are externalized, objectified, and projected onto a socially and morally salient other” (p. 75).

Marshall & O’Keefe’s (1995) research involved fourth-year medical students listening to a PWA tell his story of infection and illness. The students were then asked to write a short account of the story and the subsequent group interview as if they were the HIV-infected speaker. The findings showed that the reconstructions were filtered through the subjective understandings of the students and the culturally constructed meanings that define HIV within the master narrative. Fear and shame were common themes that ran through the students’ stories. The students were encouraged throughout the assignment to discuss their narratives with each other and in so doing, to voice their vulnerabilities regarding the meanings they assigned to HIV. Evident throughout the exercise was the interpretive dissonance between the original PWA narrative and those of the students. Without a doubt, the medical students’ versions actively recreated the identity and experience of the patient and in many cases were more telling of the perspective of the student doctor than that of the patient. Recognition of the interplay between patient construction of their illness experience and that of healthcare providers is essential in understanding how the lived experience of illness does not happen in social isolation.

Marshall & O’Keefe (1995) suggest that narrative exercises, such as the one discussed above, that can provide opportunities to “transform fear into compassion will be crucial in alleviating student anxiety about working with patients infected with the AIDS virus” (p. 75).

The practical implications for illness narratives to influence medical policy are made obvious through the above-discussed research. Learning how to engage the illness narrative as a dynamic interpretive act between subjective communicative partners rather than reconstructing the patient in objective biomedical language will undoubtedly improve the agency of the ill person. In a practical sense the patient, rather than being undone by the biomedical reconstruction of their illness experience, may find they are able to become active participants in their own healthcare narratives. Given the exacting nature of anti-retroviral drug regimes, compliancy in taking the drugs is often a problematic issue in treatment and care. Healthcare practitioners who see their patients as valuable communicative partners in building a care plan that gives voice to the patient's experience may witness a greater degree of compliancy than those who objectify and deny agency to the patient. Paying attention to how meaning is articulated by the teller and the listener(s) of illness narratives forces all communicative parties involved to address the subjective nature of how meaning is constructed. What it means for an HIV-infected person to live in fear of their virus is different from the fear of HIV that may guide an HIV-negative healthcare provider. Recognition of the heterogeneity of ways that experience is endowed with meaning is essential in developing an appropriate healthcare policy that works with HIV-infected persons rather than for them.

Kleinman's writing on the value of subjective narrative experiences as a viable healing strategy can be linked directly to Nelson's assertions regarding the narrative repair of identities damaged by dominant disease discourse. Providing a space for illness stories to be told, ethically witnessing one's illness experience, and reflexively exploring the researcher's role in this have laid a foundation within anthropology to critically examine the complex contexts within which people experience chronic and/or serious illness, cope with disability and death, and aim to restore agency and identity that a biomedically-defined disease diagnosis often takes away.

Alex's story: Illness narrative as an interpretive process

Early in Alex's illness story she writes of the isolation, fear and loss of agency that is associated with illness in general and with HIV specifically. Her story traverses two decades of HIV, first, among other factors, as an advocate for safer sex and then as an HIV-positive woman and caregiver of an HIV-infected husband. In recounting her experiences from the early years of her infection to the present, one can see a shift in the telling, from the story of a frightened, ashamed, and dying young woman, to a much older and more philosophical person living with HIV. While this may seem a moot point, I intend here for the reader to realize how significant it

is for Alex to recognize that she has lived long enough to ‘get older’. It is in the shifting of her storyline that the seeds are sown for the counterstory to emerge.

Over the course of her adult life, Alex’s illness narrative has changed to reflect a coherence that she “uses to interpret the past, act in the present, and plan for the future” (Ezzy, 1998, p. 177). While multiple plot lines are constantly merging in her story, they are reflective of the intersection of the socio-cultural discourses, biomedical constructions, and personal interpretations and lived experiences with HIV. As Hawkins (1993) maintains, illness narratives allow insight into experiential aspects of illness that the biomedical model ignores. Throughout the telling, one gains a sense that her story is about the struggle to find a sense of self-hood that is denied by the very institutions upon which she and James rely (Sakalys, 2000). In the struggle to reclaim her unique experience with HIV, which is often subsumed under the homogeneous moralizing of fear-laden master narratives, the words of her story acquire an emancipatory quality (Frank, 1991). This is clearly laid out in the way she writes of hiding her HIV status during a 1987 medical procedure at the Cancer Control Agency of British Columbia, and of her subsequent shame and guilt surrounding the denial. That she can reflexively write of this event, including the associated negative feelings, and come to the place of self-forgiveness, has not only helped restore her agency and self-hood but has also provided the reader with a clue as to how she could both forgive and empathize with the friend who she believes infected her the previous year.

In the opening of this chapter, Alex writes of how her role as caregiver for her husband has not only dominated her adult life, but has also provided a diversion from focusing on her own health issues. While Alex has recognized that this delay in self-care reflects denial and avoidance of her own health status, it is also characteristic of women’s traditional caregiving behaviour (Bunting, 2001; Stein, Crystal, Cunningham, Ananthanarayanan, Andersen, & Turner, *et al.*, 2000), and thus can be seen as a normalizing activity in many ways. The policy implications of women’s care-giving narratives can be seen as a guide for medical practitioners to develop health plans that consider a woman’s determination of her priorities and where she places her own health needs in relation to those of her family. Clearly, Alex’s caregiving role was of primary importance and often meant that her health needs went unattended to. For a medical practitioner who does not understand the complex caregiving role of many HIV-infected women, they may misinterpret a women’s reticence toward her own health as reflective of her being an irresponsible and unruly or problematic patient.

In the mid-1980s, as discussed earlier, Alex’s chaotic life with HIV was spiralling out of control, as increasingly her agency was being denied by the varied contingencies of an HIV

diagnosis. Meeting James, obtaining an HIV seropositive diagnosis, getting married, and stepping into a care-giving role, became key elements in both her narrative and her self-identity. It revealed not only how HIV had come to take over both of their lives, but also how she navigated her way through the chaos. Even throughout the years of her self-destructive behaviour and use of injection drugs in an attempt to bring an end to her suffering, Alex always ensured that James' needs were met. This plot is interwoven through her narrative and is not to be understated.

In listening to Alex, the subjective caregiver story is one that is both burdensome and sorrowful, yet is also replicated in the stories of many couples, of all sexual orientations, where terminal illness is a lens through which the relationship is filtered (Wrubel & Folkman, 1997). Many of these stories become a testament to qualities of love and commitment that one often finds normalized within many mainstream romance narratives. Filtered through the stigma associated with HIV, the master narrative does not give voice to what it means to love another to the point that one would willingly give up her own health to help her partner. This story line is old and enduring. Associating it to many persons living with HIV, regardless of sexual orientation, needs to be addressed within interpretive analysis. These narratives exist as more than gender-biased quest plots (Squire, 2003). A point of critical discussion here is to recognize that in the subjective experience of caregiving, including that based on love, there are many positive factors that are often overlooked in a researcher's haste to reinforce the marginalizing nature of such a stigmatized illness (Wrubel & Folkman, 1997). As an outsider attempting to be a caregiver to my sister, I have come to understand how and why Alex tenaciously hangs on to her role as protector and caregiver to James when her own health is so clearly compromised. What I have at times neglected to see is that in the desire to ensure that James receives the requisite care; Alex has found a reason to live with HIV.

An interesting example that represents this happened a couple of years ago in the story of her experiences with anti-retroviral drug therapy. From the time of her diagnosis until the spring of 2002, Alex spoke on numerous occasions of how she would not become involved with AIDS drugs as she knew of their toxic side effects and of the lifelong reliance on them once started. James' health improvement, subsequent to his beginning an anti-retroviral therapy, began for the first time throughout their marriage, periods where Alex was noticeably sicker than her husband. Clearly as James' HIV levels receded and his immune system became stronger, his focus on life was considerably more oriented towards the future. Where Alex had done most of the caregiving in the past, James was now providing similar services for her. The shift in their roles was

something that often came up in conversations between James and myself. Throughout this time, Alex had difficulty giving up her control over caregiving within the home though many times her health left her few options but to accept the role reversal.

During the summer of 2002 when Alex was consistently ill and not sure of whether or not to begin taking the drugs, James expressed the fear to me that she might become sick and die at a time when he was beginning to feel that there might be a future, however contingent, for him to look forward to. Not wanting to go forward without his wife, but not wanting to influence her decision about the AIDS drugs, placed James in a precarious position. Alex's desire to ensure her husband would never be alone again provided the impetus for her to begin drug therapy. Whether or not this will prolong her life is unknown though both James and Alex have begun to talk in future-oriented terms. Though somewhat tentative, the orientation toward the future is something that was seldom present in their narratives prior to taking the drug therapy.

HIV, life, and the clinic

Throughout the years that Alex has been living with HIV, finding appropriate medical care that does not usurp her agency has been a recurring theme in her narrative. The very nature of HIV/AIDS, particularly with the current treatment regimes, requires that one maintain an ongoing and closely monitored relationship with biomedical care teams. Alex's experience of watching her friends struggle to find appropriate healthcare, her own diagnosis story, and the fear associated with HIV seropositivity, are factors that impacted her delay in seeking medical care. Not an uncommon response among many who suspect they may be infected, Alex clearly articulates a number of factors that have led to this.

As discussed earlier in the dissertation, the homosexualization of HIV, coupled with the moralizing about the 'kind of women who get it', provided the most significant barriers to her seeking medical care. Alex's story tells of how she knew that the manner in which she was informed of her HIV diagnosis was just a harbinger of what was to come and that control over her own life would diminish with the diagnosis. In a study conducted by Raveis, Siegel & Gorey (1998) of HIV-infected women and their delay in seeking care, a number of factors were identified. In addition to those listed above, competing role demands of those women who were caring for an infected partner or child, denial of the reality of their status (including not informing physicians), needing to get to a place of readiness to accept the reality of HIV, seeing HIV as a death sentence, fear of dying, and being singled out and subsequently ostracized were the primary

reasons listed. In Alex's narrative, each of these barriers have played a role in her own relationship with the medical community at various points over many years.

Additionally, the excessive use of drugs and alcohol, after diagnosis, was also identified not only as a barrier to medical care but also as a way to deal with the fear associated with HIV. Throughout the period after Alex's diagnosis, the stigma of IDU made it difficult for her to seek out medical care, as her shame was compounded beyond that associated with HIV. The infiltrated consciousness that she experienced deprived her of the opportunity to seek out appropriate medical care as is, allegedly, the right of every Canadian. As Alex has often mentioned, "When you have IDU on your medical chart, no matter how far in the past it is, it really impacts the kind of care you receive." For many years Alex struggled to put in place a care team that would validate her own knowledge of how her life with HIV would best be served by biomedical intervention and, in doing so, listen to how Alex wanted her life with HIV to proceed. Unfortunately, many medical practitioners, seeing the IDU designation on Alex's and James' medical charts, found the moral justification to deny them respect and thus agency.

When the Oak Tree Clinic opened its doors in Vancouver in 1994, both Alex and James were able to become patients there. After years of being marginalized by the biomedical community, Alex finally found a place where she felt she was being treated as both a valuable human being and as a necessary member of her care team. Her doctor's willingness to reinforce Alex's agency is clearly reflective of a recent trend in some HIV/AIDS medical care options. With anti-retroviral drug regimes being so exacting and physiologically demanding, they extract an immense toll on patients, often resulting in a high degree of attrition and non-adherence (Roberts & Mann, 2003).

In 1995, Meredith & Delaney (1997) conducted a study among HIV-seropositive women attending a newly opened health clinic in St. Louis, Missouri. This clinic had a similar mandate to that at Oak Tree Clinic in Vancouver, British Columbia. The clinic was set up to provide comprehensive care and researchers were employed to survey willing patients regarding how the clinic could best meet their needs. The findings of the study identified the following: women wanted positive, supportive, non-judgmental, and personal relationships with healthcare workers; of healthcare practices, the respondents wanted honesty from doctors who would be truthful and take the time to fully answer questions; improved education and coping strategies; a place where care would be delivered in a positive manner regardless of the terminal nature of HIV; and a greater sense of control or involvement in their HIV care plan.

Throughout Alex's story of her interactions with the medical community prior to 1994, one is continually confronted with examples of her being marginalized, being silenced, and being treated as a dying woman. This is reflective of both the master narrative of HIV and of the privileged position accorded medical doctors. The research abounds with case study examples of the ways in which HIV devastates those infected and, in Alex's experience, much of this had taken place in clinics, hospitals, and doctor's offices. With medical management of HIV being deemed crucial in maintaining its social construction as a chronically manageable terminal illness, some areas of the biomedical community have sought ways to improve delivery of healthcare. Clinics such as Oak Tree are being set up as a result. Based on female-centred models of healthcare delivery, they are essential to "improve the health status of women, remove barriers to healthcare, and honour women's role in society" (Hills & Mullett, 2002, p. 95). The care model includes a place for women's narrative experiences of HIV to be given voice and for women to be active participants in the construction of both the meaning and experience of living with HIV.

While the care received at Oak Tree Clinic has made a considerable difference in Alex's and James' lives, they still must access other medical services that are based on a more traditional medical model. Often these services are reflective of biomedical marginalization reflected in oppressive master narratives. Though I have heard stories for years from James and Alex about the derogatory care they have received from persons in the medical community, I often thought they were being overly sensitive or perhaps too demanding, that is until I witnessed the abuse in action. Whether this was reflective of HIV-related marginalization, of the stigma associated with IDU, in response to Alex's vast knowledge of HIV treatment options, or from economic pressure of an overburdened healthcare system, the ability of some healthcare professionals to discount and discredit James and Alex is a very real and often-occurring phenomenon. In this third decade of HIV, the biomedical community, in general, still has considerable room for improvement in its treatment of PWHA. It is here that illness narratives, as counterstories, can provide a missing element in the improved delivery of healthcare for PWHA.

CHAPTER V: ADVOCACY AND ACTIVISM: BUILDING A COUNTERSTORY

Masks and Unknown Faces: My Public and Private Selves



Photograph 17: Sculpted by Alex Keating, Spring 2002³⁸ ■■■

³⁸ Photograph by permission of Jesse Cooper.

Alex's story

I moved to Vancouver from Cranbrook, British Columbia in the latter part of 1983. When I moved to the city I knew three people. One of these was a man I had done theatre with in the town of Cranbrook where I grew up. I had made arrangements to share an apartment with two girls I had met while writing my hairdressing license at Camosun College in Nanaimo, British Columbia, so I had a place to live when I arrived in the city. This living arrangement lasted all of 30 days as they drove me crazy. At the end of that month I moved into a small bachelor apartment just off Commercial Drive and found a job at the downtown Hyatt Regency Hotel hair salon. Within a couple of months of this move I contacted my friend from Cranbrook. He and I got together for a drink a few days later at a downtown bar called The Castle Pub. I knew a couple of the men with whom I'd done theatre in Cranbrook were gay but this was the first time I had ever been to a gay bar.

I remember having an absolutely wonderful time. Through him I made many new friends who were part of the gay community. I began to hang out and party with these people to the point where all my social activity involved these new friends. I became very close with a few people, relationships that lasted for years. I continued doing hair for a living although after eight months at the Hyatt Regency salon I'd had enough of what I saw as a pretentious atmosphere so I changed employment to a more youth-oriented salon.

In mid-1985 I also got a Saturday night job working coat check at the hottest gay weekend dance club going at that time. The bar was called John Barleys. There were three floors to this bar, the top was a seating area, the middle was a dance floor and the bottom was the leather bar. I worked in the coat check, which was located in the leather bar where all the leather and S&M [sadomasochism] guys hung out. I had a great time working down there. I would dress in sexy leathers and party with the boys, it was a wild and eye-opening time for me. I met many casual and a few close friends through this job.

I also became friends with a woman who was very active in the gay community although she herself was not gay. She was a socially and politically active woman who opened my eyes to the broader picture of the coming epidemic of AIDS. Although I was aware that

this new illness was being talked about with concern among my friends, it did not seem to be something of imminent importance. None of my friends to this point were disclosing that they were infected with this illness so there was distance. After I met her I was exposed to a few people who were willing to admit they were infected with HIV. I became aware of the expectations these informed people had regarding the potential spreading of this illness and of the treatment persons with HIV were receiving. What I was learning seemed very wrong and created a sense of outrage in me.

Through her I found something I could do to help. I began distributing condoms, lube, safe sex handouts, and safe sex pins. At first the pins were just your basic safety pin to signify "safe sex" but later they had slogans on them such as "on me not in me." I would help distribute them at John Barleys on Saturday and, on Friday, rounds of the gay bars would be made by myself or a group of us dropping these off and partying with our friends. I began doing this because I felt a need to do something about this "HIV thing" that was affecting and killing my friends. My purpose would later be fuelled by circumstances that struck even closer to home.

Early in 1986, I applied for and got a job with the Expo Corporation as a manager of the Canadiana retail outlet on the Expo grounds. When the training for the Expo job began I decided to quit my hairdressing job. I had been doing hair since 1981 and I wanted to do something different. I could always go back to it. Just before Expo 86 began, I also got a part time job at Doll & Penny's restaurant in the West End of Vancouver. I had wanted to work there for a long time, as it was a hot spot of the social scene of the gay community. I knew a few people who worked there and wanted to work in the fun & stimulating environment that it was. I had also moved to a new home at the beginning of that year when I learned my activist friend was moving out of her apartment and her roommate was looking for a replacement. I knew her roommate casually so we decided to move in together for one month to see if it would work. It did and we continued to be roommates for more than three years. My roommate also worked at Doll & Penny's as a shift manager and for us, being co-workers and roommates seemed to work very well.

In September of 1986 I was offered a full time position at the restaurant. Knowing that Expo was going to be over in little more than a month and that I was making great

money in tips, I took the offer and quit Expo. I also stopped working at John Barleys except for a few special events when I would work in costume as a cigarette girl. As 1986 began more of the people I knew were disclosing that they were infected with HIV and a few people I considered close friends died of AIDS, it seemed to be everywhere. Then a man I knew who lived upstairs from us was diagnosed with HIV. He was diagnosed on a Tuesday and died a week Thursday. Nine days, that's all he had after his diagnosis. Suddenly it all became very real.

Throughout this time I would on occasion go out dropping off condoms and lube at the bars but not as often as before. I was involved in getting the safe sex message out in other ways. Often this took the shape of behind the scenes logistical help for events or campaigns being staged. It was in August of 1986 that I went to Seattle to celebrate my 21st birthday on the Tacky Tourist Boat Cruise. It was a great party weekend that ended in my not practicing safe sex and most likely becoming infected with HIV. The time I had spent in the gay community had done wonders for my self-esteem. I had found a way to have safe relationships with men that were not sexual in nature. I had finally come to believe that I was a pretty, intelligent, likable, and funny woman. With all this I still had loneliness and insecurity inside that would not let me place a high enough value on "me" to protect myself. It took me years to realize that self-esteem was the missing component to the safe sex message that still seems to be missing today.

About six months after this boat cruise when the man I had been intimate with died, I stopped handing out condoms in bars. I did continue to help with planning events and functions, as my roommate was often involved in putting them on. My personal denial regarding HIV began at this time.

My life went on like this until late 1988 at which time my roommate decided to leave so that my mother who was coming to Vancouver could move in. I had dated my husband James a few times the year before and as 1989 began our dating was more frequent. I was attending Douglas College and applying to SFU to attend the fall semester as a mature student. I think it was summer when my mom moved out and James moved in. We moved to SFU in October 1989 and I was tested at the health clinic that December. James and I

married in February 1990 and moved out of SFU that April into a shabby apartment on Welfwyn St. in Vancouver.

It was in this apartment that my world began to close in on me. I was living, if you could call it that, in a state of hopelessness. This belief was reflected in my home by the clutter and lack of care present there. I was not only ashamed of myself for having this illness, I also became ashamed of my home and the way I had begun to live my life through starting to use heroin. By now I was out of school, had stopped working and was facing welfare; more shame. All these factors resulted in my not inviting my family to visit and I had made it very clear unannounced visits were not welcome. I also felt a certain rejection of my husband James on the part of my family. I took the position that if they rejected him then I rejected them. This exacerbated the distance. We lived on Welfwyn St. for close to two years.

Spring of 1992 we moved to Burnaby, just down the street from where my mother lived. My world opened up a little more here but not much. The drug use, that began while we were living on Welfwyn St., by this time, had become a serious problem. Family was rarely invited over but on occasion I would go visit them. James and my mother became closer during this time and he would visit her often. I think the shame of what my world had become made me want to control what people saw. It was in February of 1993 that I attended the women's retreat on Bowen Island and my life began to open up. I had made contact with an addiction doctor around this time and my life long struggle of battling my addictions had begun. At the retreat I made a commitment to volunteer my time with the women's organization that had put on the retreat. During that retreat I came to realize I had something to give regarding this illness. I also realized that there was much I could get from being involved. I think my drive and determination to effect change came as a result of my experiences with both the medical and welfare systems.

When I began volunteering with this women's organization it had about 30 members including the half a dozen women who had organized the first retreat. This work also put me in contact with the other AIDS organizations in Vancouver, most of which were located in the Pacific AIDS Resource Centre (PARC). Also located within PARC were AIDS Vancouver (AV), the PARC Library, AIDS Vancouver Food Bank, and Polly & Esters (a

place that gave away used clothing and house wares). There was also a lounge area for members and a smoking room for those who indulge in that habit as I unfortunately do.

PARC was a new facility that had just come together the year before. Prior to PARC, BCPWA and AIDS Vancouver were located in separate locations and the women's organization was a kitchen table operation, so this new location was wonderful. It allowed for easier access to these organizations for their members and it also allowed the individual organizations to better utilize their funding. By evaluating the services each organization had to offer they were able to make some changes and not duplicate services, thereby utilizing their money more effectively. From day one of my volunteering I was answering phones, giving information, doing referrals, counselling peers, and advocating for women. There was no time for training. Being such a small organization with one paid employee and a few volunteers, there were many tasks to be done.

I was one of the first women from the retreat to volunteer with the group and as such was much needed help. My volunteering started within a week or so of the retreat. They increased their paid staff to two by hiring a woman who had attended the retreat. She was hired to work as an office assistant, someone to be in this new office space during the advertised hours of operation. She was not comfortable doing peer counselling and advocacy. She was only comfortable keeping the office running and referring the women to someone else for peer counselling/advocacy help. Furthermore she was choosing to remain anonymous regarding her status. Volunteers were needed to do this work. I seemed to take to advocacy and counselling like I had done it all my life. I was a good listener, empathetic and compassionate. I had more legal, medical, social policy, and welfare policy information in my brain than I realized and I learned fast. I was able to navigate in and negotiate with the medical and welfare systems using their jargon and policies to counter their positions, which were often incorrect or unenlightened. As an advocate this allowed me to approach the "powers that be" on a more level playing field. For these and many more reasons I was an excellent advocate. Finding a sense of accomplishment and fulfilment doing this work led me to be in the office regularly.

I don't remember the exact order in which my public work began and progressed but I will do my best to document it. By 1993 there was a growing movement to bring the women and HIV issue to the foreground of the public, medical, and political arenas. The growing public awareness increased the number of inquiries by the media regarding the specifics of how HIV was different for women. Due to these inquiries, effort was made to acquire input from all the HIV-positive women we had access to and with that input a document was created that would lay out the basics of women's reality in living with HIV. It was no more than a couple of months after I began to volunteer that I participated in an HIV conference as a speaker on a panel that addressed women's issues.

This panel consisted of doctors, frontline workers of AIDS organizations, and myself with a personal testimonial of my experience. I remember that as I sat on the stage and began to tell the story of my journey I became very emotional. This was the first time I stood up in public and spoke to strangers about my HIV. At one point during my story there were tears running down my face and as I looked to the audience and saw their tears, I could see that I had touched them. This was very powerful for me as I did not feel judgment coming from them, I felt empathy. My next public exposure was through the media. The TV reporter who handled the medical stories for his station came to the women's group and I was interviewed regarding the services that we offered at this organization. I was also able to discuss some of the specific issues that affect women with HIV. I'm not sure if the fact that I was a woman living with HIV was part of the story but I think it was.

During my first year I began to get involved in their speakers/education program. Many requests were made for women to speak in public settings. Due to the very few number of women involved in this organization who were willing to go public about their HIV status, the demand outweighed our ability. The document we had produced which specified woman-specific issues became an important resource we sent to these organizations when we were unable to send a woman representative in person. I also participated in AIDS 101 and safe sex education sessions in high schools and junior high schools. It seemed logical and necessary for me to give this information out to these young people at a time when many of them were beginning to make choices regarding their sexual practices.

Putting a face to this illness was of major importance, that human face seemed to help break down barriers and challenge preconceived notions. All this education and public appearance work was important. By doing these activities I was helping to effect change, not only in people's sexual practices but also in the public face of HIV that would influence the social and political climate. I had also taken on the role of resource person and was responsible for researching and producing user-friendly information sheets regarding women-specific issues. Even more important to my own personal healing was the one-on-one counselling and advocacy I was doing for other HIV-positive women. To be able to offer to these women something I didn't have for years, someone who could truly understand the fear, sadness, and shame was powerfully healing for all involved.

Advocating for these women was also very empowering for me. I came to understand the "system" very well whether it was medical, governmental, or societal. This understanding and my own ability to be logical and concise in presenting arguments on these women's behalf allowed me to be successful in most of my advocacy endeavours. Working with these women became very cathartic for me and helped in the finding of my own power and self-esteem again.

I also participated with the AV speaker's bureau. Their speaker's bureau received many requests for school presentations as well as facilitating educational workshops for the welfare department, medical personnel and home support workers. AV also had a women and AIDS department that worked closely with the women's group. Through AV, I became involved with some very interesting projects. I think one of the more interesting and challenging was the FAW educating and sensitizing workshop. This was a two-day workshop facilitated by the AV education department where welfare Financial Aid Workers (FAW) were educated in the reality of living with HIV on a disability income and sensitized to the needs their clients may present.

The hope was that this workshop would produce more empathetic FAWs and more compassionate treatment towards those living on welfare with HIV. The morning of day two of this workshop was when persons living with HIV on welfare disability would present their perspective to the FAWs. This was the aspect in which I was involved during my participation in a couple of these workshops. I would have liked to participate in this project

on more occasions but that was not always possible. I had become involved in many projects and activities and was often busy.

Some of the other interesting projects that I participated in with AV were the medical personnel and home support workers education sessions. The home support workers education sessions were a 4 hr. evening class during which we taught the basics of AIDS 101 as well as universal precautions to those already working in this field. For me the most important message to pass on to these workers was that, unless they were exchanging body fluids with their clients, their clients were no risk to them. They in fact were a greater risk to their client's health through the illness they themselves carried and by not adhering to universal precautions than their clients would be to them. As for the medical personnel, in this instance they were UBC nursing students. The format for these education sessions was that someone from the AV education department would conduct the information and sensitizing class and a PWA would provide personal testimonial component; this was my role.

Early in the summer of 1993 a notice was received at the women's group from the Global Network of Persons Living with HIV AIDS (GNP+) announcing their upcoming conference in September '93. This conference was to take place in Acapulco, Mexico and was expected to be a huge gathering of PWAs from around the world. I wanted to go. My desire to attend the GNP+ conference was expressed to the group of women, both volunteer and paid staff, since most decisions in our group were made by consensus at that time. I was told to make some inquiries regarding expenses and requirements and get back to them. With this information I was able to make a convincing argument as to why I should attend. Permission was given for me to attend representing the group and the funding approved to send me there.

Three other people I knew were also attending this conference. One was a man who was serving on the BCPWA board of directors, the other a man who worked in the advocacy department of BCPWA. The third was a woman I knew through the women's group and who was going to Mexico as a representative of the Canadian AIDS Society. The BCPWA advocate and I were good friends and he became my traveling buddy. This was my first trip to another country (besides the United States) and I was very excited. I was also somewhat concerned as I would be required to change planes in Los Angeles and entering the United

States if you have HIV is illegal. When the Security/Customs people in Los Angeles were questioning me, I omitted the fact that I was attending this conference as a participant. I told them I was attending as a presenter who worked in AIDS education. That was a lie. I was not attending as a presenter but as a participant. This lie made me feel like a criminal and I guess in their eyes, by virtue of my blood, I was. This barrier overcome, I continued on to Mexico.

Interestingly enough, I met a man from Botswana on my first day in Acapulco who experienced discrimination when changing planes in Texas on his way to this conference. When he was going through security he was asked the purpose of his trip and he was honest and told them he was going to participate in a conference for people living with HIV/AIDS. He was asked if he had AIDS and he answered yes. He told me he was unaware of the possible repercussions of answering the HIV question honestly while in the United States. Once his HIV status was in the open this man was taken out of line to a private room and airport administrators were called to deal with the situation.

He was held in this room away from all other passengers and his traveling companions while the powers that be decided if they were going to allow him to continue on to the conference or make him return home. They also had his luggage removed from the plane and brought to the room where he was being held. Once the luggage arrived it was immediately wrapped in plastic and sealed with tape as though it was contagious. This man missed his connecting flight to Mexico as the decision of what to do with him was being made. Eventually he was given permission to continue on to the conference but the discrimination didn't stop.

He was kept isolated from all other passengers in this room until it was time to board his new flight. All the other passengers were boarded and then he was escorted to his seat that was at the back of the plane where he was kept separate from everyone else. He was told to stay in his seat and not wander in the plane. It was as though he was a criminal or a walking contagion. His luggage was boarded but kept sealed in plastic. It seemed they wanted to protect the general population's luggage from his. This man told me that he felt absolute humiliation by the way he was treated by the airline staff and the way he was looked at by the

other passengers. I know he was concerned about what treatment to expect when he went home. I know listening to him tell me his story made me grateful that I had lied to the airport authorities.

Unfortunately this would not be the last discrimination incident I would be told about or observe during my time in Acapulco. The conference was thought provoking. There were more than 600 PWAs attending from around the world. The plenary sessions and workshops were interesting and stimulated my desire for change. I learned so much. The opportunity to network with other PWAs, who were doing the same work as I, was empowering. Some of the social and political conflicts I observed were frightening but understandable. These were people who were fighting for their lives. At this conference we were able to speak directly to those who affect world politics on the AIDS issue. Leading researchers, authors and World Health Organization representatives were some of the people we had access to during this conference. I met some inspiring people, some from absolutely impoverished countries that were able to do so much with so little. I left that conference and that country knowing how lucky I was, how lucky all of us Canadians are. I also left with a stronger determination to make things better. When I returned home I jumped back in with both feet.

I am also a member of BCPWA and AIDS Vancouver (AV) and have been since 1990 and 1991 respectively. Once I began volunteering with the women's group and was regularly around the PARC offices I became more actively involved with these two organizations. Since I was doing advocacy work I began interacting regularly with those at the advocacy department of BCPWA. This offered me an excellent opportunity to learn as the advocates at BCPWA are excellent and know the "system" well. Through my friends there I gained much information about the welfare department and how it functioned. These fellow advocates also gave me a copy of the welfare policies manual that the FAWs base their decisions on. This gave me an advantage in my dealings with the welfare department, being able to quote their own policies to them when making an argument of assistance and being able to show them under which policies this FAW could offer assistance if they chose to.

Sometime in early 1994 I was approached by the Board of the BCPWA society and asked if I would consider completing the two-year term of a board member who had to resign due to health reasons. It was expressed that they specifically wanted a woman to fill this position in order to have their board more reflective of the changing demographic of those infected with HIV. I agreed and became a member of the Board of Directors, a commitment that was for just more than a year.

I continued to work in both the office and the public domain. I continued to participate in a multitude of projects with these different organizations. By mid-1993 the women's group had grown and had hired an executive director. As a full-time volunteer I had been involved in the hiring process. I believe it was in the fall of 1994 that I was approached to participate in the Physician Education Project, a joint project between the women's group and AV women's bureau. How this project worked was that a doctor who specialized in HIV and its manifestation in women and a woman who was living with HIV would co-present to the doctors who came to the workshops. The specialist would present the medical aspect and the woman would present the personal aspect of the realities of HIV. This project was very successful and well received and continued for a year or so. During this time I participated as presenter on four occasions. I was unable to participate more often as my life had become busy with other involvements.

One unexpected side effect of this participation was that I was contacted by a woman I knew who worked at the British Columbia Centre for Excellence. She was someone I knew casually who was aware of the work I had been doing. The reason she contacted me was that she wanted me to fly to a small community up the coast, with herself and an HIV specialist, to participate in a workshop much like the physician education program. I was very honoured by this request. She could have asked anybody but she didn't, she asked me.

An AIDS awareness event was planned to take place in Cranbrook, British Columbia. This was the brainchild of my sister Leila Cooper that came about as a result of her sense of helplessness in coming to terms with my illness. She decided at some point the year before that she wanted to put on an AIDS awareness event in Cranbrook on World AIDS Day, December 1, 1994. She contacted me about this plan and told me her ideas for it. I said I would

participate and gave her the names of people she may want to contact and a few ideas I had. The rest she did with her planning committee.

At the end of November I travelled to Cranbrook for a week and participated in a number of activities. These included radio interviews, education sessions at East Kootenay Community College, education sessions at the junior high schools, and culminating with the AIDS awareness gala on the evening of December 1st. She managed to line up known entertainers from out-of-town to volunteer their time and talent. She also arranged for a local television station to record the event and then to play it at a later date to their community. The money that was raised from these events stayed in their community. I was and am very proud of her for what she did. Going back to my hometown was challenging and somewhat frightening. It was also very cathartic and I left there with a sense of pride.

At some point in early 1995 I was asked to participate in a pilot project being funded by the Canadian AIDS Society (CAS). This was called The National Women and HIV Project and I was asked to participate as the British Columbia representative. This project had started two months prior to my becoming involved. Why I was approached at this time was the person who was representing British Columbia, a friend of mine, was going to have to quit the project. Her duties to the board of directors of CAS were taking up too much of her time and she was no longer able to fully participate in this project. I was a little overwhelmed by the prospect of working on a national project but I accepted.

The premise of this pilot project was as follows. One woman from Edmonton Alberta was hired as the organizer; her job was to assist the representatives and set up meetings and travel. She would also be responsible for writing the final report. One woman was chosen from each of the provinces of Canada to represent their region. All the women involved in this project were infected with HIV. This group would get together four times during the year and in between meetings the representatives would make contact and gather information from positive women in their province.

By the time I came onto the project, the first meeting, in Toronto, had already happened. My first meeting was in Montreal about one month after I joined the project.

These meetings tended to last four days with very little free time; they tired me. The Montreal meeting proved to be different than any other. Representatives of women specific AIDS service organizations from across Canada had been brought together in Montreal to network with each other at the same time the women of the national women and HIV project were meeting. On the third day of our meetings in Montreal, these two groups were brought together to strategize and network.

What I found disturbing was that as the meeting progressed, many of these AIDS service organization representatives began to seem threatened by the national women and HIV project. I could not understand why our simply wanting to speak for ourselves was so threatening. These AIDS service organizations worked from the mandate of empowerment for their members, so, why did they feel so threatened when we became empowered? During this day tempers seem to get hot and words were misunderstood. At the end of the day little consensus was reached and a few of these organizations refused to support The National Woman and HIV Project. What I found particularly disquieting was that it seemed that the most vocal opposition came from some of the AIDS service organization directors. I left that day feeling sad and confused by what I had witnessed.

After the Mexico conference, this was my next most serious experience of the negative politics involved in the AIDS field. The women involved in the National Women and HIV Project spent much of the fourth day working through the residue of the third day. I personally lost respect for a number of people through that process and began to question the commitments of individuals at certain women's organizations to honour their group's mandate. The residue of this experience has stayed with me to this day and I'm sure has coloured my opinion of certain situations. The final two meetings of this project were held in Halifax and Vancouver. The information gathered during the course of this project was compiled into a document and presented to the Canadian AIDS society.

This project was a success and the first of its kind. It was the first project to focus on women's issues on a national level and it was the first national project to be directed and worked on by HIV-positive women only. There are also failures with this project. We failed to get the support of all the women's AIDS organizations we tried to network with. There

was something about the autonomy the members of the national women's project demanded that seemed threatening to some people. It was like we were seen as trying to take their power away so they fought back by claiming their ownership of the women AIDS arena. I am proud of my participation on this project. I am proud I was part of a group of positive women who demanded their voice and power stay with them and did so in the face of some powerful opposition.

At the same time that I was involved in the National Women and HIV Project, I was still volunteering with all the organizations at home. I had some very limited involvement with BCPWA prison outreach program. My involvement was, on a few occasions, participation in an outreach panel at a local prison. These presentations were focused towards prisoners and their families. A group of us from PWAs would tell our stories then make ourselves available for one-on-one discussions with the prisoners and/or their family members. I had a great deal of interest in pursuing more involvement in this project but the business of my life and a decline of my health interfered.

When my commitment was up with BCPWA Board of Directors I did not run for the position again. The politics of the business of AIDS was taking its toll. I found I no longer had an interest in participating in any aspect of AIDS service work that was ingrained with politics and political power struggles. I know that just talking about the topic of AIDS is political in itself, that's not what I'm referring to. What I'm referring to are the political power struggles that happen within AIDS service organizations, between two different AIDS service organizations and between these organizations and the government.

The fact that funding for AIDS projects was insufficient was a large part of the problem. It seemed to me that if the government could keep the different AIDS organizations fighting each other for a small bit of the funding pie then the groups wouldn't come together to fight the government for more money. This seemed to work for a while but eventually we all seemed to smarten up and pool our lobbying resources and aim them at our government. Funding to AIDS organizations was increased but it still didn't meet the need. It did make it better though. The inter-agency fighting was only a part of the politics I didn't want in my life any more.

There was also the struggle between gay and straight. It was like the gay men's community began feeling invisible as the women's community became vocal. I remember gay colleagues stating their resentment at the attention the women were getting. Some were angry as they were beginning to feel invisible as women's issues began coming to the table. I remember one man saying that the gay men had started the AIDS help scene and that if it weren't for them we women would have nothing and that the focus should be theirs and that we should butt out. In a way he was right. The gay community was the one who began addressing the AIDS issue on a grass roots level. I am truly grateful to them for this as they created a place where I was able to get some support long before women got organized around this issue. I also do empathize with those who felt that they were invisible once the women began to organize and get attention of their situation. What I found difficult is the sense that it had to be one group or the other, that there wasn't enough room at the table for all afflicted with this illness. And let's be frank, I too wished that women could butt out of the issue. I wished that there were no illness affecting us for which we had to fight for that piece of the pie. Unfortunately that wasn't the case and our silence was killing us. So we fought. We fought to be seen, to be heard, to be counted, to be alive.

The other aspect of this that I found disturbing was between the HIV-positive and the non-infected people involved in the AIDS movement. It began to seem that people who were not infected with HIV held the positions of power within many organizations. I also watched them hold on to that power with both hands. It was like some of these people felt threatened by HIV-infected people wanting to represent themselves. I saw some very disempowering actions coming from those who were hired to help empower. This turned me off. I did not want to be part of this struggle anymore. I found it was all I could do to struggle through my own life the best I could. I didn't need any extra stuff on my plate.

Some time in 1994 I had a falling out with certain people who made up part of the power structure of the women's group (see Appendix 13). I'm sure some of my present opinions of what transpired were coloured by the circumstances surrounding the national women's project and the way I believe that project was disrespected. Mostly my opinion of what transpired was reflective of how I believe certain individuals acted in a manner that was not

consistent with their organization's stated position. I believe the actions of these people were diametrically opposed to the mandate of the organization they represented and upon which these organizations base their funding requests and public persona. Although I believed at that time, and still do, that certain actions taken by these individuals on behalf of their organization violated the actuality and the spirit of their mandate, I chose not to pursue it either politically or legally. This being the case, I have decided it would not be fair or right of me to go into specifics of what transpired and point fingers. What I would like to do is comment on something that I find disturbing.

It can be difficult for people living with HIV to find employment; this is for a number of reasons. An individual's health can get in the way of being able to attend work eight hours a day, five days a week. The potential for inconsistency of one's health and the suddenness with which that health can change can make fulfilling employment commitments difficult. There are very few job situations in which disclosing one's HIV status would be considered absolutely necessary. In circumstances that the nature of the employment is such that the risk of HIV transmission is an actual possibility, I would think one might want to consider whether they should be in this employment and if so should inform their employer. Circumstances of employment where there is no inherent risk of HIV transmission can still pose a problem for those infected with HIV. Many employers are just not willing to take on an employee who discloses they have HIV. This may be for many reasons from ignorance-based fear to concern of losing clientele due to the stigma of HIV.

In my opinion, an HIV-positive person's inability to guarantee ongoing good health would be the biggest barrier to long-term employment but this rarely seems to be the stated reason why people are not hired. With that said, many people who live with HIV have the ability to hold down employment, even full-time employment. For those whom full-time employment is not realistic, part-time work would be an option. But even this can be hard to find if your status is known. Choosing to not disclose your HIV status to an employer is not only an option, but also a right, as long as it is not a job that, by its nature, is high risk for HIV transmission. Unfortunately for many who choose to keep their HIV status private, some employers require a physical examination by a doctor to be eligible for the medical benefits

they offer. This can lead to their status being discovered. There have been many situations where employers have fired an employee because they find out they have HIV. They don't come out right and fire them for having HIV; that would be discrimination. They find other reasons to let them go.

The other aspect of this employment thing that concerns me is the number of HIV-positive people who are not employed by AIDS service organizations. What kind of message is being sent to the outside world when few of the employees of grass roots AIDS organizations are HIV+? It is my opinion that these organizations should set an example to the rest of society by their actions, not just their words. HIV+ people are often offered volunteer positions or contract work but not full time employment. There are the exceptions and some organizations are better than others when it comes to the ratio of HIV-infected and not HIV-infected employees. But those who offer equal employment access are rare.

After this falling out, I stopped my regular in office volunteering at the women's group but did on occasion continue to speak publicly at their request. When it would be arranged for me to speak, I would not state I was there as a representative of an organization. I would state I was representing myself as a positive woman. I also continued speaking with the AIDS Vancouver speakers' bureau and participating with the BCPWA society. What seemed to happen was that I started being contacted directly to request my speaking services. I was asked to speak to some intro anthropology classes at Kwantlen University College (KUC), which I did. I was also asked to speak to some sociology and liberal education classes there. There was a student who had listened to me speak at one of these classes and she told her sister about me. Her sister was a nursing student who contacted me asking if I would present to her class as part of her class project. The instructor of this nursing class contacted me to come back the following year and speak to her students again.

There was another student who had heard me speak in one of these classes who was involved with a youth organization. This organization was having a weekend retreat. They asked me to come and present an afternoon workshop on AIDS 101 and safe sex. I accepted and we had a good time that afternoon. I always found that mixing humour in with my message was the best way to get it across.

At some point, I think '96 or '97, I was asked to arrange for a panel for each of the Kwantlen University College campuses for their multiculturalism and diversity month. I took this on and was able to organize an interesting and diverse panel of presenters and a varied assortment of literature as handouts. This panel consisted of a man who worked at a needle exchange, a young aboriginal woman, a youth organization representative, and myself. I believe those who asked me to organize this were happy with the outcome. My speaking to classes in the anthropology, sociology, and liberal education departments at KUC continue until present day. I have also done presentations at Simon Fraser University and Douglas College.



Photograph 18: HIV/AIDS panel discussion
Kwantlen University College, 1996³⁹

By early 1997 my health had declined to the point where my volunteer activities had to be halted. This was partly due to the stress involved in the business of AIDS and partly due to the general progression of my HIV. My fatigue and the stress were definite factors in my getting ill and staying ill. On occasion I would fulfill requests by a women's group or AV to publicly speak and I would fulfill requests of organizations directly to speak publicly, but that was about it. After I stopped volunteering my advocacy work did not end, it just took on a more personal direction.

My husband was very sick and constantly involved with a medical system that was often less than empathetic. We were also living on welfare and regularly struggling with that power structure. My skills as an advocate came in handy but were challenged. I found it

³⁹ Photograph by permission of Frances Chaing.

interesting that when I called a government or medical organization on behalf of another person I would be listened to and treated with a certain amount of respect. When I would call to discuss my own situation I was often dismissed. I have always found and continue to find this very frustrating. Why was I respected when discussing someone else but disrespected when discussing my own family? The ugly double standard rears its head again. Having been treated as a peer by medical professionals and government personnel I can assure you there's a double standard when you're approaching them as a client.

Although we as a society and a medical system have come a long way since the AIDS epidemic first came on the scene, some things have not changed. The pessimist in me doubts they will ever change and the optimist is hopeful. My decision to become actively involved in the AIDS movement and then to go public about my situation had multiple motives. Yes, I wanted to effect change. I wanted to make a difference. But for me it was also about losing my shame, retaining my pride, and my ability to hold my head up and say, "This is me, take it or leave it." The work I've done has helped facilitate this.

Most aspects of my activity in the AIDS field have been positive but there are those that were not. Being public opened me up to discrimination. After having my face and name on the six and eleven o'clock news broadcasts I received some obscene phone calls. We also had to move out of our home on Welwyn Street sooner than expected because the property manager and her abusive son who lived downstairs from us found out about us having HIV, although not through the news. I'm not sure how they found out but the results were threatened violence, insults, and intimidation. So we found a new place to live and moved away. The discrimination from this landlord was not the only discrimination we've faced.

My husband James and I have faced discrimination from medical personnel, as discussed earlier. From welfare, there have been a few incidents of discrimination relating to our HIV status. Most of this discrimination has been related to our having a history of drug use, for which we presently access funds to pay for ongoing drug treatment/counselling; however, some of it could simply be from being poor. The fact that my publicity led to discrimination played a minor role in my decision to stop doing the interviews. The main reason I stopped speaking to the media was that I just wanted to take my life and my privacy

back. Being public in front of a room of 30 students or a couple of hundred conference participants is very different from being on the six o'clock news. In those situations I can do public speaking and still be anonymous. This is the route I chose for a number of years. But to be fair I didn't only make the choice to stay out of the media because of anonymity. I also made this choice because other matters had taken precedence in my life such as my husband's ill health and my own health challenges.

When I moved to Salt Spring Island I became involved with the Southern Gulf Island AIDS Support Group who jokingly called ourselves GIGI or the Gulf Island Guerrilla Immunologists. My husband and I have been attending their support meetings since we moved here three years ago. This past autumn our group decided we wanted to do a big AIDS awareness campaign for World AIDS Day. We decided we wanted to have an AIDS walk on December 1st as well as some other ideas for entertainment and fundraising that we kicked around. We also decided that we wanted to put an invitation out to members of our community who were doing work in the field of AIDS whether locally or internationally.

Our hope was to challenge the community to participate so we put an ad in the paper asking those members of the community to come together for a meeting. A few members of our group volunteered to take on attending this meeting, which had an excellent turnout. These ideas took on a life of their own as this group of community members volunteered their time and ingenuity to turning this into a weeklong event.

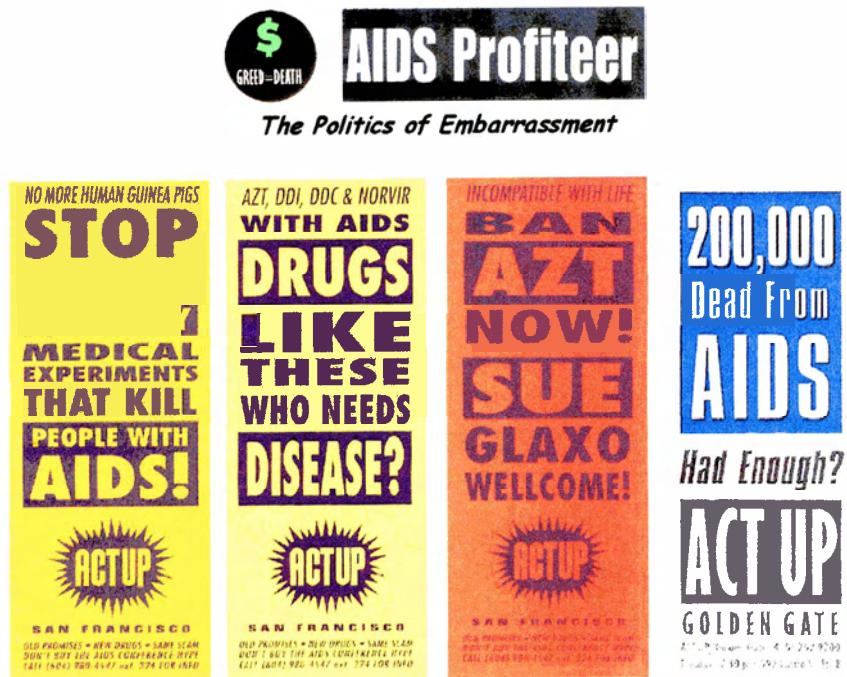
The week leading up to world AIDS day began when 7,000 crosses were planted in Peace Park located in the centre of the town. There were red crosses formed into the shape of the red ribbon surrounded by the white crosses. These 7,000 crosses were representative of the 7,000 people who die daily from AIDS world wide, that's five per minute. It was a very powerful art piece. During the week leading up to world AIDS day there were events that took place every day or evening. These included AIDS education sessions, documentary films, local dances, and 10 members of our community volunteering to live like they had AIDS for a week. We also put out red ribbon boxes to collect donations and as an awareness campaign. Ads were put in the paper regarding the events planned for that week and we had a lot of coverage of the art piece made of crosses.

There was also a reporter who wanted to do a story about the realities of living with HIV in the Southern Gulf Islands. Some members of our support group spoke with him and were included in his article, but only anonymously. I was approached by a member of our support group who knew that I had previously been public about my HIV status and was asked if I would consider speaking to this reporter without benefit of anonymity. I did tell him I would have to think about this overnight but called them back the next day to say I would do it. The man who interviewed me and wrote the article used my words in an honourable way, he did not change the context of what I said and for that I'm grateful. It can be dangerous speaking with the media. They have great power as they can change your words by what they emphasize and how they put them together.

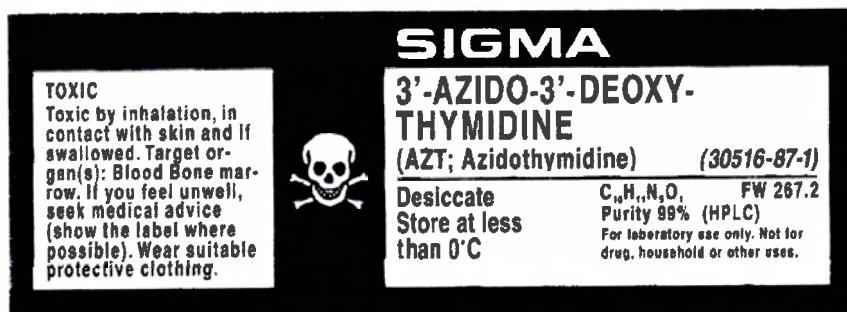
When I was asked to do this interview I had to reevaluate how I felt about having my name publicly linked with HIV once again. As I said earlier, you can be in the classroom and still retain your anonymity. For that matter in a city the size of Vancouver you can be on the six o'clock news and still be fairly anonymous. But on an island of 10,000 people it's hard to be anonymous once you have taken a public position. I had to consider this and I had to discuss this with my husband, as it would also impact him. Fortunately, he expressed that I should do what I chose, that he did not mind if I went public here on Salt Spring. I was very careful not to speak about James in this newspaper article as disclosing his HIV status is his business, especially here at home. I know that James prefers not everybody knowing he is living with HIV.

In the dissertation I do speak about James and his personal business but only to a point. During my years of public speaking I most always spoke from a personal perspective and James was a big part of that. I believe he consented to this because my speaking in the forums I did rarely had direct impact on his life. On those occasions when the public did invade the private he took it in stride. In that this dissertation is taken in part from transcripts of some of my presentations, it seemed necessary that James be a part. He was agreeable to this. I have always tried to stay within the boundaries James has chosen and he trusts me to honour his wishes. There are areas of James' life that he does not want for public consumption and I respect that as I too have chosen to keep parts of me for me.

Alex's scrapbook



Photograph 19: Alex collected these stickers at various national and international AIDS conferences in the 1990s⁴⁰



ACTUAL COPY OF AN AZT LABEL

This label has appeared on bottles containing as little as 25 milligrams, a small fraction (1/20-1/50) of a patient's daily prescribed dose.¹

Photograph 20: AZT label⁴¹

⁴⁰ Permission for use granted by ACT UP, New York.

⁴¹ Source: Maggiore, 1997, p. 14. Caption footnote cites the Physician's Desk Reference, 1994, p. 324.

Laura's response

Alex's narrative of her activism and advocacy work, both before and after her HIV diagnosis, is reflective of a complexity of personal and public factors. In her quest for a safe and supportive living environment, as discussed earlier, she moved into the West End of Vancouver as a straight woman in the city's gay community. Through her work and living situation, she became sensitised to the ways in which HIV/AIDS devastated her community of friends. Rather than falling prey to socially-acceptable stigmatising and moralizing about those who got it, Alex chose to take a stand against this as her good friends were becoming sick and dying from, as she puts it, 'a horrible death'. Bearing witness to the lives and the debilitating deaths from AIDS put Alex in a position of advocacy long before her own suspected infection.

In this early AIDS advocacy work, Alex benefited from the way in which the gay community was able to mobilize in response to HIV. In Vancouver, as in other major centres with established gay communities across Canada, were support groups of persons who had collectively fought for the right to live their lives in an open and free community of their choosing. In Vancouver's West End, one could find a community in which a gay person could live in relative safety from those who found a gay lifestyle immoral. The West End had a degree of institutional completeness, much like that which existed in many of the city's ethnic communities. This meant that when HIV hit the community, there were already political and social structures in place that could be utilized in the struggle against HIV/AIDS. As an individual supportive of her ailing gay friends, I would argue that Alex's early advocacy work endowed her with symbolic capital that years later she would draw on in an effort to build her own counterstory.

Nelson (2001) writes of the way in which oppressive master narratives influence the identity development of sub-populations. She explores how abusive power relations result from "material, political, and institutional arrangements and practices" that influence peoples' thoughts and actions (p. 107). With the development of a successful counterstory, the weaknesses in the master narrative can be found and dismantled to the benefit and identity repair of those oppressed. While altering a master narrative is no easy feat, a successful counterstory must be able to do so, at least in the area where the oppression is rooted. The counterstory must be able to create a shift in the master narrative such that the moral redefinition of the oppressed person(s) becomes accepted. In doing so, the marginalized person's access to opportunity can be restored; thus, identity and agency can be repaired. The "narrative acts of insubordination" (*ibid.* p. 8) that fuel

the counterstory are at the core of AIDS activism and create the vehicle through which oppression is challenged.

The homosexualization of HIV, within the master narrative, was constructed as a ‘natural’ fit. It created a group that was presented as morally deficient and thus to blame for their circumstances. In this case it was HIV transmission. Supported by political and religious leaders, sensationalized by the media, and promoted within the biomedical circles, the oppression aimed at the gay community and their supporters bore the characteristics argued by Nelson (2001) that constitute the power base of oppressive master narratives. Exploitation, marginalization, powerlessness, cultural imperialism, and violence were used to create an ‘us and them’ scenario that many believed would provide protection from the scourge of this allegedly morally-discerning plague. Unfortunately, the narrative would ignore the biomedical reality that “our ability to pass viruses connects us across space and time, across race, religion, and social class” (Shapiro, 2002, p. 2198). It would ultimately be the efforts of the growing AIDS consciousness and resulting activism, coupled with the rising death toll, which would reflect a more appropriate reality about who could get HIV. This began the process of exposing weaknesses in the master narrative to which the counterstory could assert itself.

By living within a gay community, Alex was subjected to the direct and indirect impact of wide-scale oppression against those persons who made up her intimate circle of friends. The sadness and helplessness of having so many dear friends die such tragic deaths ignited a fire in Alex that enabled her to choose activism and advocacy to help keep her community safe. It also enabled her to believe that those who were dying from AIDS were not suffering in vain. Aware of the social constructions around the kind of people who got it, Alex chose to focus her public behaviour on promoting safer sex within her community, while her private actions revolved around caring for and supporting her dying friends.

Alex’s initial foray into AIDS work resulted from her support of the gay community, though her own suspected infection brought an end to her advocacy work for a number of years. While denial is a common response to suspected HIV infection, as discussed earlier, the reasons are as varied as are those who become infected. Alex had witnessed extreme stigma, marginalization, and violence directed toward the homogenized ‘risk group’ of gay men, and believed that, regardless of mode of transmission or gender, much of this would come to define and constrict her public world once she was diagnosed. The use of risk group, though a viable epidemiological category, was used to stereotype and marginalize “people already seen as outside the moral and economic parameters of the general population” (Grover, 1987, p. 7). In 1987, one

year after Alex became infected and during the time when women with HIV were invisible, the United States senate declined funding for AIDS education among gay men. This decision was based on moral judgments targeted against this risk group, regardless that they comprised the highest rates of HIV infection to date (Grover, 1987). Clearly, the AIDS education projects that existed at the grassroots within many gay communities across North America needed stronger platforms from which to challenge the oppressive master narrative. These narratives were not only being aimed, once again, at gay lifestyles, but were also contributing to fear-based behaviour and ignorance that were costing many people their lives, regardless of sexual orientation. The resistance movements were necessitated by the damage brought about as much by the socio-cultural constructions of HIV/AIDS as from the rising infection and death rates. These resistance movements were key sources of power from within which many infected persons could use their own experience of marginalization and stigma to challenge the moralizing of the master narrative and thus begin to repair damaged identities and restore agency. By targeting the immorality of the master narratives for complicity in the growing HIV epidemic, the narrative insubordination (Nelson, 2001) of the counterstory was launched.

Resistance and power

Though not a homogenous narrative, the story that evolved to counter the misinformation that made up the dominant AIDS discourse in the 1980s developed primarily within gay communities for a number of key reasons, not the least of which was an effort to save the lives of many gay men. The political coordination necessary in the post-Stonewall days⁴² (Padgug & Oppenheimer, 1992) that resulted from the fight for gay liberation and human rights in the 1960s and 1970s created an organizational structure which could be used as a vehicle for communication of the key ideas. People were dying and the dominant narrative accommodated and explained their deaths as inevitable due to lifestyle choices and immoral behaviour. The inhumanity of this blame-the-victim narrative provided the impetus for many activists to challenge the morally degrading representations around those who were infected. Nelson (2001) suggests these resistance strategies are necessary elements in freeing moral agency (p. 150). Repeatedly, the gay lifestyle was attacked, to the detriment of accurate information about HIV transmission making its way into the public consciousness. The ability to ‘other’ the gay

⁴² On June 27, 1969, police in New York City raided a Greenwich Village gay bar. Patrons of the Stonewall Inn fought back, sparking the beginning of three days of rioting against the hostility and punishment inflicted by mainstream society. The Stonewall riots are believed to have laid down a foundation for the gay rights movement that followed. (Milestones in the gay rights movement, <http://www.infoplease.com/ipa/A0194028.html>)

community is clearly reflective of the way master narratives construct the identity of a marginalized group. The counterstory that had been mounted by the gay community in the 1960s and 1970s, in the quest for legitimacy and liberation, was a successful one. According to Nelson (2001), however, the onset of HIV/AIDS in the 1980s disrupted this carefully constructed, though vulnerable, identity.

Throughout the 1980s, increasingly more people from diverse backgrounds were contracting HIV, becoming sick, and dying. The reality of the changing face of AIDS was not making its way into the public consciousness, while the death toll rose at an alarming rate. In the spring of 1987, Larry Kramer, an activist who was instrumental in the 1981 creation of the Gay Men's Health Crisis in New York, called for those who were affected by HIV to mount a more focused attack on the powerful forces that were controlling the lives and deaths of infected persons. The resulting formation of ACT UP (AIDS Coalition to Unleash Power) "was devoted to direct action to end the AIDS crisis" (Harrington, 1997, p. 275). Circulating leaflets, ACT UP suggested they would, "Hold the government publicly accountable for the genocide it has perpetrated on [the gay] community and others" and they "believed the government failed to act swiftly and effectively against AIDS because it was seen as a disease of expendable minorities: gay men, IV drug users, and people of colour" (Corea, 1992, p. 80). In an effort to do this, ACT UP, as well as other organizations, focused "on social and institutional reforms, such as encouraging increased government funding for prevention and treatment efforts, through public demonstrations as well as private deliberative interactions with government and industry representatives" (Brashers, *et al.*, 2002, p. 114). In the area of treatment activism, ACT UP forged new ground by learning the language of their adversaries and mobilizing on many fronts to gain as much ground as possible (Harrington, 1997).

As counterstories, the treatment activism of ACT UP, and other resistance organizations, mounted challenges against politicians who withheld funding for education and research and who supported the discriminatory policies aimed at HIV-infected persons. This activism also targeted the United States Food and Drug Administration (FDA) for its inappropriate policies on drug regulation and testing, the AIDS Clinical Trial Group (ACTG) in general for its exclusionary practices, and the biomedical community through the National Institute of Health (NIH). The successes and failures of the various campaigns throughout the 1980s were multifaceted. The counterstories being developed were changing the face of HIV/AIDS, at least in the area of education, as many gay men were hearing the message of safer sex. Though gay men still had one of the highest infection ratios at the time, the numbers were declining. Being able to protest

in the language of the oppressor gave ACT UP a powerful, though disquieting, edge over the agencies and individuals upon which it focused its attack. Still, however, infected women remained relatively invisible and those with IDU continued to be marginalized. Furthermore, the ‘ga’’ lobby of ACT UP tended to represent a primarily white, middle-classed group of men. The more complex identities and divisions brought about by classism, sexism, and racism would continue to plague AIDS activism. Reflective of the heterogeneity of PWHA, the political struggles within AIDS activism clearly suggest that sharing a terminal illness may not be an adequate common ground to overcome the different needs and perspectives of those trying to restore the sense of self and health denied by the stigma associated with HIV.

In 1987, the women’s caucus of ACT UP formed and began to challenge the invisibility of women in drug trials and to question the CDC surveillance data that ignored gynaecological manifestations of HIV leading to an AIDS diagnosis. Furthermore, the caucus sought to expose the fallacy of research that presented women as merely vectors of disease transmission to men or as vessels of vertical transmission to child during pregnancy, and to call into question the treatment of HIV-infected female sex trade workers, women of colour, and injection drug users. By 1990, women’s activism was only having marginal impact on improving the inclusion of women in the ACTG (Laurence & Weinhouse, 1994), of getting the attention of politicians to support women’s treatment concerns and to set aside money for women’s AIDS support groups. Lobbying for welfare reforms for HIV-infected mothers and their children became crucial because many women could not access disability support and additional assistance for their children without CDC recognition of the many HIV-related manifestations of sickness (Corea, 1992). Regardless of the mode of infection, these persons often suffered stigmatization and blame as being somehow responsible for their own infection.

In order to build an effective resistance, some activist groups implemented the politics of embarrassment as one of the weapons in the challenge against the dominant narratives of HIV. Many activist organizations used graphic sexual imagery and messages to garner attention and support to their cause. Rooted in ACT UP, the slogans Silence = Death and Greed = Death were used to expose the alleged weaknesses of the public health campaigns that communicated misinformation, and drug companies that were pursuing profits before people.

In terms of a master narrative, the AIDS = Death message was often used to justify the lack of attention to HIV-infected persons as their progression toward death was inevitable. This narrative also acted as identity constituting and alienating to those who were infected. In Alex’s life, the realization that she had a stigmatized terminal illness was never far from her

consciousness and was reaffirmed in the media, at doctor's offices, and among her family and friends. She saw herself as a dying woman. This belief infiltrated her consciousness and drove her into hiding as she faced a number of identity challenges associated with such a stigmatised and feared illness (Brashers *et al.*, 2002; Ciambrone, 2001; Ezzy, 2000). This barrier was one that many who engaged in activism work had first to overcome in the quest for a restoration of personal and moral agency.

The widespread nature of HIV has led to a heterogeneous group of activists; some infected some not, each with their own personal and public issues needing to be mediated in the movement toward collective activism. The diversity of agendas has created situations that often pitted activists against each other, as separate interest groups used a variety of methods while vying for social, political, and biomedical attention to infected persons. Further compounding the hurdles facing AIDS activists is the terminal nature of HIV that has cost the movement many key members. What was becoming a reality by the 1990s was that HIV was not going to be easily brought under control by drug treatments and that at the end of the first decade of AIDS the death toll was still rising.

Activism, identity, and agency

Interestingly, AIDS activism has required of its members degrees of knowledge that were previously common only within expert domains of virology and immunology: "The need to engage in debates with experts has led activists to educate themselves about virology, pharmacology, and other pertinent scientific skills; develop social skills; and practice these skills through social action" (Brashers, *et al.*, 2002, p. 17). In an effort to challenge master narratives of biomedicine, some activists were burdened with exposing the weaknesses in the "objective representation of the diseased body" (Good, 1994, p. 116) that was the basis for health, social, and political decisions impacting the lives of infected persons. In many ways the HIV/AIDS counterstories are of the domain of critical medical interpretive anthropology as they expose the political, economic, and social factors that have challenged biomedicine's objective constructions while presenting the narrative meanings assigned by individuals to their own illness experiences. In doing so, the dominant biomedical response to HIV has been exposed as being racist, classist, and sexist, thus a challenge to the possibility of objective representations of diseased bodies. Examples of this can be found in the early 1990s when a group of treatment activists discovered the misappropriation of grant money that was to have been directed toward treatment research and development, or in other cases where drug companies have falsified the results of drug tests

in favour of their product, regardless of the health cost to infected persons, or in the well-publicized political struggles between the co-discoverers of HIV (see Corea, 1992; Harrington, 1997; Laurence & Weinhouse, 1994; Schilts, 1987).

The counterstories that have emerged as a result of AIDS activism were fundamental in influencing the trajectory of research, including the 1993 changes to the CDC surveillance definition of the complexity of diseases that constitute AIDS. It was at this time that the CDC, on the urging of activists, supportive medical persons, and grassroots organizations, as well as from the documented deaths of women from immune suppression and resulting diseases, included some gynaecological manifestations of HIV in their definition. With the new definition, the statistics of female AIDS deaths increased substantially, enough so that women could no longer be seen merely as vessels of transmission to men or children. They too were being infected and dying in great numbers. As was discussed in chapter one, the pernicious plot that renders women with HIV invisible, even in the face of evidence to the contrary, has remained embedded in the master narrative to this day, albeit to varying degrees. The counterstories of women with HIV/AIDS are as necessary today as they were twenty years ago.

Alex's activism as an HIV-infected woman

When Alex re-entered the activist arena in the early 1990s it was largely due to the powerful influence of the women's retreat on Bowen Island. As she said, she met, in person for the first time, other women who also were infected with HIV. Regardless of the mode of transmission, they did not fit the stereotype of the kind of women who got it. Throughout the weekend, the damaging narratives that had earlier infiltrated her consciousness about HIV-infected women were exposed. She heard narratives that resembled her own, found empathy and understanding among the participants as they shared their experiences, dreams, fears, rages, and hopes, and found a fertile environment in which to explore her own story. It was in hearing these stories, and in finding connections to her own life experiences, that she was able to find common threads. This opened the door to collective activism.

Kleinman (1988) suggests that, "To understand how symptoms and illnesses have meaning, therefore, we must understand normative conceptions of the body in relation to the self and world" (p. 13). Among the women at the retreat the lived experience of stigma, racism, classism, and gender discrimination, which was embedded in the master narrative, made up the shared normative conceptions of their bodies in relation to the world. Regardless of mode of infection, the illness narratives of the participants reflected the common experience of

powerlessness, isolation, and a pariah status that silenced them in the outside world. Through sharing their stories they were able to give voices to suffering and recognize the myths that made up much of the normative contemporary story of women with AIDS. The ethic of listening (Frank, 1995) that was employed by both positive and negative women at the retreat set the stage for Alex to enter a healing journey through the telling and sharing of women's stories.

Ciambrone (2003) suggests that formal and informal support groups provide settings within which HIV-infected women can develop relationships. By sharing each other's stories, they can begin to repair identities damaged by HIV and adjust to the consequences of their illness. As Ciambrone (2003) suggests, they also find positive aspects of their lives with HIV. The organization of women that sponsored the retreat became a primary women's support organization in Vancouver. Alex's membership in this organization provided resources, employment, friends, and a normative environment within which to further explore her public story of HIV. She had a considerable body of personal experience, appropriate research skills, and a tenacious personality that made her an attractive public figure to represent women with HIV. Using this symbolic capital, she became one of the spokespersons for women's HIV stories. As a married, heterosexual woman, Alex challenged many stereotypes.

Early on in her association with the women's group, public knowledge of Alex's status brought forward consequences that were threatening to her personal safety. After a landlord found out they were infected, Alex and James were threatened and given until the following morning to relocate. An unfortunate, though not surprising reaction, Alex and James were confronted once again with the ramifications of an oppressive master narrative. Rendering many peoples' lives with HIV unworthy it reinforced the fear of contagion as one of its identity constitution elements. The difference, this time, was that Alex's membership and activities in various HIV/AIDS support organizations provided supportive connections that resulted in relatively secure housing for the couple. This lasted until they relocated on Salt Spring Island a number of years later.

Alex's work as a research/resource person required that she learn the language of the biomedical community that was necessary to advocate for women's rights. As with other activists, Alex developed research skills, knowledge of conventional and alternative or experimental treatments, physiological understanding of women's gynaecological manifestations of HIV, and strategies that would enhance an activist position and develop self-advocacy values. Through the BCPWA sensitisation workshops, Alex spoke about the impact of economic and biomedical marginalization associated with a disabling illness. She presented to those very

individuals that were in positions of power over her financial and medical life. During the times when some welfare workers were reinforcing the hegemony of the oppressive master narrative to clients with HIV/AIDS, Alex was able to use her position to present an alternate narrative. This one was aimed at exposing the weaknesses of the normative beliefs, values and behaviours embedded in oppressive master narratives. Though not always successful at breaking through the barriers of stigma, the sensitisation workshops enabled Alex's voice to be heard as representative of lived experience with HIV. Bringing a human face to the economic suffering of many with HIV, in a controlled setting, presented a reality that welfare workers could, if they chose, utilize in the workplace. In advocating for a better life for all PWHA, Alex was reinforcing her own worth and identity as a morally deserving person and building or restoring her agency through her counterstory.

Brashers, *et al.* (2000), suggest that the personal and intellectual skills acquired through activism work situate positive persons to be better able to negotiate their treatment concerns/needs, to be able to navigate paternalistic medical institutions, and to have more productive dialogues with the experts controlling the flow of information. These skills can provide the tools to act on personal experiences in a way that reflects a symbolic capital, to wit, the development of agency and a new personal identity. Rather than dying from a stigmatised illness, within a few weeks of the retreat, Alex became a valued source of support for other infected women. The skills and experiences that she acquired volunteering and working for AIDS Vancouver and the BCPWA Society positioned her to advocate for both herself and her husband, and to realize that through advocacy and activism, the oppression of the master narrative could be challenged. The downside of her public AIDS work reflected the political problems inherent in AIDS activism throughout North America. It was, ultimately, this stress that drove her away from the collective activism of formal HIV/AIDS organizations.

The politics of AIDS activism

While there are many positive attributes associated with collective activism (Brashers *et al.*, 2002; Ciambrone, 2003) that are crucial in building a successful counterstory, there are also many attributes of a less-positive nature that warrant further examination. Nelson's (2001) assertion that a successful counterstory must not, itself, become an agent of oppression seems plausible in theory, but in practice, when applied to collective AIDS activism, presents some difficulties.

The heterogeneity of those infected with HIV creates disparate groups of people whose lives are touched in different ways by their infection. For many infected persons HIV leads to oppression of agency, though it might be only one of a multitude of oppressive agents in their lives. Brent Stockdill (2003) in his book, *Activism Against AIDS*, discusses the way in which multiple oppressions impact collective HIV/AIDS activism. He suggests that oppressive hegemonic consciousness (inherent in master narratives) often coexists alongside oppositional consciousness and, when they infiltrate social movements, can reinforce inequality: "When a group expresses one form of oppositional consciousness while simultaneously espousing hegemonic consciousness, partial consciousness exists. Examples include sexism and homophobia in antiracist struggles and racism and classism in feminist struggles" (ibid, p. 31). The existence of partial oppositional consciousness and the power it has to reinforce inequality in AIDS activism consciousness reflects the hegemonic nature of master narratives. As discussed earlier, master narratives, whether or not they are oppressive, are imbued with values, norms, and ways of behaving that are deeply embedded in one's socio-cultural learning. The hegemony of these narratives suggests that many persons pass moral judgments that have been normalized within their worldview without thought to the implications on those being targeted.

When applied to AIDS activism, partial oppositional consciousness can be found at many levels, rendering certain groups silent. Within many AIDS organizations, infected women were seen as taking attention away from gay men when the focus was shifted to using available resources for women's issues. In the case of IDU, many were marginalized due to the stigma associated with drug dependency in general that is part of the hegemonic stigma embedded in the master narrative. Further marginalized within AIDS activism were imprisoned populations. Though many imprisoned HIV-positive women did begin to organize and fight for their rights, it often occurred without overt support from mainstream activists (Corea, 1992). Also, heterosexual men have often found themselves marginalized or silenced within men's support groups. Alex's husband, James, has spoken of how support groups for men often are more representative of issues specific to gay men; thus, intentionally or unintentionally, marginalize straight men.

Throughout Alex's narrative of collective AIDS activism, she recounts many positive examples in her experiences of the ways in which groups of individuals worked together, negotiated meanings, intents, and common goals. Where her narrative takes a more critical tone she reflects on the way the political struggles she experienced served to diminish the positive nature of the work, at least for her. The experiences she recounts of the political struggles at the Mexico conference, within the National Women and HIV Project, and at the women's group

reflect the partial oppositional consciousness discussed earlier. The complex intersections of multiple marginalizing elements, of which HIV may be only one, bring a complicated scenario forward which can undoubtedly create stress for those involved. The link between stress and immune suppression, at least in Alex's case, eventually made collective activism untenable and unhealthy. Clearly one can find a link with Nelson's assertions regarding counterstories that oppress. However, Alex's ability to reflect on the combination of factors both internal and external that influenced her decision to quit collective activism has been instrumental in her ability to build her individual counterstory and, in doing so, continue to restore her identity and moral agency.

Alex's story of her experience with collective activism reveals the complex nature of developing oppositional consciousness when the activist's goal is aimed at life and death issues. Because the nature of AIDS activism is to build a successful counterstory to combat oppression, the core elements of this are political. The apparent ease with which hegemonic consciousness invades oppositional activism is reflective of the heterogeneity of PWHA, the desperate circumstances facing those whose quality of life and death are often contingent upon the success of their counterstories, and the various influences of HIV-negative activists. Thus, I argue that in the twenty-plus years of AIDS activism and counterstories, there have been changes at varying levels within master narratives that have resulted in restored agency and repaired identity for many infected persons. Whether focused on public health, biomedicine, community and familial relations, or religious moralizing, collective activism has had its share of successes. In Alex's case, the collective activism provided her with the symbolic capital to negotiate the strengths and weaknesses of the oppressive HIV/AIDS master narratives, and to act against them on intellectual, political, medical, and emotional levels. Embedded within this same collective activism were marginalizing forces and political struggles that influenced her health and impacted her sense of agency and identity. Importantly, the activism work provided Alex with a degree of narrative repair and restored agency such that she was able to recognize that she needed to leave this work, although she continued to advocate for change on an individual basis. Therefore, while there are oppressive agents within the heterogeneous HIV/AIDS counterstory, I suggest that it still can be seen as successful in many ways contrary to Nelson's (2001) assertion that a successful counterstory never oppresses those it represents.

Independent advocacy, activism, and the counterstory

Shortly after Alex left the women's group, I recall she underwent a period of prolonged depression. During this time Alex was not well medically, emotionally or spiritually. The toll of HIV on both herself and James was unmistakeable, and struggling with the circumstances around the termination was exacerbating the situation. Though she continued to work for BCPWA and AV on specific projects where a positive woman's representation was requested, this work lessened as she dealt with the realities of compromised health. By the end of 1996 Alex had pretty much ceased any collective activism but continued to advocate for both herself and James. The advocacy skills and personal experiences that she had acquired over the previous years had given her insight into the areas of medical and welfare systems that continued to marginalize the couple. Doubly stigmatised due to their HIV and IDU status, regardless of the fact that they were under drug treatment and no longer using heroin, meant that Alex would continue to be met with disdain by many medical professionals and FAWs. Having taken up the struggle to be treated fairly and equitably by the institutions that controlled her life meant that Alex would continue to challenge the weight of moralizing stigma. Alex earlier juxtaposed the respectful way she was received when representing a support organization against the marginalization she faced when advocating for her own or James' health concerns. It is useful to question why the knowledge she possessed was often seen as threatening. The articulate woman arguing for improved treatment and care did not fit comfortably into the marginalizing identity of an HIV-infected former IDU, regardless of the fact that IDU was not her mode of infection. The very nature of Alex's injection drug use resulted, in part, from the infiltrated consciousness and damaged identity that accompanied her HIV diagnosis. However, to many representatives of those agencies that were controlling Alex's life, the timing of her spiralling into heroin addiction was not taken into account. She merely became for many another stereotyped statistic of those who deserved what they got.

As an educator, I have long recognized the value to social science students of hearing first-person narratives to which students can apply theories or through which they can develop critical thinking skills. Teaching at a university college in a community whose public school board voted against condom machines and Planned Parenthood programs in the high schools in the 1990s provided me with the impetus to expand AIDS awareness on campus. Around 1996, with the support of some colleagues, we contacted Alex to have her set up three AIDS panel discussions at Kwantlen University College, as she discussed earlier. Using narrative as well as other communication and education strategies, the panels appeared to have a profound impact on

the students who attended. Through these, Alex became known to some of my colleagues in the social sciences and she began speaking in the sociology, anthropology, and nursing departments. In the seven years that Alex has been telling her story to students, she has developed her personal narrative in a manner that challenges the stereotyping and stigma associated with HIV, welfare, and injection drug use.

Interviews conducted with two of my colleagues that have had Alex talk in their classes for six and four years respectively have yielded some interesting observations of Alex's counterstory⁴³. In her presentations to students of social policy, the instructor suggested that the greatest value Alex provides is giving a human face to the impact of social stratification where persons on disability live below the poverty line. In presenting her budget the students have an opportunity to see the precariousness of trying to get by on social assistance. Of further importance, the instructor found that Alex's story of her encultured work values was important for the students to hear, as many simply believed that those on welfare were just too lazy to work. My other colleague spoke of the value of Alex's institutional analysis of medical and welfare systems, from a micro perspective, and how these systems work and don't work. Of further importance was the powerful perspective of Alex's self-awareness and self-development that is evident when she talks of living with a chronic terminal illness. Living with HIV and not dying with HIV was an important idea for many of the students to hear. It challenged the identity-constituting features of HIV as a death sentence. Also discussed was the importance of Alex's perspective on the difference between the biomedical determination of sickness and health and her own conceptions of health. Alex's more holistic approach to health revealed the way in which the biomedical model can further stigmatize persons it deems to be sick.

When assessing student reactions to Alex as an HIV-infected woman, it was suggested that the articulate manner in which the narrative is presented, and the way in which Alex accepts responsibility for engaging in unprotected sex, is a powerful element of her story. One colleague felt that it was particularly important that Alex's story causes people to care about her when she talks, so much so that many students follow up with the instructor throughout the term asking after Alex's health. This was identified as being significant in its reflection of the value system and educational philosophy of my colleague: that of openness, empathy, and equality.

As both colleagues have a history with Alex, I asked them about how her story had changed over the years, if at all. Both voiced the opinion that Alex had become more organized

⁴³ In December of 2003, I conducted semi-structured interviews with two colleagues. See Appendix 17 for a copy of the interview schedule.

in the delivery of her narrative. As one said, “she began to connect the dots between welfare issues, stigma issues, hospital issues and such, and in doing so became more confident as a speaker, confident in her self and in her role...The theme of development is self identity. Each time she came back there were new experiences that she could draw on and I found that interesting to watch.” My other colleague suggested that: “in terms of presentation to the students, she is a pro...she can be going through hell personally but she does not let on. I would pick up bits and pieces about Jim being ill and in hospital or some other issue but it would not influence her presentation to the students.” Their observations are in sync with my own of witnessing the ‘maturing’ of Alex’s narrative. I believe this was due, in part, to the narrative becoming a vehicle through which Alex could counter the moralizing stigma associated with HIV and IDU. Through telling the story Alex is able to answer questions, draw the links between the social constructions of HIV/AIDS and stigma, poverty, and marginalization. Furthermore, she is able to juxtapose this against her personal history of hard work and activism and in doing so provide evidence to students that not only exposes the weaknesses of oppressive master narratives, but often causes students to critically explore how they have come to view PWHA. In addition to this, Alex possesses a vast knowledge of HIV prevention and AIDS care which she is able to share with the students.

I asked my colleagues about the strengths and weaknesses of Alex’s narrative as an educational tool. The only weakness identified was that it was “hard to test in a specific way, a typical concern of students, ‘is this going to be on the exam’. This is also a strength because it is so different from the standard educational formula that people will remember this ten years from now.” The strengths identified coalesced around the following: the way the narrative worked to challenge a variety of stereotypes including the linearity of HIV progression toward death; that one did not have to be a passive recipient of healthcare; that it was all right to challenge the norm that the doctor knows best; that an HIV diagnosis means asexuality and aloneness; that one can question the beliefs about the type of people who can be infected; and that one can confront the stigma associated with welfare.

The final question my colleagues addressed was whether or not Alex’s story worked as a counterstory. One responded, “Her story is powerful and personal, and in terms of challenging the master narrative I think it does because the master narrative is impersonal.” It is the impersonal nature of oppressive master narratives that enable them to damage identities and deny agency. Clearly, not putting a human face to the suffering brought on by the social construction of HIV makes the oppressive master narratives all the more powerful. When Arthur Frank (1995)

calls for us to witness suffering, perhaps it is in the context of personalizing and humanizing individual illness experiences; thus, challenging the way in which the politics of blame is applied within master narratives.

In the classroom, Alex is able to break down the barriers that have stigmatised her as deserving of her HIV and as a drain on the welfare system. Students are confronted with a sensitive, articulate, stubborn, political, and intelligent former IDU who engaged in risk activities when she was a 21-year-old college student and contracted HIV. For many, the parallels to their own behaviours or worldviews are evident and Alex is no longer a stigmatised immoral other. As an educational tool, every student who connects with Alex's story, on whatever level, may at some point think about the human costs of the suffering associated with the stigma attached to HIV/AIDS. It seems that counterstories, such as Alex's, challenge the master narrative through the individuals who listen and are willing to critically question how they have come to construct persons with HIV.

HIV, activism, and family support

Over the years since Alex was diagnosed, our family has undergone a range of reactions and responses. These are reflective of the complexity of factors that result from the emotions, fears, and the unknowing that accompanies HIV. Our family's reactions have been very heterogeneous and they also are constantly undergoing processes of change. Earlier in this chapter, Alex discussed the AIDS benefit that our sister Liela produced in 1994. Upon my request in March 2004, Liela emailed me her story of this time in her life. With Liela's permission, I have chosen to end this chapter with her email. I believe it speaks for itself in providing another interesting dimension to Alex's story.

Dear Laura,

I hope I am writing what you are looking for. Mom told us in the spring of 1990 that Ally was HIV positive. Considering what we had been through in the past few years, it was a pretty devastating blow to all of us. So anyway, we all dealt with it in our own ways. Life went on but Alex, Louise⁴⁴ as I always knew her, was never far from my mind. Often when I would think of her, I would wonder if she was doing the same things as I, laughing at the same things as I or sad and scared all the time. I had many long conversations with her in the few years since we had known. In that time, she and Jimmy fell in love and got married. He was also HIV positive and I

⁴⁴ Alex was given the birth name of Louise Alexandria. In the 1980s, after moving out on her own, she began using Alex rather than Louise.

can remember the profound feeling of sadness the day she walked down the aisle. Given away by our mother, it must have been unbelievable for Mom to think that, most likely, she would outlive her own daughter. When they exchanged their wedding vows, it was a strange mixture of joy and grief, one I hope to never feel again.

On Dec 1st, 1993, I happened to be watching BCTV Evening news and saw Louise being interviewed because she had been speaking at a World AIDS Day function. She spoke with such honesty about her disease; I was almost transformed that night. I remember going to bed that night and all I could think of was how much I wanted to make a statement in a small rural community such as Cranbrook, British Columbia. It was all about information, understanding and compassion. It was like she said, "When you grow up in a small town, you never think it will happen to you." She was so right; I believed that Cranbrook and other small communities needed a wakeup call before more kids from small towns think they can conquer the world.

The next morning, I spoke to a good friend at work, whose judgment I value, and told him of my plan. At that time the plan was to have "something" in Cranbrook on December 1, 1994 to heighten the awareness, or lack thereof, of the issues surrounding HIV/AIDS. I felt compelled to do something the instant I saw Louise being interviewed on TV the night before. In my mind, it was almost a tribute to her and the way she lives her life, with courage, and the drive to educate. That night, I phoned her and told her of my plan. By that time it had a chance to start to formulate in my brain. I knew I wanted to do some sort of show where she could bring her message to Cranbrook. I remember promising her that I would do this. I asked her to speak at it, whatever "it" was going to be, and then lay awake half the night trying to figure out both what I was going to do and how I was going to do it. I had 363 days left to figure it out. It now seems like a lifetime ago, but it was probably one of the busiest years of my life. Right away I got talking to as many people as I could that I thought would want to be involved. As soon as Christmas was over, I really got on the bandwagon and got to work. By then, I knew exactly what I wanted to do; have a wonderful "event" at the 600 seat theatre in Cranbrook, have excellent entertainment, great speakers and Louise as the Keynote speaker. Since it was all about her and a tribute to the way she lived her life, I felt it was essential to have her share her message with us. Brent Carver, who was a Cranbrook native and had just won a Tony for "Kiss of the Spider Woman", agreed to come as well as Valdy and Shari Ulrich. From the cast of "Ain't Misbehavin'" at the Arts Club Theater in Vancouver, Sibel Thrasher, Dennis Simpson, and Marcus Mosely agreed to perform at the benefit. As speakers, besides Louise, were Rev Neil Gray and Minister of Parliament Svend Robinson. To top off the night, the Master of Ceremonies (MC) was Bill Munroe, the well known MC of Starry Nights AIDS Benefit in Vancouver. I owe Bill a huge debt of gratitude because his endorsement for the show, and willingness to MC, opened many doors when it came to finding entertainers. All of this was done out the goodness of everyone's heart, and for all the right reasons. My sister Laura became involved right from the start. She helped me get out all the

promotion packages in the beginning and found all the technicians I would need for the show at the end. She managed to convince them to come to Cranbrook from Vancouver and then donate their talent as well. Laura was a constant support as well as a good sounding board for my ideas. We kept in close touch throughout the year and I relied on her for staying in touch with Louise. I don't know if I could have done it without her support. There were many hurdles along the way, right up until the night of the show. From finding funding, to a bomb scare that would have evacuated the theatre before we ever opened the curtain. Every guest who entertained, every sponsor I spoke to, every person who worked endlessly on making this show a success has a special story in my heart. It would take volumes to tell them all. Mostly because they gave so completely of their talent and time to come to this little city in the southeast part of our province to help me see this vision through to the end. It took on such a momentum. The whole experience was unbelievable, I think, because the people of this city and those who came from out of town were so ready to accept the message the "Benefit" brought. It became much bigger than my sister just coming to town to talk at something that had no shape yet. At the end of the day, it was a "sell out", a wonderful success financially. But most of all, a success because the people of Cranbrook embraced, not only Louise, but the vital message she and others brought to our town. The legacy lives on, 10 years later. That's how I know my plan worked. It's probably one of the top five things I'm most proud of. It was worth every minute.

I hope this is sort of what you're looking for, if not please let me know. I can drink some more wine and take another stab at it! Love ya,

Liela



Photograph 21: Liela and Margaret Cooper, AIDS GALA, Cranbrook, B.C., December 1, 1994⁴⁵

⁴⁵ Photograph by permission of Paul Kavanaugh.

CHAPTER VI: CONCLUSION



Photograph 22: Laura, James, & Alex in Yellowstone National Park, Summer 1999⁴⁶

In conducting this dissertation research, I set out with three objectives in mind. The first was to examine the way in which the social constructions of HIV/AIDS are communicated through oppressive master narratives. Using the analytical model of the three bodies and critical interpretive medical anthropology, I examined the complex interface of political, religious, economic, medical, social, and academic institutions in the creation of oppressive HIV/AIDS identities. The second objective was to examine the emergence of HIV/AIDS counterstories that are intended to restore agency and repair identities damaged by oppressive master narratives. Collaborating with my sister Alex Keating and using her life story as the foundational narrative, we examined her lived experiences with HIV. The tension between the identity-constituting marginalization that resulted from the oppressive master narrative, and Alex's resistance to this produce a successful counterstory. The third objective was to engage in collaborative research with my sister and in doing so address the ethical, methodological, and reflexive factors that arose from this.

⁴⁶ Photograph by permission of Jesse Cooper.

Master narratives

Throughout the dissertation I have argued that the narratives that make up the dominant accounts of HIV, and those who get it, draw their evidence from multiple institutions, each with varying degrees of political, economic, and social influence. Certain religious institutions whose dogmas contribute to a marginalized identity construction for infected persons also inform this narrative. It is the precise combination of identity-constituting criteria, contributed by a heterogeneity of forces, which has created such a profoundly powerful and damaging social status associated to many with HIV.

Alex's narrative gives examples of how hegemonic HIV master narratives deny agency and damage identity. Institutional marginalization for Alex began with the phone call about her HIV test results. It could be argued that the extraordinary fear of HIV within the medical community at large resulted in her diagnosis delivery being profoundly different from that of other communicable blood-borne diseases or other terminal illnesses. The stock characters and plot templates that are part of master narratives influence the social definition of those who get it and the expected behaviour associated with the social role (Nelson, 152).

The stock character of the promiscuous woman unable to control her sexual self (the whore), or that of the morally deviant IDU, serves a ‘blame-the-victim’ scenario where one is seen as deserving of her sickness. Further compounding this are plot templates that portray HIV-infected persons as morally corrupt, socially dangerous, and incapable of taking responsibility for their own and others’ safety. They are defined as a threat to the common good; thus, denying basic human rights becomes justified. A good example of this can be found in Alex’s narrative of James being refused treatment at a local emergency room in Burnaby because, as the receptionist said, “We don’t treat your kind here. Go to St. Paul’s, they treat your kind.” This person was responding to James needing emergency services to cauterize an uncontrollable nosebleed, and Alex and James willingly informing the receptionist about his HIV status.

While Alex’s narrative provides many examples similar to the one above, these occurrences continue to impact her and James’ lives. Those who act toward Alex and James as if they are damaged moral agents or contagion-spreading entities can find support for their actions within the diversity of oppressive master narratives. Nelson (2001) refers to these as organic ensembles that contribute to the complexity of master narratives. The worldviews that result assimilate opposition and shape reality for members of society. Whether worldviews are positive and life enhancing or oppressive and life degrading, they are undoubtedly complex phenomena. They provide the schemas for how one’s world should operate in a comprehensive way. Thus,

for the emergency room staff that refuses help to HIV-infected persons, or the physician who won't give platelet transfusions to a "dying addict," or the welfare worker who "knows everything about you people there is to know," or to the landlord who threatens violence in order to evict his HIV-infected tenants, their worldview supports their actions. Had these been isolated incidents, one might entertain more psychologically-reductionist explanations. As examples of such marginalization are often occurring throughout Alex's narrative as well as those of many PWHA, one needs to look to systemic forces that construct infected persons as righteously and justifiably marginalized. Within the narrative, risk groups are constructed; the HIV-infected individual becomes absorbed into the pariah-designated group. Being blamed for his or her own circumstances is justified through constructing the PHWA as capable of inflicting both moral and physical harm upon society. The person is seen as a serious threat within the worldview of the oppressive HIV master narrative and any degrading actions or behaviour directed at them is often sympathetically "understood."

Nelson (2001) refers to epistemic rigging within master narratives that can stop opposition before it starts. They do this by hiding "the forces that subjugate or marginalize certain groups of people so that nothing objectionable appears to be going on" (p. 162). In portraying homosexual men as morally deprived, and in finding religious support for this designation, the oppressive ideas take on a natural and truth-like tone. For those who believe, unquestioningly, that homosexuality is against God's law, it is not much of a stretch to rationalize that HIV is God's retribution; hence, the victim is responsible, naturally, for his own sickness. Similarly with IDU, the master narrative is epistemically rigged to naturally present this group as morally deprived and dangerous persons, deserving of what they get. These ideas are so deeply rooted within the organic assemblage of institutions that make up the knowledge base of master narratives that they appear, naturally, as truth-constituting ideas. The rationalized support for the homosexualization of HIV within the biomedical community is evident with these beliefs being so widespread as to silence HIV-infected women's voices.

The Madonna/whore dichotomy that is rooted in master narratives can be seen as a form of epistemic rigging that draws its 'evidence' from a patriarchal version of history. Women have continuously been written of as the source of sexual infection to men and have been punished for sexual promiscuities with little regard for them as more than immoral creatures. Whether it was the syphilis outbreaks in fifteenth-century Europe, or HIV in the 1980s and 1990s, women have been constructed as vectors of disease to men and children. This designation rationalizes the lack of attention to women as victims of the disease themselves. Within the HIV master narratives,

the patriarchal nature of biomedicine naturally constructs HIV as a male disease in women's bodies, thereby justifying the lack of attention to gynaecological manifestations of HIV in women. While master narratives contain strengths that allow them to construct identities that marginalize and alienate those who are members of the group being targeted, they also contain inherent weaknesses that counterstories can capitalize on to restore identity and agency.

Nelson (2001) defines these weaknesses as resulting from the heterogeneous nature of master narratives. They are made up of collections of ideas, beliefs, values, versions of history, ethnocentrisms, political and religious influences, cultural aspects, gendered perspectives and, as such, are not as uniformly constructed as they might first appear. The tensions that result from this assemblage of characteristics can provide a vulnerable point of entry for a counterstory to assert itself. The master narrative, whose plot templates of women as vectors of disease, and HIV as a gay disease, has been shown to be a false representation of reality. The differences between these plot templates and the reality of HIV, as a non-discriminating virus, is an example of the tensions that exist. Master narratives, which set out to construct an identity of the marginalized group that can be proven as inaccurate, reveal an internal inconsistency that a counterstory can challenge. Women's stories, like Alex's, have contributed to the body of knowledge that constantly challenges their subordinate position. These stories broaden one's understanding of the complex reality facing many positive women, thereby exposing weaknesses in the master narrative.

Another point of challenge is the construction of biomedicine as expert knowledge aimed at reducing suffering through treatment and its continuing search for a cure. The multiple failures of drug treatment research to be conducted without gender bias or political and economic influence has been taken up by advocacy agencies as fundamental in building their counterstories. Narratives of living with HIV can be powerful sources of disconfirming evidence and Alex's story contains a considerable amount of such. Nelson (2001) asserts that "no oppressive master narrative can absorb all disconfirming evidence-there is simply too much of it" (p. 166).

Counterstories

A successful counterstory must aid the individual in repairing damaged identity and restoring agency and in doing so must have the attention of the subgroup that it alleges to represent. Furthermore, it must also gain some degree of acceptance within the dominant group making it possible to dislodge the deeply rooted constructions toward the subjugated group. In

the case of HIV counterstories in general and of Alex's narrative in particular, these have challenged master narratives on a number of different levels.

In an attempt to develop a counterstory that can be recognized as morally worthy of attention, Alex's credibility was established. Through her narrative of collective and individual activism and advocacy, she created an identity that garnered respect from individuals who are representative of the hegemonic institutions of the master narrative but are not necessarily supportive of its homogenizing nature. Dr. David Burdge is an example of a biomedical physician and infectious disease expert who respectfully positions Alex as the content expert for her own life and healthcare plan. Treating Alex as a fully developed cognitive and moral agent, he diverges from the master narrative. There are a growing number of medical care providers, such as Dr. Burdge, and clinical care models, such as that at Oak Tree, that have undoubtedly been influenced by counterstories that expose the deplorable and morally-corrupt manner in which many PWHA have been constructed and treated. Valuable to policy analysts, Alex's story and its insights into relations with Dr. Burdge and of how Oak Tree has changed her life should be examined. PWHA stories of what works and what doesn't work lay out potential frameworks for more inclusive clinical care health and wellness policies. Reframing an ill person as the content expert in their own illness trajectory and allowing the meaning that they attach to their pain, suffering, and determination of wellness and illness to be heard is a powerful mechanism of restoring some of the agency that an exclusive biomedical narrative denies.

Further validating the credibility of Alex's counterstory are the sensitisation workshops with physicians and welfare workers. These involved persons who were typically representative of hegemonic and identity-constituting institutions participating in workshops to learn how to better serve PWHA. Alex's narrative was deemed as representative, to a degree, of issues facing HIV-positive women. Other PWHA narratives and theoretical examinations also support her story. The need for workshops of this kind is evidenced throughout this dissertation. As with Marshall and O'Keefe's (1995) research among fourth-year medical students discussed in chapter 4, learning to hear what ill people are saying without misinterpreting their narrative can have profound policy implications for healthcare providers for PWHA.

Alex's story poses very important questions for both healthcare personnel and FAWs. Why does her story lose credibility when she is representing herself or her husband (self-advocating) and gain credibility when representing another non-related PWHA? The double standard of treatment has occurred repeatedly over the years. Like medical marginalization, this form of discrimination by FAWs occurs too frequently to be explained away by personality

conflict, individual misunderstanding, or some other psychologically-reductionist position. The structural forces that either do not challenge such discrimination, or outright embrace or communicate it, can be deconstructed through narrative. As has been shown, such marginalization has a direct impact on quality of life and in constituting the other, can have dire consequences. Mapping out power relations in the manner in which we have done, and providing supporting documentation of this in the appendices, provides more depth of understanding into how master narratives attempt to absorb opposition. The bureaucratic structure of social services for disabled persons is not a user-friendly institution for those it is mandated to serve. Rather, it is largely, as Alex says, a “system of penalties.” As I have discussed in chapter 3, the current British Columbia provincial culture of self-sufficiency for administering to disabled on welfare is creating more angst among ill persons than it is alleviating. Narratives of what it means to live with chronic terminal illness in these times of neo-liberalism must be heard. Having the narratives available to the public at large can enable and inform those advocating for change.

The interviews with my colleagues, to whose students Alex has lectured, provide additional evidence of the credibility of Alex’s counterstory. After Alex’s presentations many students are left questioning the foundations upon which they have come to understand how PWHA or those on welfare are socially constructed. Having an opportunity to place Alex’s narrative against what they have been encultured to believe is true often reveals a dissonance that opens the doorway for further understanding of how the ‘other’ is narratively constructed. Some students, who initially fear Alex as representative of the pariah status associated to many PWHA, come to realize that they pose a greater threat to a person with compromised immunity. Many students have expressed to me over the years that this was one of the most profound identity-changing pieces of information they have received from hearing Alex speak. Although not fodder for educational policy development, these students’ insights speak to the area of human rights and moral agency for HIV-infected persons. Deconstructing the myth of the other, in whatever form, can only have positive outcomes for all involved.

While the success of Alex’s narrative as a counterstory can be found in the many ways that it contests the application of the master narrative to both herself as an individual and to the subgroup that her story represents, one must not overlook the heterogeneity of HIV counterstories that have, in the past, marginalized persons they seek to represent. Though Nelson (2001) asserts that successful counterstories do not oppress those for whom they speak, I have shown that the heterogeneity of the HIV counterstories challenges this idea. While Nelson’s assertions appear logical on paper, in theory the complex ways in which the master narratives have constructed

dichotomised categories of those who deserve it and those who are innocent victims belies the simple application of her idea. The moral degradation of those who get HIV, coupled with the terminal nature of HIV/AIDS, the various modes of infection and their associated stigmas, mean that multiple counterstories have been developed. In a generalized sense, they have attacked the trajectory of treatment and research, the construction of surveillance data, and the stigma associated with HIV-related poverty and thus have had policy implications.

Through these counterstories, changes have come about within various biomedically, economically, and politically hegemonic institutions that have had a resulting shift within the generalized HIV master narrative. In a specific sense, however, there have been segments of the HIV-infected population who have not benefited from certain counterstories that are not representative of their HIV experience. A clear example of this can be found within the counterstory of ACT UP in the early 1980s that was more reflective of middle-class white gay men than women, or other ethnic groups of homosexual persons, or IDU. Clearly, however, the treatment activism of ACT UP created changes within the HIV master narrative from which many with HIV could benefit. Also, ACT UP itself changed due to the counterstories of those whom it did not represent. Thus, in measuring the success or failure of HIV counterstories, it is imperative to first explore the many levels upon which counterstories, as heterogeneous entities, can exist.

Alex's narrative provides cogent examples of collective activism being both a vehicle for her to restore moral agency while serving, on another level, as an oppressive agent in and of itself. The political nature of collective activism, coupled with the diverse body of terminally and chronically ill persons it alleges to represent, has within in it the seeds of discord. Deconstructing the power relations within activism agencies, as we have done in chapter 5, can enable a more efficient and appropriate level of support and care for PWHA. There are many levels of meaning attached to why persons choose to work for social change. It is naïve to assume that all persons define and operationalize the mandate of an organization in the same way. Systems of communication that underlie the day-to-day operations of collective advocacy groups need to be understood as to how they can have direct impact on those they claim to represent. Alex's narrative of the politics of collective activism contains relevant information for those, both HIV negative and positive, who are intent on providing a better level of service to PWHA.

At the same time, collective activism also enabled Alex to reconstruct her self-identity thus enabling her to advocate for both herself and James after her collective activism ended. Alex's narrative counterstory results from the culmination of her life experiences to date. Over the years of encountering oppressive agents, or witnessing others' oppression, Alex developed

symbolic capital that she could draw on to legitimise her agency as morally and cognitively developed. While living her counterstory is an ongoing process, she strives to remain as fiercely in control of her life as the illness and its associated marginalizations will allow.

Collaboration

The decision to conduct this research resulted from a desire to complete my doctoral work in an area that I was passionate about and that I felt had an applied relevance in the classroom. While I spent the first four years of my doctoral program preparing to conduct research in the West Indies, I was continually thwarted in my efforts to return there to complete a year in the field. Whether it was family responsibilities or work commitments, I was not going to get there before running out of time in the doctoral program. At the same time, as an educator, I was watching Alex's public presentations impact the students and faculty she was presenting to while her private life continued to be a struggle for appropriate healthcare and reasonable support from welfare. I approached Alex with the idea of doing research together, of collaborating on my doctoral dissertation and after some thought and discussion, she agreed.

The collaboration involved Alex and me laying out the thematic areas to be covered. We had a body of audio and videotapes of Alex's public work spanning 12 years. I was to extract the story from these tapes, Alex then would edit it, I would write my own sections, while continuing to talk and just live our lives as sisters. When I introduced the idea of collaboration to her, I intended to use this method to address authority and voice in the ethnographic text. I had heard Alex telling her story on numerous occasions and had watched countless hours of her lectures on video and listened to audiotapes. I believed these tapes would become the key source of data. Thus, I would compile her words, as excerpted from the tapes by me and edited by her; these would stand on their own. This appeared a solid methodology, as we would actively work together to construct the particular stories being told.

Within the first three chapters of writing, I recognized that Alex's story, as I envisioned it, resulted not just from my personal observations of her lectures and from viewing the tapes but also from a lifetime of knowing each other as sisters and friends. When I examined the influence of this on the research I thought about the different stories that were simultaneously being developed in this work. For example, the tapes of Alex's lectures clearly presented elements of her life experiences with HIV. They were also thematically and theoretically influenced by the expectations of the faculty she was presenting for or the venue she was speaking in. Critical discussions of welfare stigma or medical marginalization filled the tapes as Alex spoke about

whatever was requested. The events in her and James' lives in terms of medical issues, among other influencing activities, also impacted the particular narrative. What I did not realize until I tried to draw a storyline from the tapes was that Alex spoke very little about personal medical issues or about her collective activism and advocacy work. Much of her medical story revolved around James' caregiving and of his medical issues. The taped narratives presented a series of whole stories on their own; however, being sisters gave us both depths of knowledge about the other that was not reflected in the tapes. I saw different dimensions that I wanted her to voice.

While Alex addresses this herself in chapter 4, my realization that the story was not going to come solely from the tapes required that Alex and I rethink collaboration. I could not seem to separate my knowledge of Alex acquired as an anthropological fieldworker from the more intimate knowledge that I had from knowing her for all of her life. Also, I had to revisit how much my intimate knowledge influenced the story I wanted to present in the dissertation and whether or not this was ethically appropriate. To request additional narrative from Alex, so that her story took on a shape that I wanted it to have, meant increasing her vulnerability through greater personal intrusion. Furthermore, this also meant an increasing workload for her that was not a part of what she had agreed to.

The initial plan for me to pull her story from the tapes required Alex's editorial collaboration to complete her sections, as well as earlier input into how each chapter should proceed. Her collaboration, in terms of time commitment, was to be minimized in as many ways as possible so as to not place undue stress upon her health. Also, with me doing the initial work of getting the storyline down, the dissertation work could carry on, for the most part, at a pace set by her.

By the summer of 2002 when we were working our way through the welfare chapter, we both realized that there was more required of Alex than I had planned in the beginning. The welfare issues that surfaced while she was editing the document that I had prepared needed to be addressed in a more thorough way so she began to dig through years of communication with welfare and to sort through her journals for additional information. The time and emotional toll of this task were evident and upon completion of the welfare chapter, Alex and I needed a break. My requests of her as a collaborative partner had increased throughout the spring and summer of 2002 and as she dug deeper into her own experiences she was confronted with reliving many painful experiences again and again. As both a researcher and sister I reaffirmed to Alex that we could stop the work if necessary. Looking back, and knowing my sister, there was no way that she would pull back from this project if she were capable of finishing it. Regardless of the fact

that I assured her that she could quit at any time, it was more likely that I was guaranteed a completed work. Having said this, I tried to ensure, though not always successfully, that Alex's needs came before academic constraints.

Methodologically, the research was designed so that Alex would not be pressured to commit to the time constraints posed by the university. We took breaks when necessary and for as long as was required. Also, my doctoral committee accepted that the dissertation would be completed on Alex's time, not theirs. Though I tried to honour what it meant to give up control over the time commitments surrounding the dissertation, I would be remiss if I did not say that it was not always easy and that I was not always successful. Having said this, Alex was still influenced by my desire to complete by the summer of 2004 and worked diligently, when her health permitted, to achieve this goal. Alex and I have talked about the workload and its effect upon her health. Though she speaks of these in the next chapter, Dr. Burdge monitored Alex's health throughout and continually checked in with her as to whether or not she was well enough to continue with the dissertation. Throughout a roller coaster ride of hospitalizations, sicknesses, adverse drug reactions, and of fighting for appropriate healthcare for herself and James, Alex has stuck with this project. Had we not been related and had Alex not desired to see me complete my PhD, it is unlikely that she would have allowed her story to be told in this format, as the price for her participation, whether emotional, medical, or physical, has at times been steep.

As an anthropologist, I tried to envision the contingencies that would impact Alex's participation and to ameliorate, if I could, their effects on her. At the same time, I was encouraging her to go deeper into her experience for the sake of this project. As her sister, I believe I was able to entice and cajole her story at times when she might have otherwise have pulled back. My ability to do this resulted in no small part from the dynamic of us being sisters. As with many long-term communicative partners, we have been able to exert subtle and not so subtle manipulations of the other in effort to get what we want. I would be dishonest if I did not recognize that this communication tactic influenced the dissertation research. Whether or not I may have crossed ethical boundaries is for Alex to decide.

Throughout 2003 and into January 2004, Alex narrated her story of medical issues and of her experiences of advocacy and activism, what have become chapters 4 and 5, as this information was not on the tapes. When she agreed to provide information additional to what was on the tapes, we discussed various methods of enabling her to narrate her story with what we thought would be the least amount of effort on her part. She eventually selected voice recognition software so that she could work on her own time, without undue influence from me. While I do

recognize that these chapters did require considerable effort from Alex, the story that emerged was not first filtered through my narrative lens. For me, this was a turning point in the collaborative process. Though we did communicate about her story, these chapters reflect the least amount of influence from me.

When it came time to put all segments of the dissertation together for the first time, Alex and I met for four days and cut, pasted, and negotiated our way through the document. It was important for me to explore the many ways this story could be told while keeping Alex's voice central through collaboration and ensuring the doctoral demands for academic scholarship and integrity were addressed. These days, like the project itself, were a process of continuing to learn to ethically listen to each other and to be able to hear and give space for discord to exist. It also meant giving voice to each other's lived experiences, no matter how personally painful or how much we entertained our own contrasting or contradictory versions of reality. Embracing the discord, albeit with difficulty at times, was elemental to our really understanding what it meant just to listen to each other without judgment.

In my envisioning what collaboration meant, I saw that she was giving me her story while I was putting it into a format that would continue to educate and impact people's lives whether or not Alex was still alive. In this way, I believed that we were both equally benefiting from the dissertation, as her story would serve as a continuation of her public activism as well as a testament to her life as lived. In hearing her speak of how she would not have done this if it were not so I could complete my PhD, I felt at first as though I had taken advantage of her illness story to further my academic career. I also came to the realization that among the many things that collaborative research represented for me, it did not mean the same things to her. Alex's suggestion that she had done this not for herself but for me was necessary, but difficult, for me to hear.

Margery Wolf (1992) writes that power is associated with ethnographic research, even when one tries to conduct research in a non-exploitative manner. In reflexively examining the dimensions of power and its expressions throughout this collaborative process, there were times when Alex's needs and or requests altered the method. In positioning Alex as having full editorial control over her story, and of her having the final word, unedited, we attempted to ensure her representation throughout the entire research process. While this is likely the only way this collaborative effort could have been conducted, I believe it does not diminish the value of the diverse collaborative methodologies employed throughout.

This collaboration was about the negotiation of shifting voice and authority; of multiple stories intersecting; and of stories being created and recreated as the process itself alters the dynamics of the telling. It is also about accepting responsibility for the myriad of ways that we tease the narrative from each other and about examining the way in which power is mediated between all parties involved. This experimental ethnographic process made it possible for Alex and me to come to know each other in ways that would not have occurred had we not engaged in this research.

Alex wrote the letter that follows in response to the above section on collaboration. This section was presented as a paper at *A Symposium on Culture Community & Well being: Community Collaboration & Research Ethics* held at Kwantlen University College in Surrey, British Columbia, on March 1, 2004. Alex and I had hoped that she would be well enough to co-present but as she was unable, she emailed me her comments to be read along with my paper.

Dear Laura,

I have read the pages that relate to your presentation. I think it is quite good and don't have a lot of comments to make. The few things I do want to comment on are as follows.

I do not feel you crossed ethical boundaries in doing this research. Yes, you did push at times for certain things to be included that I was not planning on putting in and there were times you wanted things in places I didn't feel they belonged. As hard as you would push for what you wanted, I would push just as hard for what I wanted. There were times when we would butt heads so intently that we would have to be away from each other for a while. With that said, when we would come back together we were able to talk about these issues. Sometimes I would get what I wanted and sometimes you would get what you wanted. If we came to a place where it felt all right for me to include these specific items I did. When I felt strongly that the issue we were discussing was something I didn't want to share or to talk about in the way you envisioned it, then I would stay true to myself on these occasions. When this would happen you honoured my final decisions and didn't expose areas of my life I wanted to keep private. By doing this I feel you stayed within ethical boundaries and let's be honest, the dissertation is better for the challenging and negotiating. Though I believe this process was necessary to achieve the final outcome, it was not easy.

The other area I want to comment on is my reasons for doing this research and the benefit we will get out of it. Yes, I did do this for you. I did this so you could complete your PhD. It is very important to me that you complete this and are able to do so while writing about a topic you feel passionate about. My desire to have you finish was a selfish one and I am happy I was able to help you do this. Although my reason for doing this project wasn't so that I could leave a piece of me behind in writing, that is what has happened. I believe that every time I speak publicly I have left a part of myself behind with those I have touched or helped and of that I am proud. Now with this dissertation a piece of me will go on forever. And who knows, maybe some one will find something in these pages that will speak to their heart or their mind. Maybe someone will make better choices for themselves or not feel so alone. If this is the case, then the work that I've spent more than a decade doing will go on whether I am here to do it in person or not. That is a blessing and for this I thank you.

Ally, February 25, 2004

Self-reflexivity: Post-defence

The following discussion on self-reflexivity is in response to a request by the examining committee to address their belief that my presence is barely reflected in the dissertation. I unsuccessfully argued that this was an intentional methodological element and believed that I had provided theoretical rationale for keeping my voice to a minimum. While I am uncomfortable engaging in more self-reflexive discussion, I agreed to do so.

My initial doctoral work began in 1994 in the general area of environmental anthropology. I began with the intention of spending a year in the West Indies looking at entrepreneurial subsistence strategies among low-income women working in tourist areas in Trinidad and Tobago. After completing my course work, my 15-year-old son and I travelled to the West Indies looking for a suitable location from which to conduct ethnographic fieldwork. After three months we returned to Canada and I settled back into my full-time teaching job while attempting to find a way to afford taking a year of leave to complete my doctoral research.

Between 1994 and 1997 there were a number of issues that occurred in my personal life that made me question whether or not the PhD was worth the effort. In 1995 I was hospitalized with a tumour that required a long period of convalescence; thus, I took medical leave from both my job and my studies. The next year my mother became ill with cancer and died within two

months of her diagnosis. During this time I again took leave from my doctoral studies. After returning from the West Indies in 1997, I was informed that I would need to teach an additional three years before leave would be granted from my job, at a reduced rate of pay, that would facilitate my fieldwork. As a long-time single parent and student, I did not have any savings to rely on while in the field, and needed adequate money to support both myself and my son so, feeling deflated, I just stopped the doctoral process. It seemed that there were constant roadblocks in my life that were keeping me in Canada and away from completing the PhD. Throughout this time, Alex and James were dealing with serious health issues and this also impacted my desire to not leave the country for extended periods of time.

In the spring of 2000, Dr. Marilyn Gates, then my senior supervisor, called me asking what I intended to do with my PhD as I already had 6 years in the program and my time would run out in two years. I told her that I was going to quit, that I had had enough of struggling to keep up with my family and work commitments and that the PhD was exacting just too high a price. She responded by encouraging me to rethink my decision even if it meant changing the topic to one that would fit more easily with my other responsibilities. She also assured me that she would support the change even if it meant that she would no longer be in a senior supervisory position. At this point, I began to consider that the work Alex and I were doing around stigma and marginalization might make a suitable research topic. As discussed earlier, Alex and I started a dialogue about the possibilities for collaborative research and eventually negotiated our way to a statement of research intent that appealed to Dr. Parin Dossa, who agreed to come on as senior supervisor. After applying to the Chair of Graduate Studies within the Sociology/Anthropology Department at SFU for a change of topic and focus, it was agreed that I would redo two courses before moving on to the comprehensive exams.

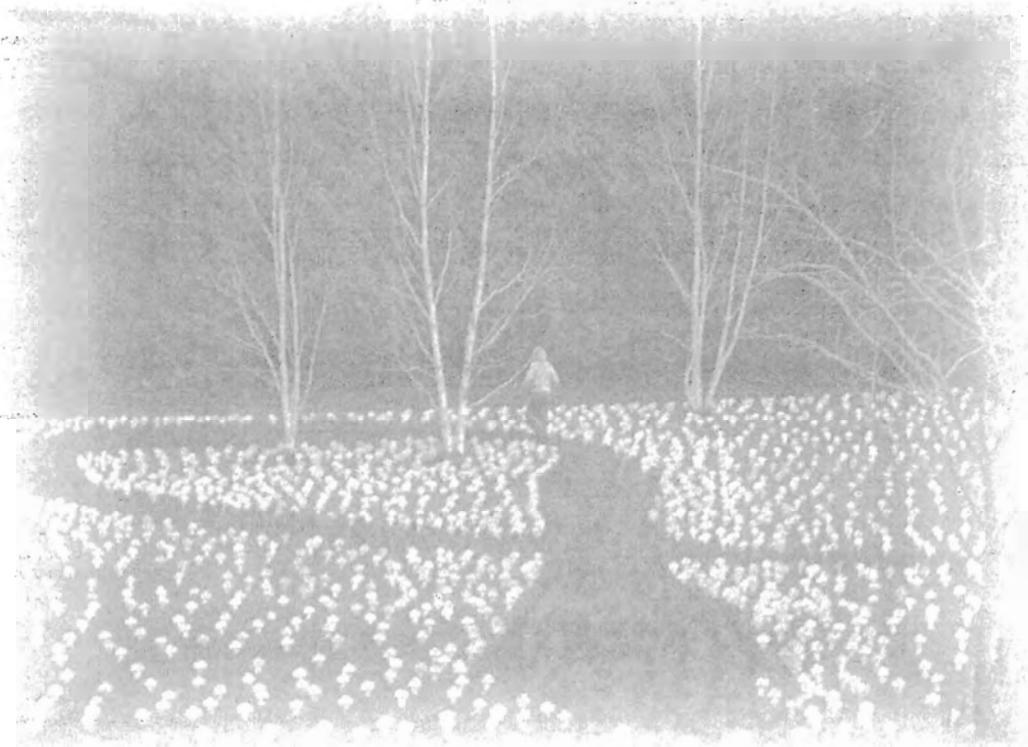
Both Dr. Dossa and Dr. Gates supported, unequivocally, my intention for Alex to have full access to the committee, the opportunity to comment on how her words were being used by me as well as on the committee's reactions to our work. I cannot stress how important it was that if this project were to move forward, Alex be treated as a collaborator rather than an object of research. This belief stemmed from years of witnessing how marginalization had damaged her self-esteem. I was determined that if this story were to be told, it would take place on her terms and in her voice, as much as possible. I believed then, as I do now, that there was no need for me to objectify my sister or her narrative for the sake of retaining my position of academic authority. Having said this, sharing power in a collaborative manner was more easily said than done.

In hindsight, one of the factors that I overlooked in the research design was the role that would be played by James. Though Alex and I do discuss this in the following chapter, there are some comments I believe are relevant at this point. Throughout their marriage Alex had often acted as a buffer between James and our family. I began to notice that throughout the research process, I was increasingly being drawn into James' life, in a manner unlike in the years before our collaboration began. I was finding that often I would ask James a question and more often than not Alex would answer for him. While this was a long-standing communicative pattern, it increasingly got in the way of the relationship of trust that was developing between James and me. This was a touchy area for the three of us to explore, for as protective as I felt toward Alex, she felt even more protective toward James. I needed to assure her that I would not hurt or take advantage of him. Once we were able to engage in the dialogue about who was speaking for James, it became obvious that both she and I needed to take a step back and let James speak for himself. Given that I was so forthright in assuring that Alex's voice be heard here, I was humbled by how my actions were silencing James' voice. This caused a shift in communications that led to James beginning to share some parts of his personal story with me, something that likely would not have happened otherwise. This also opened the door for James and me to begin to really get to know each other without Alex as the filter. Once this began, I was able to more fully understand the context of Alex's life as James' wife and the degree to which this influenced her decision-making processes in relation to her life with HIV, her relationship with me, and her work on this dissertation. What also became apparent to me is that the two-way collaborative project I plotted out with Alex really became, at times, a three-way collaboration. I believe that my committee recognized this before I did, for it was at their request that I approached James for him to include some of his story in the dissertation.

The dispersion of power within the collaborative methodology impacted my life at times in a manner that took me quite by surprise. There were a few occasions throughout the years of conducting this work where I felt powerless and vulnerable. I realized that I had not designed this research to address the helplessness that comes from witnessing a loved one struggle with HIV. In this respect, I too had a story to tell that my sister and brother-in-law's HIV had silenced. After all, I was not the one with a catastrophic terminal illness, nor was I living under the marginalizing forces of welfare disability, so why was it necessary that my personal voice be heard? This caused me to look at the way I had developed the methodological foundations for mediating power, yet had neglected to address these in relation to my role as Alex's sister and James' sister-in-law. While these feelings were shame inducing, they also presented an opportunity for me to think about the complexities of power-sharing both within families that are

impacted by HIV as well as within collaborative research and writing. At the end of the day, my little sister and her husband still have HIV and, regardless of how much I love them or how much I analyze marginalizing within master narratives, these will not do one damned thing to extend their lives. Having said this, the exploration of family dynamics within HIV narratives is the topic for another time and place and so will not be taken up here.

The role of reflexive writing in narrative ethnographies such as this one presents an interesting dilemma. While I accept that Alex, James and I each have influenced the production of knowledge within this dissertation, I maintain that my presence needs to stay in the background, at least for the intent and purpose of this particular document. Throughout the dissertation, I do engage in reflexive writing where my position impacts the discussion being undertaken though I have chosen to disperse my story throughout the various chapters rather than focus it on one area.



CHAPTER VII: A CONVERSATION WITH MY SISTER



Photograph 23: Laura and Alex, Saskatoon, Saskatchewan, Summer 1967⁴⁷

Alex: This project began with two stories: my story, your story and then an idea for a third. When you first asked me about this I agreed, yet I went home after agreeing and thought, "what have I gotten myself into?" I think subsequent conversations we had allowed me to feel more comfortable about what you proposed. You allayed some of my fears by promises that you made me.

⁴⁷ Photograph by permission of the estate of Margaret Cooper.

Laura: What were your fears? What were my promises?

Alex: Well... I think the main fear was that I would be exposed more than I had chosen to be, that more would be asked of me than I was able or willing to give, I had a fear about how we would negotiate through some of the stuff that was bound to come up for us. What you promised me was that you would honour those areas that I absolutely deemed private, for things in that grey area, we would negotiate. I would have final say to the content in my portions. If ever I were unable to go on due to health or whatever, we would work that out. Through these conversations my fears about how we would negotiate the stuff were eased.

Laura: What stuff?

Alex: Interpersonal relationships, the stuff you find in any family closet.

Laura: Should we discuss the research by looking at the theory, methods and ethical aspects, though I know the ethics and interpersonal issues are interspersed throughout the entire process?

Theory

Laura: What are your thoughts on the theoretical models that we have applied to your narrative, specifically the way that a master narrative is constructed?

Alex: Before we began this process I had never heard the phrase master narrative, but I certainly knew it existed. I had experienced what it was but I didn't know what it was called. I thought it was simply oppression. As I began to understand what a master narrative is and how it functions, it made sense.

Laura: Do you think learning about the formal concept, master narrative, influenced how you told your story here?

Alex: Not a lot. It might have encouraged me to make certain connections or to expand on connections I might have made in the past, but as for how I told my story, it is pretty much the way I would have told it before I learned about master narratives. I think what the master narrative theory did was provide me an academic framework for the realities I have been experiencing.

Laura: When I asked a colleague, in whose class you had spoken, how your narrative has changed over the years, he replied, “a part of the theme is development of self-identity, each time she came back there were new experiences she could draw on. I found that interesting to watch. She wasn’t the same person each time she came back so the talk wasn’t the same.” My other colleague said, “In terms of her presentation she is a pro. She can be going through hell personally but she does not let on...I would pick up bits and pieces that, you know, Jim is ill and in hospital but it did not seem to influence her presentation to students.”

Alex: *I do understand that at times being in the chaos can be overwhelming. I also know there have been times of chaos where I have been able to put it aside, put on my mask, and give my presentation. For me chaotic times might include things like when James is in hospital and I am being told he is dying and they are refusing to treat his ailments. They are focusing on his demise yet my gut tells me that if they would treat him he would get better. That for me is chaos, fighting to get him that treatment. And to try and understand why he is not seen as valuable enough for them to fight for him too. Things like hospital policy, where they begin your discharge planning the minute you walk in the door. Medical treatment be- damned when they try to send you home before they even begin to make you better because they want your bed for another patient. Or welfare medical policy where they will authorize payment of medications that are not necessary but will deny authorization for the medicine that will stop you from dying. In situations like this the ability to trust my own instinct as to what I know is right, regardless of what I am being told by practitioners, is the foundation of my own healthcare and my advocacy position to James' healthcare.*

Laura: A. Frank writes of the plots of chaos, restitution and quest. He suggests that when someone’s illness narrative is embedded in chaos that they are incapable of reflexively looking at their life and using this reflexive experience to alter the chaotic state. How do you reconcile this with the interview comments I just mentioned?

Alex: *The chaos could be consuming but it was never the totality of my life at any given point except the time just before I went on the retreat. At that time I was unable to*

come to terms with my HIV, with using heroin, and with the chaos that was my life. I guess going to the retreat was the beginning of the quest. I don't agree that when you're in the middle of the chaos you can't be reflexive. I think my journals are a prime example because in them it is just not pouring out the circumstances of the chaos, but talking through my own solutions. Even in the most chaotic times there were life-affirming elements that helped normalize it: my marriage, my spiritual quest, my animals, my gardens, my art. The acquisition of animals is a prime example of this because they are a longtime commitment. Sammy, our cat, had been with us 14 years but was put to sleep a few weeks ago due to illness, Marley, our dog, 12 years. Now we have a nine-month-old puppy, Brutus, so I guess we'll be sticking around a little longer.

Laura: While chaos is a cultural construction, it is also impacted by individual experiences and skills. We learned very powerful survival skills as children, how to live in stressful situations and to land on our feet. Do you think this influenced how you handle the stress of living with HIV?

Alex: *Absolutely, I am a fighter.*

Ethical and methodological negotiations

Laura: Let's talk about how your participation in the dissertation research and of the collaborative method we employed. Was the workload what you expected it to be?

Alex: *More, it was more. More time consuming, it was more everything.*

Laura: Okay. What did you think it would be?

Alex: *I thought that I wouldn't have to actively write some of my own sections that I could tell it to you and you would write it or take it from the tapes and videos. What became obvious once we got in to it was there were areas of the story that were absolutely missing from my presentations. Even though you did provide me with a dictation machine so I could fill in the gaps and you could transcribe it, I didn't fully utilize it. The solution that we came up with was voice recognition software, which resulted in me sitting at the computer telling it my story. Where*

this became more work is that I had to make what I wrote cohesive and readable. Putting a story into words on paper is different than orally telling your story. This was a shift for me, not to mention the problems inherent in voice recognition software.

Laura: Will you expand on the problems with the voice recognition software?

Alex: It was a study in frustration. Even though I did the software training many times to try to improve its recognition of my voice, it would regularly type words or sentences that I did not say. I spent a lot of time saying "scratch that" to erase the errors. Those times when it would seem to be working well I would read back over what was written and find the oddest word or phrase in the middle of a paragraph. It was a bit frustrating but all in all it was a blessing as I was able to dictate and correct faster than I am able to type from scratch.

Laura: When you were writing your story first-hand, rather than working from my construction, were you satisfied with the end result?

Alex: Yes. I think it worked well. It was very good for me to sit down and look at areas of my life I had not examined for years. Not everything ended up in the research but I think it ended up well rounded and reflective of my life.

Laura: Did you go back to your journals during this writing? If so, what kind of insights did these give you? Did they shift your perspective?

Alex: Yes I did go to the journals. What they gave me was a view of the moments as they occurred. In some cases they reminded me of fact or situations I had forgotten about. Other times, they allowed me to feel the pain of the moment all over again.

Laura: In reflection, did you ever see the event from an entirely different light or perspective, given the distance and life changes that you have gone through?

Alex: The most significant examples of the journals allowing me to go back into the moment were the times when James was very sick and we were afraid he was going to die. The entries in my journal would be made in the middle of the night when James was asleep and all my fear was at the surface. In reading through these

entries, I was again aware of how many nights I sat up watching him sleep and fearing his death. It was painful. It also allowed me to see how far we have come and left me feeling grateful that life is different now. As for perspective, the journals allowed me to see that my perspective of certain events was very narrow, from inside the trauma. In retrospect, I guess it couldn't have been any other way for me; I was living in that moment and my journals were my outlet. This is because I would do my best to hide my true fear from James. I believe that if he saw how truly frightened I was that it would be more difficult for him.

Laura: While working on the welfare chapter, did going through your files, letters, and communications stir anything for you that you want to mention here?

Alex: That chapter was hard. When we were writing the welfare chapter it was during all those changes the government was implementing and my future seemed very unsure. I felt angry at the lunacy of it all and of how our government approaches its people. Also of how disposable people in my position are to the powers that be. It also made me aware that the struggle I was having with the government was the norm and had been going on all along. In a way it made it better because it gave me some perspective from looking at the history. As you know, things settled down with welfare, then more difficulties came up. They still come and go and I am left knowing that that will be my life as long as I am on governmental assistance. It does not change.

Laura: What other methodological issues surfaced for you?

Alex: There were times when the schedule required by academia didn't always work with my ability to participate. I'm sure that it made it difficult for you to have to rely on me fulfilling things within the time constraints you had. For me I would feel bad when I was unable to come through in a timely way for you. I also want to say that for the advocacy and medical chapters it was good for me to dictate them to the computer and not to you. I found this more in keeping with the way the first couple chapters were done, being taken from transcripts and tapes of presentations. By

dictating it to the computer, I was able to tell my story without outside filters influencing it. Then we could look at it together.

Laura: Can we talk about ethical issues that result from us being sisters and friends? What do you think is the most vulnerable position that I placed you in during this research?

Alex: The most vulnerable position that the research placed me in was trusting my words to somebody else. But the most vulnerable position that you placed me in through this research was sharing my shame with you, opening up about my shame.

Laura: I know that the knowledge I have about your life just from having known you for so long influenced the story I wanted to tell. It is what made me pursue the IDU narrative. Did I cross the boundary ethically?

Alex: No I don't believe so. You knew what you wanted to present and I think we had a miscommunication at the beginning; still you honoured what I said and waited until I was ready. There are parts of this dissertation that are difficult to read. Coming across the rape in there took me by surprise. I knew that we had talked about it but forgot that you were going to write about it. Reading about what you found when you walked into my home on Salt Spring that time when James and I were both sick and in the city made me cry. It made it too real to see it through your eyes.

Laura: Ethically, as an anthropologist and researcher, I am not supposed to make things more difficult for you. The vulnerability for me is that I am first your sister and, as such, I am privy to knowledge that I otherwise wouldn't have. With this knowledge, I have constructed my own version of your life events.

Alex: I believe that our relationship as sisters makes the potential for ethical violations very real. Because we are aware of this we have had conversations about what you would have access to as an anthropologist and as my sister and the grey area in between where you and I would negotiate.

Injection drug use

Laura: Can we talk about the injection drug use for a bit? It was an area that posed considerable difficulty for both of us, perhaps one of those grey areas you suggest above.

Alex: I knew how hard you would push when you wanted something, and I knew that when I wanted something I could push as hard, especially around the drug issue. I think, initially, you wanted it to be much more a part than what it is. I wanted it only to be brought in when it directly impacted the story that I was trying to tell.

Laura: For me, it was more central. I guess it resulted from my experience with your HIV, and of witnessing the hold that the heroin had on your and James' lives during those difficult and chaotic times. In those years, I felt so much helplessness about your HIV that the heroin use became a target to focus my fear and anger on. Also in much of the literature I was reading of how hegemonic narratives can oppress, it was clear that IDU was linked to stigma, marginalization and low self-esteem. Theoretically, I saw your IDU as a powerful element in your narrative.

Alex: I remember having a great deal of concern that once the drug issue entered my story on these pages, that it would invalidate me in the eyes of many reading it and I would be dismissed again. The sad fact is that I believe this still will happen with some and that's okay. I did not want to bring in the drug use for the sake of it being there, I wanted to bring it in when I was talking about how it impacted my treatment by a doctor or treatment by a welfare worker. It also seemed necessary to discuss at the appropriate time why and when I began injecting heroin.

Laura: This truly was a negotiation process that became more like a journey of discovery for both of us.

Alex: My drug addiction, that I alluded to in presentations, was my shame and I wasn't sharing the details of it for anybody unless it was done in the way I wanted it done. Although it was difficult, this was an excellent first hurdle to be overcome. It was the first negotiation about content where we hit a stalemate, it seemed.

Laura: I think this was where we first realized that there was more than one story on the go here but that I had to keep my ethical obligation to you regardless of what I envisioned the story to be.

Alex: *The end result is that the issue of the drug use in the document is reflected in a way I feel is effective yet safe.*

Intrusions

Laura: One thing that I want to address about the method is that it required me to have a presence in yours and James' lives that became intrusive. At times I felt that quite strongly. I believe that the method, while it was great in that it gave us the opportunity and reason to spend a lot of time together, also demanded that we spend more time together than might have always been desirable.

Alex: *Yes, it sometimes was intrusive. I am a very private person who does not usually have much company in her home. I think why, at times, it felt intrusive was that we were talking about very private things and sometimes being in the very confined space of our home didn't allow for the distance that we might have had if we had not been family. Also, the desire for discussion about areas of our lives that were painful is inherent in the feeling of intrusion at times, especially when these discussions needed to happen within a time frame required for the dissertation and not because one's soul needed to share it.*

Laura: I also think that there being no clearly defined boundaries, if there can ever be in the process of life, between us as sisters, friends, and collaborators, has had a profound impact on me. The intrusion that we speak of, it impacted you and James, no doubt, but it also impacted me to have this knowledge of you and of your painful experiences. As an older sister, I felt a moral weight of how your life with HIV has been. As an anthropologist, in the sense that knowledge is power, it placed me in a position of power that I really did not want. That it happened, as you say, due to the dissertation and not because "one's soul needed to share it," makes it even more problematic for me.

Alex: Yes, the lack of boundaries was difficult. Trying to figure out what was life and what was research was at times difficult for me so I can only imagine how difficult it must have been for you.

Laura: Also, there was more than just me and you involved, as James played a key role as well. This brought another element to the table that added dimensions of issues and painful stories.

Alex: Yes, James is a huge part of my life so I could not talk about my life without him being part of it. Because of that it was important to not only have his permission to talk about him but it was necessary to have his cooperation.

Laura: I agree. Also, as he impacted the process of conducting research, his role cannot be understated. In terms of my involvement in your lives, a considerable amount of our time together during his sick years was around his healthcare. Whether it was me caring for you while you were caring for him, or some other combination of caregiving attention over his dire health needs, this presented an intensity and vulnerability to the research.

Alex: Absolutely. It inserted a degree of intimacy that would not have been present had we not been in the trenches of the life and death struggle together. It also added a degree of difficulty to the research in a number of ways. It impacted the time factor since when he was sick the research took a back seat. It also made our time seem limited as to life expectancy; it seemed as though time might run out. This added to the struggles of our work. The "James factor" was also a blessing, as I believe his story added a dimension to your understanding of our lives that you couldn't have had if he had not chosen to share his story with you.

Laura: What you have written is important. I also think that my involvement in your lives around health issues related to HIV, and my support of both of you during the sick times, predicated the research by years. It did not exist because of the research. Also, without a doubt, the research took a backseat to the familial responsibility that I felt toward both of you. Also I believe that for many years James was unable to look reflexively on his life; it was only as he began a more holistic healing process, as he writes himself, that he was able to share his story.

Alex: I think the idea of the research was in part a result of your involvement in our lives including your caregiving and not the other way around.

Laura: I guess that is what I was saying.

Alex: Although James shared much of his life with me years ago, his perspective of it has changed. Also, he would not have been able to reflexively tell his story to others a number of years ago. This is a direct result of the healing and spiritual path he has chosen for his life in the past few years. To watch him come to a place where he not only feels valuable enough to deserve to be happy but to feel that his experiences have value. This has been wonderful for me.

Laura: When the research began there was much sickness in your and James' lives. I was looking for a way to be able to spend more time with you. I wanted to be able to watch over you as you were becoming more ill and James was never very well. The impetus for the research resulted from a number of factors, not the least of which was my desire to watch over you during the sick times you were having. While you were afraid of losing your husband, I was afraid of losing you. The PhD enabled me to spend more time with you and to watch over you, though this was not always a good thing for either of us. Without a doubt, I took on a sense of duty that was not mine to have.

Alex: I don't know if it was your duty or not. I do know that when our loved ones are ill we find whatever way we can to feel like we have some control over uncontrollable situations.

Representations

Laura: Do you want to talk about the issue of representation? Do you think the research was representative of your life in an accurate way? Was your voice ever subsumed or silenced under my power as the ethnographer?

Alex: I do not believe that my voice was ever silenced in this. I was able to say what I needed or wanted to say. When it came to the theory, this was your part and I felt it was your place to say what you wanted to say. In general I do believe that this research is representative of the view of my life that we portray. There is much more about me than what is written here regarding the experiences we wrote about. Yes it

is a well-rounded representation. I do not think all the theories quoted in this dissertation are accurate in my life but that is what makes this a wonderful process, the sharing of different perspectives and positions regarding the same topic.

Laura: What theories do you believe were inaccurate portrayals?

Alex: *The only one I can think of is the one regarding chaos that we talked about earlier. The author is welcome to his perspective but I don't think it applies to all the same way. Theory is academic and while it may accurately reflect a moment in time it can't represent the whole truth, especially when dealing with life issues. Life is fluid and impacted by many variables and people involved. Look at the history of your field of study and how the accepted theory has changed over the years. Do you know what I mean?*

Laura: Yes I do. I think this is a key area between the positivists and non-positivists. My philosophy colleague who said that the social sciences make up their theory as they go along is reflective of your idea, though not in the derogatory way he intended the comment to be when he made it after hearing about my research design. The exciting thing for me about some postmodern theories is that they provide a place for us to critically examine how we represent each other. Also, they hold us morally and ethically accountable for what we say about each other. Can you imagine how your story would be if it was written by a positivist?

Alex: *A scary thought. It would not be with my cooperation, that's for sure but then from a positivist perspective, my cooperation may not be of necessity. From that perspective a fact is a fact.*

Laura: Yes, though facts are, by necessity, socially constructed. It is like how truth is relative to the person who perceives it as such. For me as a researcher, it was very emancipating to embrace those elements of postmodernism that provided a way to critique inequality and domination that are embedded in patriarchal positivist Anglo-centric academic agendas.

Alex: *I think it is healthy for any discipline to critically look at itself. Without this the discipline stands still. Is it a bit risky for you to do this?*

Laura: Well, not yet, but the dissertation has not yet been defended and examined. Having said this, your comment has opened the door to a key hurdle presented to me by the academic process regarding this research. Being denied the opportunity to have you listed as co-author on the title page of this dissertation was a real blow for me. I never presumed that the process would be so rigid as to deny what I see as your rightful place as co-author.

Alex: I know this was very hurtful for you. I know in my heart that I will always be a co-author and that you see it as such. With that said, it is once again an example of how voices can be silenced and realities invalidated based on preconceived positions.

Laura: Not being able to put your name as co-author is reflective of a master narrative that can and does silence that which challenges its position of authority. It is telling that we have written a paper that is aimed at challenging marginalization only to have you marginalized again. This is not the way I intended for this research to end.

Alex: I am aware of that but what a powerful way for it to end. It supports so much of what was said in this document. An example being the difference in the way I was treated when an educator of welfare workers as opposed to a client of welfare. One is an equal; one is a subordinate. In the situation of the dissertation, I have been made a subject. These are kind of controlling words don't you think. With that said, I have learned a long time ago to allow these institutions to believe what they need to, especially if the circumstances are such that fighting has too high a price. In this case the price is too high.

Laura: You are right about a price being attached. I was told that if I pursued co-authorship I would not be granted a PhD. A PhD must be independent work. I expressed that my research was different and that you were a co-author and collaborator, and in no way did this diminish my workload as a doctoral candidate, but to no avail. I am wrestling with compromising my principles by putting this PhD before challenging the decision about authorship.

Alex: Unfortunately sometimes we have to play by others' rules to get what we want. Use their system to get what you want, what I want you to get, and make this

experience a teaching tool as to the flaws in the system. Maybe this would be a good topic to write about after your PhD is done?

Laura: I suppose so. Are there any areas you want to cover before closing off our work here? I think we have addressed a number of salient points that did surface for us. It has been interesting working on MSN Messenger for this conversation. Being able to take our time since we began this conversation in January of this year and talked a bit when it worked for us. This has been a unique way for me to do research.

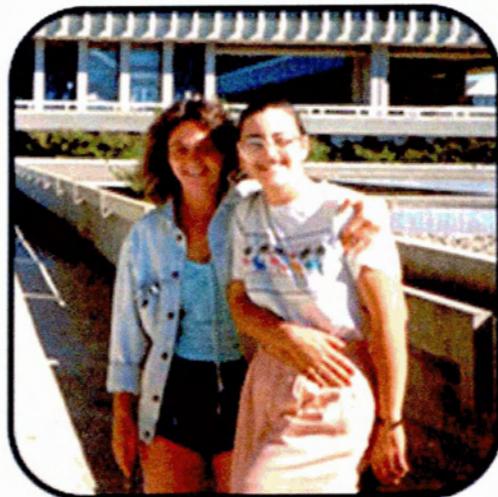
Alex: *I've liked this feature, this tool. It worked well and saved on phone bills.*

Laura: So, Alex, you get the final word here. I just want to thank you again.

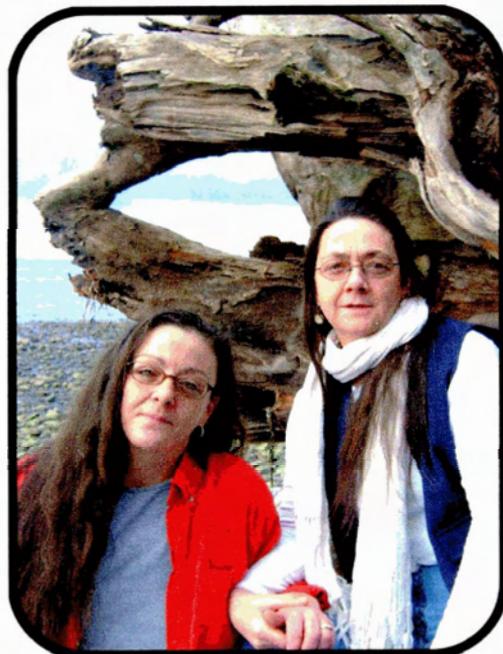
Alex: *I think we did good work here. I thank you for taking this on and for the consideration you have given my family, my words, and me. This is a great gift you've given me and I am grateful. I see in these pages a powerful tool that is available to those who want it. I hope it is taken for what it is and given the consideration I believe it deserves. If this document can stimulate conversation and challenge thought then we have achieved something. Bye for now.*



Alex's scrapbook



Photograph 24: Laura and Alex at Simon Fraser University, Summer 1988⁴⁸



Photograph 25: Alex and Laura at Crescent Beach, February 2004⁴⁹



Photograph 26: Alex & Laura in South Dakota, Summer 1999

⁴⁸ Photograph by permission of the estate of Margaret Cooper.

⁴⁹ Photographs 25 and 26 by permission of Jesse Cooper.

EPILOGUE

This dissertation has been a learning experience, to say the least. I have learned so much about the academic process, my familial relationships, and myself. I have watched Laura let go of years of unsaid emotion, I've watched James find his voice and I've put my story on paper, not just into the air. This experience has allowed me to revisit my past, its pain and joy, and to see things with my eyes of today. The eyes of a woman who is happy more often than she is sad. The eyes of a woman who has learned to find joy in the little things and honour the day-to-day successes. A woman who is grateful for her life as it is. That doesn't mean I don't desire more, I do. I desire it all.

I desire a cure for my illness and others. I desire equality and equitable distribution. I desire a life without stigma and marginalizing. I desire a world without war, hunger, violence, intolerance, ignorance, oppression, prejudice; all the biggies. I desire it all. But I am a realist. I know that I can desire it all but still find a way to be happy with where my world is at while working towards the rest.

During the years of working on this dissertation there have been many changes in my life. That makes sense, change is one of the only certainties we have in this life. James has gone from absolute sickness to relative health and I've gone from relative health to a degree of sickness I've not known before. Since I wrote down my part of the medical chapter things are different. The problems with my neuropathy got worse and Dr. Burdge decided it was time for me to change medications to try and reverse some of the neurological damage that was being done by one of the drugs I was on. Because of this change of medication I had to quit the L-Acetylcarnitine study. I have been having a difficult time adjusting to my new drug combo and am battling incredible headaches and nausea from it. I hope things will settle down soon and I can begin to feel better. I still feel a great sense of frustration as I started these AIDS drugs to feel better with more energy, and I don't. I hope my health improves before I lose my faith

in these meds and stop them. If I am not going to feel a benefit I will stop them, as they are too poisonous to keep taking if they don't help me feel better.

Our lives on Salt Spring continue to be fairly good. I guess the only down side to being here is that housing is an ongoing struggle. There is very little affordable housing and no subsidized housing. We are in the position of needing to look for a new place to live with very few options to consider. James and I have decided to give it another year or so on this island to see if we can find a long-term rental that is affordable. If we can't, we may be forced to move elsewhere. I hope this does not happen as Salt Spring has been very life affirming for us and we want to stay here. Unfortunately it is a place that is not very accommodating to those of us who are not wealthy, and it's getting worse. With that said, I still have hope that we can find a small piece of this island in which to make ourselves a home.

The issues regarding the struggle for my validity within the confines of the rules governing this PhD project have caused great upset for Laura. It is funny though that when she called to tell me what had happened, I didn't feel that surprised or upset. Maybe I didn't feel that upset because I wasn't surprised. The struggle to be treated as an equal and not a subordinate is interwoven throughout my years of living with HIV. I guess this latest situation reflects life as I've come to know it. Sometimes knowing in one's heart has to be enough. I do believe that academia is intrinsically a hierarchy. This I believe is reflective of the rules governing the discipline and not the individuals involved in active study. With that said, it sets up a circumstance of superior / subordinate. Being told that I could not be credited with writing my own words, I will go from peer to subject in the eyes of some. That is a sad commentary on the controlling mechanisms within our society in general and academia in particular. One day this may change, but not today. But this is only my opinion.

I see this dissertation as an important piece of work that challenges the systems that govern many parts of our society. With luck this document will stimulate thought and conversation. If it does that then it is a success in my eyes. I believe Laura did an excellent job of presenting her arguments and supporting her theories. This work could not have been easy for her due to the vested interest she has with the subject, myself. For her ability to

complete this with all the challenges we faced, I congratulate her and am proud. Thank you all for your time. Bye for now.

Alexandria Keating (May 10, 2004)



Photograph 27: Laura & Alex, 1998⁵⁰

⁵⁰ Photograph by Permission of Liela Cooper.

POST DEFENCE CONVERSATION

Laura: Today it has been one month since the doctoral defence. Time has flown by. It was great to be able to watch the videotape of the defence together before having this conversation. I missed you at the defence. It was difficult for me that you were unwell and unable to attend.

Alex: It was sad for me that I wasn't there; unfortunately, the infection in my lower jaw and neck had begun to move into my chest and could have put me into a life-threatening position. I had to stay home and have the IV therapy done. I am grateful to Sam for videoing the defence. I think the defence went well.

Laura: After watching the tape I would like to raise a few points with you as the oral exam brought forward some questions for me. The first one is regarding the position of your voice and truth.

Alex: The whole concept of truth is relative to one's life experience in the moment. The idea that someone can evaluate a person's truth better than that person can herself is arrogant and narrow. I think that it is amusing that there is a perspective out there that if my story is filtered through an academic lens first then it is more truthful than when told in my own voice and words. This invalidates my story and I become unnecessary. We are not talking about truth and lies here; we are talking about perceptions of one's life. My truth about my life ten years ago is different than my truth about my life today because I see it differently. My ability to go back through my journals and read them helped me to see my truth back then but I can still only talk about it through my experience of today.

There is one other issue that I would like to address before we leave the topic of truth and life perspective, this is regarding the phrase HIV-infected. At your oral exam the issue was raised that referring to me as HIV-infected was marginalizing, I do not agree with this. For me it is marginalizing to be called a PWA or a PWHA.

A person with AIDS has connotations of death attached to it and I do not refer to myself as a PWA. For me this phrase is oppressive and limiting. Let's be frank here, I am infected with HIV. HIV infection is not some abstract concept used to define. It's a fact.

Others may define themselves differently and that's ok. Persons not living with this illness cannot have the same perspective. Many of the common terms used by society, government, academia, and medicine are very marginalizing and oppressive, in my opinion, but are used none-the-less. I guess for those, these phrases are comfortable and are what they know. For me that doesn't make them any more acceptable. On the contrary, the fact that definitions that oppress are the accepted terminology is very telling and sad. One day I hope the views of those being discussed will be given more consideration. As for me, I am a member of BCPWA (not my choice of name), I am a woman living with HIV and I am HIV-infected. I am also much more than that has nothing to do with HIV, but that's another story.

Laura: Another area that I want your comment on is the authority and editorial control you had over your own story. I think some persons in the exam room had a difficult time with the power sharing that was critical to our collaborative methodology.

Alex: *I think for some people, they work so hard to gain a position of authority that the thought of becoming an equal with the subject of research, who is not an academic, is very frightening. I honestly think that the concept of anthropologist and subject is very comfortable for some because it gives them that place to evaluate and maintain distance. I think the concept of equality can be very threatening to some people and can make them very uncomfortable.*

Laura: The point that I believe I was not successful in making during the defence is the importance of power sharing. Going back to what you were saying about the willingness to power share, the doctoral committee has no issue with this because I chose the right committee. The idea of power sharing, as a core methodological element of the dissertation, was being questioned as to whether or not it diminished the academic merit of the work in terms of my contribution. Alex, at the end of the day, I still don't understand how the issue of your access to the committee, and the sharing of

power, became such a point of critique and question. Your editorial control was only over your own story.

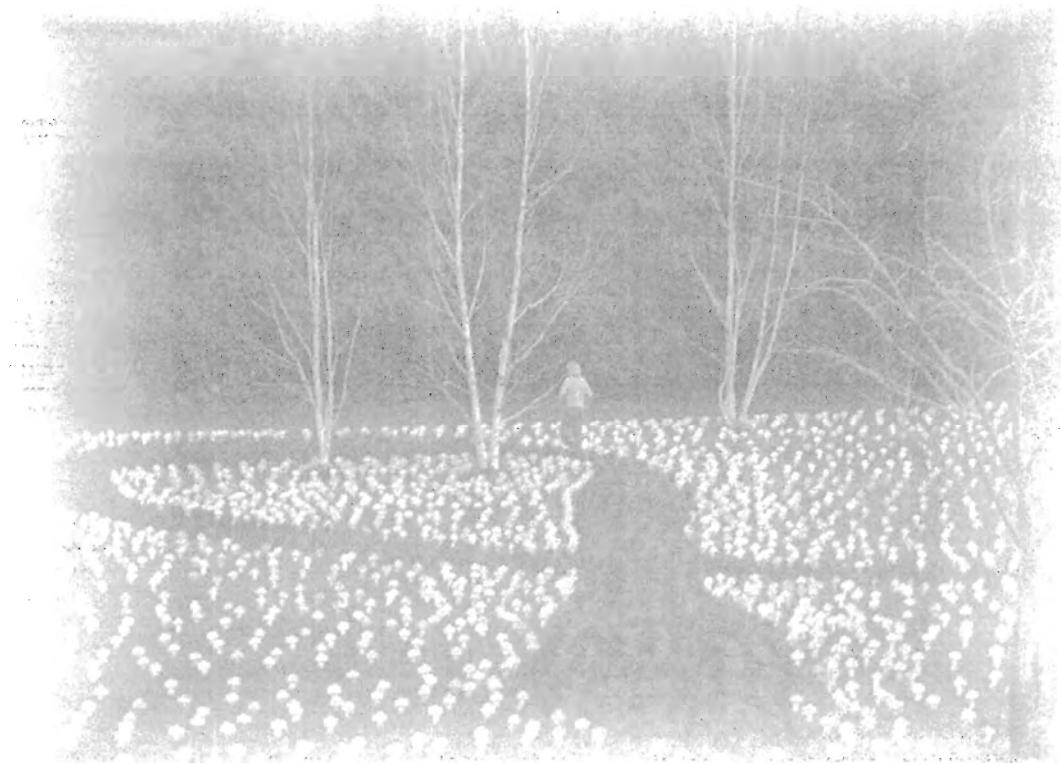
Alex: The suggestion that your academic contribution might not merit a PhD due to the fact that I was a collaborator and my story was told in my own voice is to me a ludicrous idea. What you do in this dissertation is analyzing my story as well as sharing portions and perspectives of my story that I do not. You also place James' and my stories within the context of the broader perspective by researching and making links between the stories we tell and the documented realities of others living with this illness. In this way you tell the stories of many who share the realities I do. You researched and wrote about the history of welfare, medical systems, societal perspectives on HIV, etc. allowing the reader to better understand the realities in which the HIV narrative is being told and why the social structure can marginalize the way it does. By offering this information you not only educate but you give the reader more information with which to support or challenge the theories you present.

It seems to me that at your oral exam, the challenge wasn't to the theory but to your workload. I guess I just don't get it. How could someone actually read this document and question if you did enough work to merit a PhD. For goodness sake, my words consist of one quarter of the document and although I am reflexive and do discuss social issues and occasionally the "big" picture, I mainly speak of those things which have directly impacted my life in some way. What you do is expand this view, examine different facets of these issues and challenge socially accepted perspectives. You also challenge long-standing positions and theories within your own academic discipline. I'm sure some don't always appreciate this approach. I am equally sure this approach will advance and is necessary to the life of any discipline.

Just to be perfectly clear, I had no editorial control over your words in this dissertation. What I did have was the choice to comment on your sections, an option I rarely if ever exercised. I believe my ability to comment did impact how you wrote things but not too much on what you wrote, but that's only my perspective.

In reference to the question at your defence about the big picture and how positive change can be impacted by this work, sort of a “where to now” question, my thoughts are this. Change does need to happen at the top of the power structure of government, medical systems, and social systems etc. This document can't make the government agent of welfare change their policies to a more humane stance. It won't stop the moral right from seeing HIV as a retribution by God, and those afflicted as deserving of their suffering (except in the few instances of innocence such as by birth or blood transfusion). This dissertation will not change the world in one fell swoop. What I believe this dissertation will do is contribute to change on a grass roots level, and some of the most profound change in history has come about this way. The power of this document, as a whole or in part, is that it will speak to the individual. The individual will not only hear with their brain, but may also hear with their heart. By affecting the individual, change will happen. As the peoples' views change, so does that of the power structure governing our society. It may take time but it does happen. Average people can change the world and do so every day. That is my hope with this dissertation, that change will result not only in the individual, but also through the individual into society and affect social policy. I do believe this can and will happen as a result of this story and others like it. I've seen it happen before and I know I will see it again. The power of the people is an amazing thing and I have faith.

APPENDICES



Appendix 1: Ethical approval

SIMON FRASER UNIVERSITY

OFFICE OF RESEARCH ETHICS



BURNABY, BRITISH COLUMBIA
CANADA V5A 1S6
Telephone: 604-291-3447
FAX: 604-268-6785

July 12, 2004

**Ms. Laurie Cooper
Graduate Student
Sociology/Anthropology
Simon Fraser University**

Dear Ms. Cooper:

Re: Conversations with My Sister: An HIV/AIDS Counterstory

The above-titled ethics application has been granted approval by the Simon Fraser Research Ethics Board, in accordance with Policy R 20.01, "Ethics Review of Research Involving Human Subjects".

Sincerely,

**Dr. Hal Weinberg, Director
Office of Research Ethics**

For inclusion in thesis/dissertation/extended essays/research project report, as submitted to the university library in fulfillment of final requirements for graduation.

Appendix 2: Informed consent form

FORM #2	
SIMON FRASER UNIVERSITY	
<u>INFORMED CONSENT BY SUBJECTS TO PARTICIPATE IN A RESEARCH PROJECT OR EXPERIMENT</u>	
<p>The University and those conducting this 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. Your signature on this form will signify that you have received a document which describes the procedures, possible risks, and benefits of this research project, that you have received an adequate opportunity to consider the information in the document, and that you voluntarily agree to participate in the project.</p> <p>Any information that is obtained during this study will be kept confidential to the full extent permitted by law. Knowledge of your identity is not required. You will not be required to write your name or any other identifying information on the research materials. Materials will be held in a secure location and will be destroyed after the completion of the study. However, it is possible that, as a result of legal action, the researcher may be required to divulge information obtained in the course of this research to a court or other legal body.</p> <p>Having been asked by <u>Laura Cooper</u> of the <u>Sociology Anthropology</u> Dept. of Simon Fraser University to participate in a research project, I have read the procedures specified in the document.</p> <p>I understand the procedures to be used in this experiment and the personal risks to me in taking part.</p> <p>I understand that I may withdraw my participation at any time.</p> <p>I also understand that I may register any complaint I might have about the experiment with the researcher named above or with Jane Puktingham Chair of the Sociology/Anthropology Dept. of Simon Fraser University.</p> <p>I may obtain copies of the results of this study, upon its completion, by contacting: Laura Cooper.</p> <p>I agree that my name will be divulged in this research.</p> <p>I have been informed that the research material will be held in confidence by Laura Cooper.</p>	

...2

Page 2.

I agree to participate by speaking with the Laura Cooper about my life experiences as a person with HIV described in the document referred to above, and to have my conversations audio-taped, during the time period December 2001-July 2004 _____ at a variety of locations in British Columbia, Alberta, South Dakota.

NAME (please type or print legibly): _____

ADDRESS: _____

SIGNATURE: _____ **'WITNESS:** _____

DATE: _____

ONCE SIGNED, A COPY OF THIS CONSENT FORM AND A SUBJECT FEEDBACK FORM SHOULD BE PROVIDED TO THE SUBJECT.

Appendix 3: Communication from MHR concerning loss of transportation allowance

Dec-03/97

James & Alexandra Keating

re: medical transportation.

We discussed the \$4.00 you are receiving for medical transportation, as you are able to purchase a yearly bus pass so med also need you are not eligible.

You stated you are unable to take public transit. We require a detailed letter from your doctor as to why you cannot take public transit. As well you should also look into Handi-Dart.

Any question please call

Thanks

Appendix 4: Alex's response to MHR concerning transportation allowance

RECEIVED COPY

MAY 01 1998

James and Alexandria Keatino
S.I.N.#s'

MIN. OF SOCIAL SERVICES
HAS

I am writing to you today, on behalf of my husband James and myself Alexandria, to ask your assistance in resolving a situation which is proving to be detrimental to our health and sense of well being.

We are clients of your office and our case worker is number 104. For a long time our worker was _____ but due to a redistribution of the case loads we have had a few different workers in the past year. Our present worker is _____ and it is with she that our problem exists.

We have had only a few dealing with _____ and I have been left with serious concerns regarding our future well being if we are forced to remain with worker. At this time I would like to explain for you the series of events which have lead to this letter and then outline the items we require to be addressed. Thank you for your indulgence.

My first awareness that _____ was our new worker was just before Christmas 1997 when our January GAIN cheque arrived for a reduced amount from what we usually receive. I phoned your office and was put through to the voice mail of our new worker # 104, _____. When _____ returned my message I explained the purpose of my call and asked if she could find out why our cheque was smaller. I was informed that our dietary allowances had expired. I explained that due to the permanent and progressive nature of our health situation, (that both of us are living with HIV disease which has progressed to AIDS) that I had the belief that the dietary requirement letters from our physician submitted the previous year was permanent. I requested that _____ check this out for us and if it turned out that we required a new letter that we would get one. That was Wed. Dec. 17 98. On Thursday Dec. 18 I called _____ back and was told that we required a new physicians letter each year. I then asked

that since Christmas was just days away, if I could get the physicians letter to her Thursday afternoon or Friday morning could we possibly have the cheque produced for the Friday 3 p.m. cheque pick up. I was then and still am certain she agreed to this. The letter from our physician was dropped off at your office on Fri. Dec. 19 at about 11:30 a.m. Friday at 3:30 p.m. we returned to your office and were told by the worker at the front desk that no request was put forward for an impress cheque for us. Furthermore, this front desk worker said she would make _____ aware of our inquiry and that we should return on Monday afternoon to pick up our cheque. Monday at 3:30 p.m. we returned to your office only to be given the same explination again, that _____ had not requested this cheque be produced for us.

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MAY 01 1998

Upon our explaining to the front desk worker the MIN. OF SOCIAL SERVICES circumstances of our repeated trips and the hardship ~~MASSTINGS~~ (B23) was creating for us, as we were both very ill at that time, she assured us that a cheque would be produced for us by Tuesday afternoon. Thanks to the considerate intervention of this woman we picked up a cheque on Tuesday Dec. 23 1997. I believe exhibited disregard for our health and the reality of our physical situation in this matter.

Back on Wed. Dec. 17 97 during my initial phone call with , when she went into our file to find out why our cheque was deducted she also took note that we were receiving a transportation allowance of \$54.00 per month (\$27.00 each). To this point her demeanor had been abrupt but for some reason her tone became derogatory when enquiring "well your on GAIN of handicapped aren't you?", "then you should not be getting a transportation allowance you should get a yearly bus pass!". I tried to explain to her that yes , in the past, we have gotten yearly bus passes but that last year while at an appointment with (possibly our yearly review that year) we expressed our concern for our health in riding the busses.

When James and I would use the bus we would invariably catch a cold , flu or worse and for us a simple cold is very dangerous. We never seemed to get sick for only a few days we seemed to end up sick for weeks, passing illness back and forth. Also the fact the we both are also Hepatitis C positive and that we have many unexpected medical appointments and emergencies due to these illnesses as well as the Idiopathic Thrombocytopenia (ITP) my husband James' suffers from. I T P is an illness which results in uncontrolled bleeding internally and externally due to the spleen destroying the platletts in James' body. took into consideration these factors (which in our files are documented in one form or another) as well as the fact that we have up to 20 planned medical related appointments per. month (James chest catheter flush ,blood work, I.V. treatment, Dr. appt., pharmacy, counseling etc...) as well as whatever unexpected appointments and emergencies we have, which do see to be ongoing as James health gets weaker and his bleeding harder to control. also took the fact of the risk we face with contagious elements in close quarters of the bus (Hep A, T.B., cold, influenza, ect..) and she approached a supervisor with regards to what could be done to help us. When she returned to her office she informed us of the transportation allowance we would be getting. I was aware that due to our concern for our health that we were using money we could ill afford, to pay our monthly car insurance, so this transportation allowance was to assist with this \$62.00 a month expense as it was the most cost effective approach to our needs. The transportation allowance is more cost effective than taxis, and handy dart would not be of use to us on numerous occasions as we often don't have notice of health problems especially when it is

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MAY 01 1998
MIN. OF SOCIAL SERVICES
DRAINGS (B23)

in relation to James spontaneous bleeding which generally requires prompt attention.

Although I did not go into all that detail with , I did assure her that we had gotten yearly passes in previous years but that due to the previous and present state of our health the transportation allowance was a necessity and remains a necessity. again informed me that we should not have it and when I expressed that (), along with her supervisor believed we were justified to receive it, said she would look into it and promptly ended our phone call. She seemed uninterested in understanding the reasons why we received the allowance in the first place. It seemed like since she was going to have to grudgingly reinstate our dietary allowance she was determined to take something from us. I also felt resentment from regarding the transportation allowance, like we were deceptive and not really in need of the. The following day, Thurs. Dec. 18, when I spoke to again about our dietary allowance Dr.s' letter, the transportation allowance was not mentioned. Then the problem with the printing of our dietary allowance cheque occurred, due to what I feel is intentional disregard towards us. I do not believe consideration was given to our physical limitations and the great amount of stress produced from numerous unfulfilling trips to your office not to mention the uncertainty of our ability to pay our following months car insurance. I am not sure if felt reprimanded on Monday Dec. 22 when a co worker approached her regarding getting on with the request for our dietary allowance cheque. I do know that on that same day she penned a letter to us stating that "we discussed the \$54. you are not eligible". I'm not sure who "we" refers to but I know that when we picked up our dietary allowance cheque Tues. Dec. 23 afternoon, the worker on the front desk made comment to us in relation to the yearly bus pass to the effect that we felt "above" the use of said pass. Well I would like to assure you here and now that in no way do I feel above such a pass nor have I ever voiced this view. Previously when we've had yearly passes they have been used with much appreciated. It is just that now the reality of our health has changed, I of all people wish it had not, but it has.

What I am asking from you is to have our case file assigned to a new worker. This is not a request I make lightly. I believe the disdain I feel coming from is not going to improve. The only other time I attempted to make contact with was in mid Jan. 98 when I left a message on her voice mail requesting direction on how to proceed with a request for appropriate footwear. I have ongoing deterioration in the joints of my feet as well as arthritis. The only pair of shoes I had, that I was able to walk in, were finally beyond repair and I wanted to know how I could apply to get assistance in getting some new footwear. Unfortunately . . . did not return my phone message

Appendix 4, Page 4

and after her previous treatment toward us I couldn't bring myself to beg for her assistance. I should be allowed to retain my dignity. The degree of mental and emotional distress that these circumstances created can be attested to by more than one of the physicians we see. So like the other issues that have arisen since this incident began, we've just managed to get by.

RECEIVED
MAY 01 1998

Now we would like to do something about it, so I'm requesting a new worker. I would also like to request that you review of the issue of our transportation allowance as I believe it with unjustly taken from us without consideration of all the facts, including the fact that the transportation allowance was approved by a supervisor during that office visit with . I would also like for you or our new worker to address my need of foot wear that will allow me some mobility, I can only get so much cortisone injected into the joints of my feet. Item number four that I would request be addressed is the issue substance abuse treatment.

Both James and I have been on Methadone Maintenance since 1991. Years ago we enquired into the possibility of getting ministry assistance with the monthly clinic fees and we were told that the ministry does not do that. Recently I was advised by a friend at British Columbia Persons With AIDS Society advocacy dept. (an organization of which I've been a member since 1988 and for which I used to volunteer)

(Pearce, until health intervened in 95) that there is a regulation which will allow the ministry to assist withthese costs under the GAIN act B.C. Reg. 459/95, s.2. clause 12.2 Treatment and Counselling. Under this section it is my understanding that with specified approval that each of us is eligible for assistance with our \$60.00 per mo. per person clinic fees to the total amount of \$500.00 per year per client. I would be more than grateful if the process required to attain the needed approval would be started. I understand that occasionally appeals and tribunals are required to achieve this assistance and I am prepared to proceed as necessary. So, I would appreciate getting this request underway as soon as is possible. Letters of support from family doctor, infectious disease doctor, hemotologist, psychiatrist or methadone prescribing doctor can all be obtained regarding necessity of continued treatment to maintain our ongoing state of health. Finding the money in our budget each month is getting more and more difficult and trying to decide which health, dietary and personal needs to overlook each month is getting harder to choose as they all become so much more necessary as health decreases. The culmination of all the events described in this letter have resulted in great hardship for us and I am looking to you for assistance.

Any documentation required in order to secure any and all of these listed requests will be forth coming upon notification or request. I would like to apologize for my long winded letter but I feel it is important that I try to give you a fairly clear view of the facts as I see them. I am truly thankfull for your valuable time spent reading this letter and you have my gratitude for any and all assistance you can give us. I look forward to your decision regarding our requests as well as your direction on how to proceed. Thank you again for your help!

SINCERLY

L. Alexandria Keating

James R. Keating

R E C E I V E D
MAY 01 1998
MIN. OF SOCIAL SERVICES
HASTINGS (B23)

Appendix 5: Alex's request for assistance to relocate to Salt Spring Island

James & Alex Keating
SIN # 1

To Whom It May Concern,

This letter is in regards to the upcoming move of James & Alex Keating. Due to health and quality of life factors, it has become necessary to change our living environment. For this to happen we will require assistance from Social Services for Security deposit and movers, as our health will not permit us to move ourselves.

It is our intention to move to Salt Spring Island on April 1 01. We have been talking about moving for a long time and that for our quality of life to improve we need to move someplace alone and peaceful, someplace where we have friends around us who will be there for us as our health becomes more challenging. We believe Salt Spring is our answer as we have friends and our spiritual community over there.

Our present home is no longer acceptable, not only because the neighborhood has become more crime and drug ridden but also because our apartment has become a very depressing place for us. We have mice and mice droppings all the time in the kitchen area and two or so times a year it seems they get so bad that they are running up the drapes and across the sofa back. This is a serious health ~~hazard~~ risk for us, not to mention plain unacceptable. Also, ~~our~~ apartment gets no sun. This never used to be a problem but it is now. Makey that's because we're facing so many more life & death situations these days. As a look at our house plants barely surviving I feel as though we too are struggling to survive here. A battle we are ~~not~~ not winning.

We are dying here in this city and we want to live again, for what time we have left; quality versus quantity you know.

So with all this said, we are asking for assistance to make this move

possible. We had to give 60 days notice on our present apt. so we did that on Feb. 1 and we have to vacate this suite on March 31. We are presently looking for and hope to shortly find a home to rent on Salt Spring. When we do we are asking for assistance with a security deposit. We haven't had one from Welfare in more than a decade and one was not paid by Welfare at our present address.

Also, we would like to arrange for movers as early as possible so please let us know what is necessary for this to be approved.

Thank You for all your help. We anticipate this move, once accomplished will improve our quality of and quantity of life. For this I am grateful!

Appendix 6: Physician support for moving request, February 20, 2001

Feb 20/01

To whom it may concern

Re Louise and James Keating

M + Mrs Keating have been my patients for many years and both suffer from advanced AIDS.

They live in a dark and dusty apartment which is infested with mice. The neighbourhood is also inhabited by prostitutes and drug dealers, plus there have been several murders nearby.

Their illnesses are progressing and with it their quality of life is deteriorating rapidly.

James has been hospitalized on several occasions with opportunistic complications and his CD4 count is now very low -

They are both acute depressed with their current living environment and desire a move to Salt Spring Island, where they can live in a more peaceful and natural environment in a much more pleasant accommodation.

They have many supportive friends in Salt Spring who live nearby.

Having discussed the Keating's desire to move to Salt Spring, at some length, I fully agree with this as it would certainly improve the quality of what life they have remaining.

Yours truly

Appendix 7: Home support worker's moving request letter

To whom it may concern,

Feb 15/01

I am a Home Support worker who has been working with Mr. & Mrs. Keating for the past 3 years. During this time they have experienced problems with mice. Several times, they have used traps, steel wool to drill the holes, as well as the glue covered papers all to no avail.

I have thrown out a large amount of food due to the mice chewing holes through the packages. I also have had to throw out their plastic containers that they use to store food in their fridge, as the containers are covered in mice feces and urine.

As well as costing Mr. & Mrs. Keating money to replace food, the mice droppings are a should be considered to be detrimental to their health and well being.

Thank - you

Appendix 8: Government communications regarding SIN card / BCID

<p> BRITISH COLUMBIA</p>							
<p>Date: <u>APRIL 20/01</u> <u>JAMES KEATING</u> <u>GANGES RD.</u> <u>SALTSpring ISLAND, BC V8K 2M5</u>.</p>							
<p>Dear <u>MR. KEATING</u>:</p>							
<p>In order to avoid unnecessary delays with your cheque; please submit the following information to this office by <u>N/A</u>.</p>							
<input checked="" type="checkbox"/>	Identification	<u>JAMES BCID ; LOUISE - SIN</u>					
<input type="checkbox"/>	Shelter Receipt						
<input type="checkbox"/>	Bank Statement						
<input type="checkbox"/>	Income						
<input type="checkbox"/>	Confirmation of Medical Appointment on						
<input type="checkbox"/>	Other						
<p>Comments <u>WE CAN ASSIST YOU WITH THE COST OF THE BCID BUT</u> <u>NOT THE SIN AS \$10. WAS ALREADY ISSUED TO YOU</u> <u>FOR THE SIN REPLACEMENT. I WILL NEED YOU TO</u> <u>Sincerely, SUBMIT RECEIPTS ASAP SHOWING YOU HAVE</u> <u>APPLIED FOR THE ABOVE.</u></p>							
Financial Assistance Worker		<p>NEED PHONE # FOR YOU. ONE ON FILE IS INCORRECT.</p>					
<p>• THE GOVERNMENT OF BRITISH COLUMBIA IS AN "EMPLOYMENT EQUITY EMPLOYER".</p> <table><tr><td>Ministry of Social Development and Economic Security</td><td>Sidney Employment and Benefit Centre</td><td>Box 9978 STN PROV GOVT VICTORIA, BC V8W 9R5</td><td>Telephone: (250) 655-5629 Saltspring: 537-2921 Gulf Islands: 1-800-822-9996 Facsimile: (250) 655-5633</td></tr></table>				Ministry of Social Development and Economic Security	Sidney Employment and Benefit Centre	Box 9978 STN PROV GOVT VICTORIA, BC V8W 9R5	Telephone: (250) 655-5629 Saltspring: 537-2921 Gulf Islands: 1-800-822-9996 Facsimile: (250) 655-5633
Ministry of Social Development and Economic Security	Sidney Employment and Benefit Centre	Box 9978 STN PROV GOVT VICTORIA, BC V8W 9R5	Telephone: (250) 655-5629 Saltspring: 537-2921 Gulf Islands: 1-800-822-9996 Facsimile: (250) 655-5633				

Appendix 9: Alex's response to the Social Insurance Number card request

#6 121 McPhillips Ave., Phone/Fax - (250) 537-4243

Apple Copy Centre

Fax

To: _____ From: Alex Keating
Fax: 1-250 Pages: 3 + 1 cover page
Phone: Date: Sept 24 01
Re: SIN Card CC:
 Urgent For Review Please Comment Please Reply Please Recycle

• **Comments:**

I anticipate this months issue will be
out Sept. 26. I do hope this is so. Thanks
much. A.

Fax #

A/H:

Sept. 24 01

With regards to the letter I received on Fri. Sept 21 requesting a copy of my SIN card and implying problems with our monthly cheque if copy isn't immediately forwarded, I would like to put in writing the information I left on your voicemail a few weeks ago:

I do not have a copy of my SIN card which which # is: [REDACTED] Apparently about [REDACTED] a couple years ago our then F&W had a cheque written to the minister responsible for SIN cards and mailed it along with the forms. I was told this was happening but I never saw or held the cheque, it was never issued to me or released to me. As time passed and the card did not come I forgot about it.

Upon moving to Salt Spring and having our initial interview with you, you requested my card and I related the above tale to you. You asked

that I follow up on the matter. I made 2 phone calls to their ministry and both times got nowhere. Just over a month ago you again asked me to pursue the matter, which I did. I was told by the SIN ministry rep I spoke to that they had no record of the original request in their computer. I forwarded this response onto you, again via voice mail, at which time I asked if your ministry would contact the SIN department since I was getting nowhere. I concluded my message saying that I didn't feel there was any more ~~#~~ headway I could make on the matter. Then came the letter 3 days ago.

Regarding your request, I can't give you what I don't have and haven't been able to access. I am asking that your ministry do an inquiry as to why the ID wasn't issued if, as you say, they cashed the cheque. These are answers I am not being given from those responsible.

I hope this puts to rest this matter.

with regard to my part, until I do receive my SIN card, at which time I will gladly forward a copy to you.

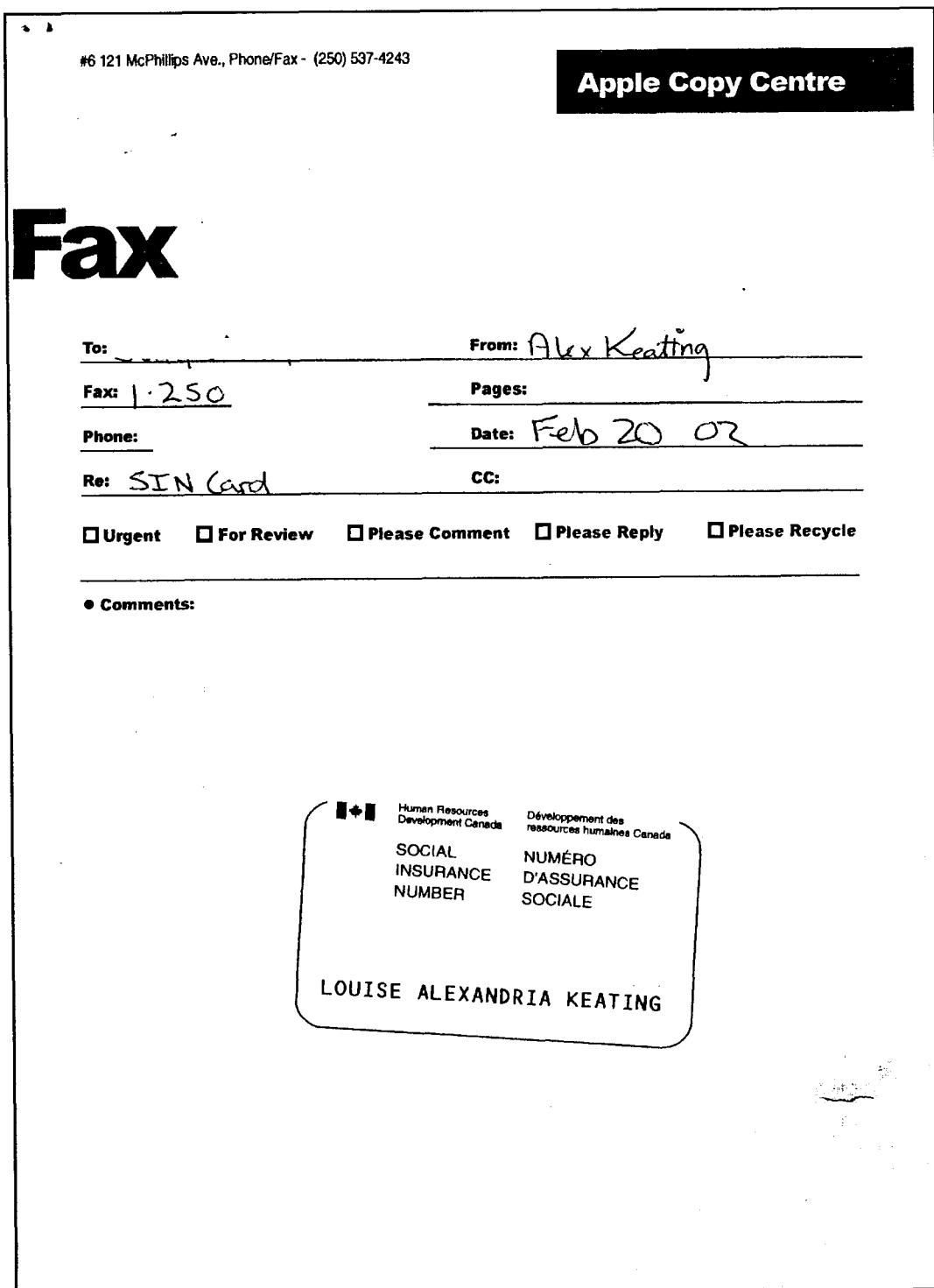
If, as your letter indicated the possibility of, there is going to be a problem for us and our cheque issue resulting from this situation I ask you inform me at your earliest convenience so I can begin appealing that decision as I do not believe the answers you seek are mine give.

As an alternative, if the ministry will pay the fee, I would gladly apply for a new card. Thanks.

SIN#

ph. # 250

Appendix 10: Faxed copy of Alex's Social Insurance Number card



Appendix 11: British Columbia Benefits Annual Eligibility Review 1998



IMPORTANT NOTICE

DATE: 98 Oct 29th

GA#: 13

To: James Keating

As per our policy, a review application must be completed annually in order to update all information. Would you please come to the office on: NOVEMBER 12 @ 9:30 AM and bring along any of the following documents which apply to you:

1. Your social insurance card.
2. Two other pieces of identification for you and your dependents (driver's license, birth certificate, passport, citizenship card, landed paper, Social Insurance Card of spouse).
3. Your B.C. Medical card.
4. If renting, a current rent receipt Issued by the landlord, with landlord's name, address, and phone number.
5. If a property owner, mortgage documents and most recent tax statement, home insurance paper, garbage and water.
6. Most recent utilities receipts (heat, light, phone).
7. Up to date bank book and/or last monthly bank statement.
8. Confirmation of any monthly income, such as Child Tax Benefit, Family Bonus, CPP, Old Age Pension plan benefits, employment or unemployment insurance pay stubs.
9. Any documents you have that can verify the assets you have listed.
10. Most recent Income Tax Assessment form (if you lost it, you can get a copy from Revenue Canada), for you and your partner.

Please note that if a review cannot be completed as set up or the documents are not produced, your next cheque will be withheld until completion of these requirements. If due to some reason you cannot attend, please contact me immediately to rebook, otherwise, I may assume that you are no longer in need of income assistance and may close your file.

If you require an interpreter present at your appointment, please contact

If you are in a relationship, both adults must attend this appointment.

Financial Assistance Worker

Ministry of
Human Resources

Kwassa

1st Fl. 666 East Hastings St. Telephone: (604) 775-0478
Vancouver, B.C. V6A 1R1 Facsimile: (604) 775-0496

Page 1 of 3

BC Benefits
Eligibility
Review

Province of British Columbia Ministry of Human Resources
 Ministry of Advanced Education, Training and Technology

Last Name ... KEATING Marital Status ... MARRIED
 First Name ... JAMES Separated Date ...
 Birth Date ... 1962MAR16 Divorced Date ...
 S.I.N. Spousal Support \$ _____
 File ID No Support Reason _____

Telephone
Address

ALL OTHER PERSONS LIVING IN HOUSEHOLD (Excluding Applicant)					Dependents	Applicant	Spouse
Last Name	First Name	Relationship	Dependent?	Birth Date			
KEATING	LOUISE ALEXANDRIA	SPO	YES	1965AUG02			
					Data moved to	Canada	N/A
					B.C.	1978APR	N/A
					Moved From	UNK	
					Canadian Citizen?	YES	YES
					Is there an outstanding warrant for your arrest?	N/A	N/A
					Eligible under LMDA?	N/A	N/A
					Seeking Employment?		
					Explanation for NO:		

ALL MONTHLY FAMILY INCOMES		Amount	ALL FAMILY ASSETS AND THEIR CURRENT VALUE		
			Owned by	Applicant	Spouse
			Dependant		
NET EARNINGS	\$ 0.00		Cash On Hand	\$ 0	0
ROOMER	\$ 0.00		1st Vehicle	\$ 1000.00	0
BOARDER	\$ 0.00		2nd Vehicle	\$ 0	0
SUPPORT OR MAINTENANCE	\$ 0.00		Recreational Vehicle	\$ 0	0
TRAINING - EARNED INCOME	\$ 0.00		Property (not including home)	\$ 0	0
OTHER EARNED INCOME	\$ 0.00		Life Insurance (cash surrender)	\$ 0	0
CANADA PENSION PLAN	\$ 0.00		Trust Funds	\$ 0	0
WAR VETERANS ALLOWANCE	\$ 0.00		Stocks/Bonds	\$ 0	0
TRAINING ALLOWANCE	\$ 0.00		RHSP	\$ 0	0
WORKERS' COMPENSATION BOARD	\$ 0.00		Other	\$ 0	0
EMPLOYMENT INSURANCE BENEFIT	\$ 0.00		Bank Name Acct No.		
CANADIAN PENSION COMMISSION	\$ 0.00		CCEC	\$ 44	0
OLD AGE SECURITY/GUAR. INC SUPP	\$ 0.00			\$ 0	0
GAIN FOR SENIOR SUPPLEMENT	\$ 0.00			\$ 0	0
SHelter AID FOR ELDERLY RENTER	\$ 0.00				
WAR VETERANS - WIDOW'S PENSION	\$ 0.00				
EXTENDED SPOUSES ALLOWANCE	\$ 0.00				
PRIVATE RETIREMENT PENSION	\$ 0.00				
PRIVATE DISABILITY PENSION	\$ 0.00				
OTHER UNEARNED INCOME	\$ 0.00				
BASIC CHILD TAX BENEFIT	\$ 0.00				
FAMILY BONUS	\$ 0.00				
BC EARNED INCOME BENEFIT	\$ 0.00				

MONTHLY SHELTER EXPENSES

UTILITIES	\$ 25.00	PROPERTY TAXES	\$ 0.00
ROOM & BOARD PRIVATE	\$ 0.00	RENT	\$ 520.00
ROOM & BOARD PARENT OR CHILD	\$ 0.00	SHARED RENT	\$ 0.00
MORTGAGE PAYMENT	\$ 0.00		

Are you receiving help with the above expenses? If so, from whom ... Amount ... \$ _____

DOCUMENTS SEEN	Facility Number ...
_____	Name ...

Initials of Applicant(s)

Date 1998NOV13 Time 09:41:11

Initials of Witness

Date 1998NOV13 Time 09:41:11

Province of British Columbia	Ministry of Human Resources Ministry of Advanced Education, Training and Technology	BC Benefits Eligibility Review
Applicant	Spouse	
Last Name ... KEATING	KEATING	
First Name ... JAMES	LOUISE ALEXANDRIA	File ID ... (For Office Use Only)
S.I.N.		

Privacy

The collection, use and disclosure of this information are authorized under the BC Benefits (Income Assistance) Act, the BC Benefits (Youth Works) Act and the Disability Benefits Program Act and are permitted under the Freedom of Information and Protection of Privacy Act.

The Freedom of Information and Protection of Privacy Act has rules about:

- how personal information is collected, stored and secured;
- how to access personal information and how to ask for corrections;
- limits on how personal information is used; and
- limits on the disclosure of personal information.

The BC Government's Responsibilities

The BC government is responsible for making sure assistance goes only to people who are eligible. For this reason, the BC government must check to ensure people who have applied for, or are receiving assistance, are eligible. Information provided may be disclosed to other agencies only for this purpose.

The BC government must abide by the Freedom of Information and Protection of Privacy Act in the collection, use and disclosure of any personal information.

My Rights

I have the right to the protection of my personal information, as well as the right to know what personal information the BC government has collected about me, as described in the Freedom of Information and Protection of Privacy Act.

I can receive more information about the collection, use or disclosure of my personal information by contacting my local Ministry of Human Resources (MHR) District Office or Ministry of Advanced Education, Training and Technology (MAETT) Skills Development Centres.

I may appeal if I disagree with a decision to refuse, discontinue or reduce assistance to me.

I also have the right to make a complaint if I believe my personal information is not being collected, used or disclosed appropriately.

I will continue to receive assistance only as long as I continue to be eligible.

My Responsibilities

It is necessary for me to sign this form if I want to receive assistance.

It is my responsibility to provide accurate and complete information when I apply for, or continue to receive assistance.

I must report all money that I receive each month.

I must make every effort to receive income from other sources such as pensions or Employment Insurance before applying for, or receiving assistance from, the British Columbia government.

I must report all changes of my circumstances that might affect my eligibility for assistance to the Ministry of Human Resources (MHR) and/or the Ministry of Advanced Education, Training and Technology (MAETT). I will also report any changes to the circumstances of my spouse (includes marriage-like relationships) or dependents that might affect eligibility.

Initials of Applicant(s) Date 1998NOV13 Time 09:41:11

Initials of Witness Date 1998NOV13 Time 09:41:11

Appendix 11, Page 4

Province of British Columbia		Ministry of Human Resources Ministry of Advanced Education, Training and Technology	BC Benefits Eligibility Review
Applicant	Spouse		
Last Name KEATING	KEATING		
First Name ... JAMES	LOUISE ALEXANDRIA	File ID ... (For Office Use Only)	
S.I.N.			
<u>Declaration</u>			
I declare that all the information I have provided in this application is true and complete. I understand the accuracy of the information I provide will be checked by comparing it against information held by other governments, private agencies and individuals. The BC government may verify and obtain information to confirm my eligibility or the eligibility of my dependents.			
<u>Notification</u>			
Person(s) having information or documents relevant to my eligibility for assistance may release them to employees of MHR or MAETT. Examples may include:			
<ul style="list-style-type: none"> - Human Resources Development Canada (Old Age Security, Employment Insurance, Employment and Training programs and Canada Pension Plan); - BC Student Assistance Program; - Citizenship and Immigration Canada; - Other federal, provincial and municipal departments; - BC Online Information such as: BC Assessment; Land Titles; Registrar of Companies; - Employers (to verify income); and - Landlords (to verify an address and amount of rent). 			
<u>Consents</u>			
The following organizations require your written permission before they will provide verification of your personal information:			
<ul style="list-style-type: none"> - Workers' Compensation Board (WCB); - Any financial institution, such as: banks, credit unions and trust companies; - Vital Statistics; - Insurance Corporation of BC (includes the former Motor Vehicle Branch); - Revenue Canada (see below); - Lottery Corporation of BC; - Cheque cashing services; and - Credit Bureaus. 			
<u>Revenue Canada Consent</u>			
Revenue Canada requires a separate signature to authorize release of relevant information.			
<p>I authorize Revenue Canada to release to MHR and MAETT, information from my income tax returns and other taxpayer information. The information will be relevant to, and will be used solely for, the purpose of determining and verifying eligibility for and for the general administration and enforcement of the programs under the BC Benefits (Income Assistance) Act, the BC Benefits (Youth Works) Act and the Disability Benefits Program Act. This authorization is valid for the taxation year prior to the year of signature of this consent, the year of signature, and each subsequent consecutive taxation year for which assistance is requested.</p>			
Signature of Applicant(s)		Signed at VANCOUVER in Province of B.C. Date 1998NOV13 Time 09:41:11	
<p>I give permission to the organizations listed above to release information relevant to my eligibility for assistance to employees of MHR or MAETT.</p>			
Signature of Applicant(s)		Signature 161179161 of Witness 161179163	
Signed at VANCOUVER in Province of B.C. Date 1998NOV13 Time 09:41:11		Signed at VANCOUVER in Province of B.C. Date 1998NOV13 Time 09:41:11	

Appendix 12: British Columbia Benefits Eligibility Surveillance and Consent Request



January 19, 1998

Dear Client:

On April 7, 1997, the Provincial Government introduced a new BC Benefits application form. In order to update your file and maintain your eligibility for assistance, you are required to read and sign the enclosed Consent form.

The Consent form identifies the agencies and organizations the Ministry may contact when verifying your eligibility for assistance. The Ministry of Human Resources will be matching data to verify income with federal and provincial agencies, including Revenue Canada.

Anyone can witness your signature on the Consent form. The witness will sign and date the form and ensure that their name is clearly printed below their signature.

Failure to return the signed Consent form to your District Office by February 20th, 1998, may result in an interruption in your assistance.

Director
Prevention, Compliance and Enforcement

**Ministry of
Human Resources**
Prevention, Compliance & Enforcement Branch

Mailing Address:
PO Box 9930 Stn Prov Govt
Victoria, BC
V8W 0P2



R E C E I V E D

JAN 27 1998

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MIN. OF SOCIAL SERVICES
HASTINGS (B23)

KEATING, JAMES 155
VANCOUVER BC

154 (v) 2
XXS

FILE ID :
S.I.N. :
CASE LOAD :
CATEGORY :

CONSENT

I give my permission to the Ministry of Human Resources (MHR) and the Ministry of Education, Skills and Training (MEST) to obtain and verify relevant information or documents required to confirm my eligibility or the eligibility of my family members for assistance through the BC Benefits (Income Assistance) Act, BC Benefits (Youth Works) Act, or Disability Benefits Program Act.

I give my permission to any person having such relevant information or documents to release them upon written or verbal request to employees of MHR or MEST. I understand examples include, but are not restricted to, information or documents from: Human Resources Development Canada, Workers' Compensation Board, Insurance Corporation of British Columbia, British Columbia Student Assistance Program, Motor Vehicle Branch, British Columbia Assessment Authority, Registrar of Companies, Land Titles, Lottery Corporation of British Columbia, Vital Statistics, Old Age Security, Canada Pension Plan, federal, provincial or municipal government departments, and the Department of Citizenship and Immigration Canada, police, federal or state related aid Agencies from the United States of America or any other country, Equifax, any bank, credit union, cheque cashing service or other financial institution, any landlord, and past, present or future employers of myself or my family members.

I authorize Revenue Canada to release, to MHR and MEST, information from my income tax returns and other taxpayer information. The information will be relevant to, and will be used solely for the purpose of determining and verifying eligibility for and for the general administration and enforcement of the programs under the BC Benefits (Income Assistance) Act, the BC Benefits (Youth Works) Act, and the Disability Benefits Program Act. This authorization is valid for the taxation year prior to the year of signature of this consent, the year of signature, and each subsequent consecutive taxation year for which assistance is requested.

SIGNATURE OF APPLICANT(S)

Eligibility information is collected under the authority of the Acts listed above, and the Regulations made under those Acts, and will only be used for verification of initial and continuing eligibility for assistance under the Acts. The accuracy of the information used to verify eligibility will be checked by comparing it against information held by other provincial, federal, municipal and private agencies, including landlords, financial institutions, Equifax, etcetera. Collection, use and disclosure of information is as authorized under the Freedom of Information and Protection of Privacy Act. If you have any questions about the collection, use or disclosure of this information, contact your local District Office.

SIGNATURE OF APPLICANT(S):	SIGNED AT: IN THE PROVINCE OF BC	DATE: YY MMM DD	SIGNATURE OF WITNESS:	SIGNED AT: IN THE PROVINCE OF BC	DATE: YY MMM DD
1998 01 26					
IN THE PROVINCE OF BC YY MMM DD			NAME OF WITNESS		

Van-BC 930269

Ministry of
Human Resources
01/06/98

Ministry of Education,
Skills and Training

Printed in B.C. 22000

Appendix 13: Termination letter to Alex

March 9 '94

Hi Alex,

I've tried calling you a few times, but I know you've been ill and unable to respond. I was very sorry to hear you haven't been well.

As you and I discussed at our meeting of January 27, 1994, the status of your job continuing with [redacted] was dependent on specified short term goals being reached. Due to your illness, you have been unable to meet these goals. Therefore, I'm sorry to inform you that your employment as [redacted] is terminated.

Resource Staff for the

In no way, Alex, does this mean you are not welcome as a volunteer. We consider you an important part of [redacted] + look forward to working with you in the future; both as an unpaid staff member and, possibly, as someone paid hourly for specific projects to be determined at a later date.

Hope you are getting well. Please call anytime to discuss the above.

Appendix 14: British Columbia Government changes to benefits for disabled

<p>S AVENUE SIDNEY, B.C. V8L1Y2</p> <p>JAMES KEATING 164/6 H4 (Q) SALT SPRING ISLAND BC</p>	 <p>BRITISH COLUMBIA</p>	
<p>March 18, 2002</p> <p>Dear JAMES</p> <p>The Ministry of Human Resources will introduce the new <i>BC Employment and Assistance</i> program on April 1, 2002. The changes that the ministry is making to income assistance recognize that the people the ministry serves are truly a resource. We will focus on assisting individuals and families in need and moving people to sustainable employment. We believe in the value of self-sufficiency in which people are supported in achieving their potential.</p> <p>There will be a renewed emphasis on employment with temporary assistance for those who are able to work. We have also committed to provide assistance to people with disabilities and to others who are unable to fully participate in the workforce. At the same time, we will implement new strategies to support persons with disabilities to move in and out of employment, as they are able.</p> <p>In British Columbia, jobs become available every day and as the economy is revitalized, job opportunities will grow. We want to assist people to have the motivation and the skills they need to get a job and lead more fulfilling and independent lives. During the next three years, the ministry will spend over \$300 million in job placement and job training programs.</p> <p><i>BC Employment and Assistance</i> will be implemented over the coming year with some changes effective April 1, 2002. Information regarding changes which may pertain to you are attached to this letter. More detailed information on these changes is available on the ministry's website at www.gov.bc.ca/mhr or by calling the toll-free ministry information line at 1-800-668-2800 province-wide or 604-775-2800 in the metropolitan Vancouver area. Staff at this number can provide information regarding the policy changes. The information line is open Monday through Friday, 8:00 a.m. to 5:00 p.m. For information regarding eligibility, please contact your local Ministry of Human Resources office.</p> <p>Yours truly,</p> <p>Murray Coell Minister Attachment</p>		
Ministry of Human Resources	Office of the Minister	Address: Parliament Buildings Victoria BC V8V 1X4

Attachment

Changes that apply to singles, couples and families receiving Disability Benefits Level 2 (DB2).

According to ministry records, you are an individual or family receiving DB2. The changes being implemented April 1, 2002, which may apply to you are:

Asset limits

- If you are a single person with a disability you may have assets to a maximum of \$3,000 and still be eligible for income assistance. Couples and families with children have an allowable asset level of \$5,000.
- The value of one motor vehicle, less any debt on the vehicle, is exempt up to \$5,000.
- A vehicle that has been modified for a person with a disability is fully exempt.
- The changes in allowable asset levels are effective April 1, 2002 for new applicants. For existing clients the changes are effective at your next eligibility review.

Security deposits

- After April 1, 2002, all new security deposits are recovered from *BC Employment and Assistance* cheques at \$20 per month. The security deposit deduction occurs on the second cheque after the security deposit is issued.
- All *BC Employment and Assistance* clients are limited to a maximum of two outstanding security deposits.
- A third deposit may be issued where the recipient is fleeing domestic abuse or has to move as a result of sale or demolition of the residence.
- Security deposits issued before April 1, 2002, are still recovered but are not considered in the maximum of two outstanding deposits.

Income and earnings exemptions

- Exemptions on family maintenance payments or orphans' benefits from the Canada Pension Plan are discontinued.
- If you have earnings (for example; income from employment), the first \$300 of earnings is exempt (up from \$200). The additional 25 percent earnings exemption is discontinued.
- The first cheque affected is the cheque issued April 24, 2002.

Appendix 15: British Columbia Benefits Supplemental Health

 BRITISH COLUMBIA	NEWS RELEASE
For Immediate Release 2001: 81 April 2, 2001	Ministry of Social Development and Economic Security
BENEFITS SUPPLEMENTED FOR PEOPLE WITH ILLNESSES, DISABILITIES	
VANCOUVER – Low-income people suffering from ill health, malnutrition and weight loss as a result of chronic illness or disability will soon receive an added monthly allowance, as well as vitamins, minerals and pharmaceuticals.	
Vancouver-Burrard MLA Tim Stevenson made the announcement today on behalf of Mike Farnworth, minister of social development and economic security.	
“People served through the BC Benefits disability benefits program who suffer from chronic illness or disability are among the most vulnerable in our communities,” said Farnworth. “Beginning in July, many of them will receive a monthly allowance, drugs and supplements worth up to \$300 in addition to their regular income assistance cheques.”	
“Greater assistance, compassion and caring for people with HIV/AIDS, other illnesses and disabilities is part of Premier Dosanjh’s commitment to restoring confidence in the health-care system,” said Stevenson. “Our government is listening and responding to the concerns of people with disabilities.”	
About \$6 million has been allocated for 2001-2002 for the allowance which will be available to people suffering from serious disabilities or illnesses such as HIV/AIDS and various forms of cancer. The package can be customized to the medical needs of the individual.	
The monthly allocations include:	
<ul style="list-style-type: none">• A monthly cash allowance of \$150.• A special water allowance of \$20.• Vitamins and minerals worth an average of \$50.• Over-the-counter drugs and prescriptions valued at \$40.• A diet allowance of \$10 to \$50.	
Single people who qualify for provincial disability benefits receive \$786 per month as well as a range of health-care goods and services. The allowance announced today is in addition to those benefits.	
Government will work with a medical advisory committee, including the British Columbia Centre for Excellence in HIV/AIDS, to define the eligibility criteria. Computer system changes to support delivery of the allowance will begin immediately. It is expected that 4,000 people may qualify.	
-30-	
Contact: Marisa Adair, Media Relations Manager 250-387-1412	
Ministry of Social Development and Economic Security news releases are available at http://www.sdes.gov.bc.ca on the Internet	

Appendix 16: Dr. Burdge's letter in support of James' dental surgery

 <p>February 27, 2002</p> <p>Dr. Fax:</p> <p>Dear Dr. .</p> <p>Re: James KEATING D.O.B.</p> <p>This is to certify that I am fully supportive of you proceeding to provide James with definitive dental care. I believe that at this point it is important that the fractured carious teeth be removed. He currently has a normal platelet count, and a much improved white blood count and neutrophil count, and at this point I believe that you could quite safely go ahead with the planned extractions. His most recent total white count was up to 1,500, and the platelet count was at $123 \times 10^9/L$.</p> <p>Please do not hesitate to contact me should you have any questions or concerns.</p> <p>With kindest regards.</p> <p>Yours sincerely,</p> <p>David R. Burdge, MD, FRCP(C) Clinical Professor Infectious Diseases Division of Infectious Diseases Department of Medicine, UBC</p> <p>DB:ah</p> <p>cc: Dr. James Keating</p>	<p>Oak Tree Clinic</p> <p>B4 West 4500 Oak Street Vancouver, B.C. Canada V6H 5N</p> <p>Phone: 604-875-2212</p> <p>Fax: 604-875-3063</p>
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*Children's & Women's
Health Centre of British Columbia*

Appendix 17: Semi-structured interview schedule

Interview Schedule:

1. Why do you have Alex Keating speak to your students?
2. How long have you been having her speak to your classes?
3. In terms of your teaching plan, what areas of sociological significance does Alex address in her lectures?
4. What is the nature of student commentary that you receive after Alex speaks?
5. What are the most significant areas of Alex's story for you as an educator?
6. In what ways, if any, has Alex's story changed over the years that you have had her presenting to your students?
7. In terms of your student's reactions, does Alex's narrative challenge or enhance many of the dominant stereotypes of women living with HIV/AIDS? Please be specific if possible.
8. What are the strengths and weaknesses of Alex's story as an educational tool?
9. Were the student's expectations of a person with HIV/AIDS (PWA) coming to speak to them similar to what they actually experienced or did they express a divergence from expectations?

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